Staying in the Circle of Life Native Cancer Survivors Support Group

Baseline Survey



Thank you for participating in the Staying in the Circle of Life Native Cancer Survivors Support Group! We are looking forward to sharing this project with you over the next six sessions. Researchers at the Washington State University and members of your community wish to evaluate whether the support group curriculum is effective. This survey is a way for us to find out what we are doing well and if there are areas where we can improve. We want to provide the best resources to our partner communities and this is one way to keep us on track. We estimate that it will take about 45-60 minutes to complete this survey.

Do not write your name on the survey. Your identity will be kept confidential. The data collected will be anonymous, and there will be no identifying information or names used in any written reports that result from this evaluation.

Your participation is voluntary. You may stop participating at any time during the process. Your services will not be affected by your participation or lack of participation.

If you have any questions during the survey, please feel free to ask the facilitator for help.

About you

Please answer the following questions to the best of your knowledge. Mark only one option per question unless otherwise stated.

1. What is your age?

_____ years of age

- 2. What is your gender?
 - O Male
 - O Female
 - O Other:
 - O Prefer not to answer
- 3. What is the highest degree you have earned?
 - O Less than high school
 - O High school diploma or GED
 - O Associate or technical degree
 - O Bachelor's degree
 - O Master's degree
 - O Doctorate or Professional (MD, JD, DDS, etc.)
 - O Other (Specify):
- 4. What is your current marital status?
 - O Single
 - O Living with partner
 - O Married
 - O Widowed
 - O Divorced
 - O Separated

- 5. Which category best describes your work status?
 - O Employed for wages
 - O Self-employed
 - O Out of work for more than 1 year
 - O Out of work for less than 1 year
 - O A Homemaker
 - O A Student
 - O Retired
 - O Unable to work
 - O Prefer not to answer
- 6. Which category best describes your annual household income?
 - O Less than \$5,000
 - O \$5,000 through \$24,999
 - O \$25,000 through \$49,999
 - O \$50,000 through \$74,999
 - O \$75,000 through \$99,999
 - \$100,000 and greater
 - O Don't know
 - O Prefer not to answer
- 7. Are you currently covered by any of the following types of health insurance? (Check all that apply.)
 - □ Private insurance
 - □ Medicare
 - □ Medicaid or Medical Assistance
 - □ Indian Health Service
 - □ VA (Veterans Affairs)
 - □ Other (Specify):
 - □ Don't know
 - □ Prefer not to answer

- 8. Have you lived half or more of your life on or near a reservation?
 - O Yes
 - O No
- 9. What is your current zip code?
- 10. How long have you lived in that zip code?
 - O Less than 1 year

- ____ ___ ___

- O 1-2 years
- O 3-5 years
- O 5-10 years
- O 10-19 years
- O 20+ years

About your culture

11. What is your Tribal affiliation (which Tribe do you most closely identify with)?

Some people talk about living life in traditional ways. How much do **you, yourself**, live by or follow the...

	Not at All	A Little	Some	A Lot
12. American Indian way of life?	0	0	0	0
13. Hispanic way of life?	0	0	0	0
14. White way of life?	0	0	0	0
15. Asian way of life?	0	0	0	0
16. African American way of life?	0	0	0	0

How important is it to you that you, yourself, keep...

		Not at All	A Little	Some	A Lot
	Your Tribal identity, and your Tribe's values and practices?	0	0	0	0
	A Hispanic identity, and Hispanic values and practices?	0	0	0	0
19. <i>A</i>	A White identity, and White values and practices?	0	0	0	0
20. <i>A</i>	An Asian identity, and Asian values and practices?	0	0	0	0
	An African American identity, and African American values and practices?	0	0	0	0

Some families have special activities or traditions that take place every year at particular times, such as holiday gatherings, special meals or giveaways, religious activities, healing ceremonies or honoring powwows. How many of these special activities or traditions does **your immediate family** take part in that is based on...

	Not at All	A Few	Some	A Lot
22. Your Tribal culture?	0	0	0	0
23. Other Indian cultures?	0	0	0	0
24. Hispanic culture?	0	0	0	0
25. White culture?	0	0	0	0
26. Asian American culture?	0	0	0	0
27. African American culture?	0	0	0	0

How important is it to you that members of your immediate family keep....

	Not at All	A Little	Some	A Lot
28. Your Tribal identity, and your Tribe's values and practices?	0	0	0	0
29. A Hispanic identity, and Hispanic values and practices?	0	0	0	0
30. A White identity, and White values and practices?	0	0	0	0
31. An Asian identity, and Asian values and practices?	0	0	0	0
32. An African American identity, and African American values and practices?	0	0	0	0

- 33. How well do you speak your Tribal language?
 - O I speak my Tribal language very well
 - O I speak it moderately well
 - O I speak it a little, but not very well
 - O I don't speak my Tribal language
- 34. What language do you usually speak at home?
 - O Tribal language
 - O English
 - O Both
 - O Other; Describe:_____
 - O Prefer not to answer
 - O Don't know

About your health

Please answer the following questions to the best of your knowledge. Mark only one option per question unless otherwise stated.

35. Who was the first person to tell you that you had any type of cancer?

□ Medicine man

□ Other health care professional

□ Prefer not to answer

36. What type of cancer were you diagnosed with?

O Breast

O Colorectal

- O Lung
- O Prostate
- O Other (please list): _____

37. What was the date of your cancer diagnosis? (Month, Year)

__/___

- 38. What was the stage of cancer at diagnosis? (If you have been diagnosed with cancer more than once, answer based on your first diagnosis.)
 - O Stage I
 - O Stage II
 - O Stage III
 - O Stage IV
 - O Other

39. Have you received any of the following types of cancer treatment? (Check all that apply.)

- □ Surgery (e.g. lumpectomy, mastectomy, lobectomy)
- □ Chemotherapy
- □ Radiation therapy
- □ Hormone therapy
- □ Targeted therapy
- □ Biological therapy
- Other (specify):
- Don't know
- 40. Have you received any additional cancer treatment(s) given to lower the risk that the cancer will come back (adjuvant therapy)? Examples may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.
 - O Yes
 - O No
 - O Don't know
- 41. Have any of the following people in your life been diagnosed cancer? (Check all that apply.)
 - Parent
 - □ Sibling
 - □ Child
 - □ Grandparent
 - □ Spouse/Partner
 - □ Close friend
 - $\hfill\square$ None of the above
 - Don't know

- 42. Has a doctor, medicine man, or other health care professional ever told you that you have any of the following conditions? (Check all that apply.)
 - □ High blood pressure/hypertension
 - □ Heart Attack
 - □ Diabetes
 - □ Asthma/emphysema/other lung problems
 - □ Depression
 - □ Post-traumatic stress disorder
 - □ Chronic fatigue syndrome
 - □ Hearing loss
 - □ Trouble seeing even with glasses or contact lenses
 - □ Arthritis/autoimmune disease
 - □ Other (please list):
 - $\hfill\square$ None of the above
 - Don't know

About your well-being over the past week

Below is a list of statements that other people who have had cancer have said are important. Please mark one bubble per line to indicate your response as it applies to the past 7 days.

Physical Well-Being

Physical Well-Being	Not at all	A little bit	Some -what	Quite a bit	Very much
43.1 have a lack of energy	0	0	0	0	0
44.1 have nausea	0	0	0	0	0
45. Because of my physical condition, I have trouble meeting the needs of my family	0	0	0	0	0
46.I have pain	0	0	0	0	0
47.1 am bothered by side effects of treatment	0	0	0	0	0
48.I feel ill	0	0	0	0	0
49.1 am forced to spend time in bed	0	0	0	0	0

Social/Family Well-Being	Not at all	A little bit	Some -what	Quite a bit	Very much
50.I feel close to my friends	0	0	0	0	0
51.I get emotional support from my family	0	0	0	0	0
52.I get support from my friends	0	0	0	0	0
53. My family has accepted my illness	0	0	0	0	0
54.I am satisfied with family communication about my illness	0	0	0	0	0
55.I feel close to my partner (or the person who is my main support)	0	0	0	0	0

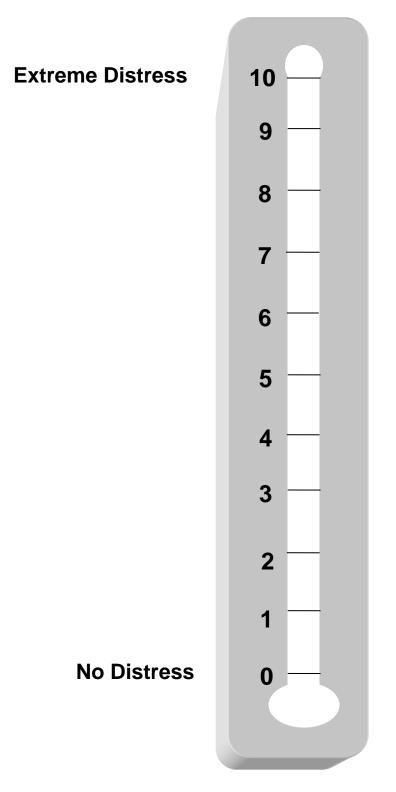
Please mark one bubble per line to indicate your response as it applies to the past 7 days.

Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box \prod_{56} and go to the next section.

	Not at all	A little bit	Some -what	Quite a bit	Very much
57. I am satisfied with my sex life	0	0	0	0	0
Emotional Well-Being					
58. I feel sad	0	0	0	0	0
59. I am satisfied with how I am coping with my illness	0	0	0	0	0
60. I am losing hope in the fight against my illness	0	0	0	0	0
61. I feel nervous	0	0	0	0	0
62. I worry about dying	0	0	0	0	0
63. I worry that my condition will get worse	0	0	0	0	0
Functional Well-Being	-	-	-	-	-
64. I am able to work (include work at home)	0	0	0	0	0
65. My work (include work at home) is fulfilling	0	0	0	0	0
66. I am able to enjoy life	0	0	0	0	0
67. I have accepted my illness	0	0	0	0	0
68. I am sleeping well	0	0	0	0	0
69. I am enjoying the things I usually do for fun	0	0	0	0	0
70. I am content with the quality of my life right now	0	0	0	0	0

About your stress level over the past week

71. Please circle the number (0-10) that best describes how much distress you have been experiencing <u>in the past 7 days</u>, including today.



Please indicate if any of the following has been a problem for you <u>in the past 7 days</u> including today. *Be sure to check YES or NO for each.*

	Yes	No	Practical Problems		Yes	No	Physical Problems
72.			Child Care	89.			Appearance
73.			Housing	90.			Bathing/dressing
74.			Insurance/financial	91.			Breathing
75.			Transportation	92.			Changes in urination
76.			Work/school	93.			Constipation
77.			Treatment decisions	94.			Diarrhea
				95.			Eating
			Family Problems	96.			Fatigue
78.			Dealing with children	97.			Feeling Swollen
79.			Dealing with partner	98.			Fevers
80.			Ability to have children	99.			Getting around
81.			Family health issues	100.			Indigestion
				101.			Memory/Concentration
			Emotional Problems	102.			Mouth Sores
82.			Depression	103.			Nausea
83.			Fears	104.			Nose dry/congested
84.			Nervousness	105.			Pain
85.			Sadness	106.			Sexual
86.			Worry	107.			Skin dry/itchy
87.			Loss of interest in usual activities	108.			Sleep
				109.			Substance abuse
88.			<u>Spiritual/Religious</u> <u>Concerns</u>	110.			Tingling in hands/feet

111. Other Problems:

About your energy level over the past week

Below is a list of statements that other people with your illness have said are important. Mark one bubble per line to indicate your response as it applies to <u>the past 7 days</u>.

	Not at all	A little bit	Some- what	Quite a bit	Very much
112. I feel fatigued	0	0	0	0	0
113. I feel weak all over	0	0	0	0	0
114. I feel listless ("washed out")	0	0	0	0	0
115. I feel tired	0	0	0	0	0
116. I have trouble starting things because I am tired	0	0	0	0	0
117. I have trouble finishing things because I am tired	0	0	0	0	0
118. I have energy	0	0	0	0	0
119. I am able to do my usual activities	0	0	0	0	0
120. I need to sleep during the day	0	0	0	0	0
121. I am too tired to eat	0	0	0	0	0
122. I need help doing my usual activities	0	0	0	0	0
123. I am frustrated by being too tired to do the things I want to do	0	0	0	0	0
124. I have to limit my social activity because I am tired	0	0	0	0	0

About your physical activity over the past week

125. Moderate physical activities are of moderate intensity, such as fast walking 3-4 miles per hour. Which of the following moderate activities did you do for at least 10 minutes at a time without stopping during <u>the past 7 days</u>? (Circle all that apply.)

•	 Walking fast (3-4 mph) 	 Walking downstairs 	 Aerobics (low impact)
•	 Bicycling (Less than 12 mph; <150W) 	• Bowling	 Calisthenics (light)
	Carpentry	Dancing	 Fishing (while standing)
•	 Gardening (planting, raking, weeding) 	• Frisbee	• Golf
	 Housework (mopping, vacuuming) 	 Gymnastics 	 Horseback riding
•	 Lifting, turning, carrying less than 50 pounds 	• Mowing lawn (power mower)	Ping pong
	 Playing with children (walking, kneeling, lifting) 	 Snow shoeing, cross country skiing 	 Skateboarding
•	• Tai Chi, Qi gong	Volleyball	Yoga, vigorous stretching
•	Water Aerobics	Washing or working on car	Weight lifting

- 126. During the last 7 days, on how many days did you do a moderate physical activity for **at least 10 minutes at a time** without stopping? _____ **days**
- 127. On those days that you did moderate physical activities, how much time did you spend **on average** doing the activities? _____minutes per day
- 128. Vigorous physical activities are of more vigorous intensity, such as jogging or running. Which of the following vigorous activities did you do for at least 10 minutes at a time without stopping during the last 7 days? (Circle all that apply)

 Jogging, running 	 Walking upstairs 	 Aerobics (high impact)
 Carrying loads more than 50 pounds 	Basketball	 Calisthenics (vigorous)
• Bicycling fast (more than 12mph; >150W)	 Judo, Karate 	 Jumping rope
• Roller skating, roller blading, ice skating	Stair Climbing/Stairmaster	Soccer
Lacrosse	 Swimming laps 	 Tennis, Racquetball
Rowing, Sailing, Canoeing, Kayaking	• Zumba	Boxing

- 129. During the last 7 days, on how many days did you do a vigorous physical activity for **at least 10 minutes at a time** without stopping? _____ **days**
- 130. On those days that you did vigorous physical activities, how much time did you spend **on average** doing the activities? _____ **minutes per day**
- 131. Compared to how physically active you have been over the last 3 months, how would you describe the last 7 days: *(Check one.)*
 - O More active
 - O Less active
 - O About the same

About your feelings over the past two weeks

Over the last 2 weeks, how often have you been bothered by any of the following?

		Not at all	Several Days	More than half the days	Nearly every day
132.	Little interest or pleasure in doing things?	0	0	0	0
133.	Feeling down, depressed, or hopeless?	0	0	0	0
134.	Trouble falling or staying asleep, or sleeping too much?	0	0	0	0
135.	Feeling tired or having little energy?	0	0	0	0
136.	Poor appetite or overeating?	0	0	0	0
137.	Feeling bad about yourself – or that you are a failure or have let yourself or your family down?	0	0	0	0
138.	Trouble concentrating on things, such as reading the newspaper or watching television?	0	0	0	0
139.	Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual?	0	0	0	0
140.	Thoughts that you would be better off dead or of hurting yourself in some way?	0	0	0	0

Over the last 2 weeks, how often have you been bothered by the following problems?

141. Feeling nervous, anxious, or on edge	Not at all	Several Days 〇	More than half the days 〇	Nearly every day 〇
142. Not being able to stop or control worrying	0	0	0	0
143. Worrying too much about different things	0	0	0	0
144. Trouble relaxing	0	0	0	0
145. Being so restless that it's hard to sit still	0	0	0	0
146. Becoming easily annoyed or irritable	0	0	0	0
147. Feeling afraid as if something awful might happen	0	0	0	0

148. If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

- O Not difficult at all
- O Somewhat difficult
- O Very difficult
- O Extremely difficult

About your feelings and thoughts over the past month

These questions ask you about your feelings and thoughts <u>during the last month</u>. In each case, you will be asked to indicate by marking **how often** you felt or thought a certain way.

	Never	Almost Never	Some- times	Fairly Often	Very often
149. In the last month, how often have you been upset because of something that happened unexpectedly?		0	0	0	0
150. In the last month, how often have you felt that you were unable to control the important things in your life?	0	0	0	0	0
151. In the last month, how often have you felt nervous and "stressed"?	0	0	0	0	0
152. In the last month, how often have you felt confident about your ability to handle your personal problems?	0	0	0	0	0
153. In the last month, how often have you felt that things were going your way?		0	0	0	0
154. In the last month, how often have you found that you could not cope with all the things that you had to do?	0	0	0	0	0
155. In the last month, how often have you been able to control irritations in your life?	0	0	0	0	0
156. In the last month, how often have you felt that you were on top of things?	0	0	0	0	0
157. In the last month, how often have you been angered because of things that were outside of your control?	0	0	0	0	0
158. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	0	0	0	0

About your diet over the past month

These questions ask about your diet. Please answer each question based on your typical habits over the **<u>past month</u>**.

Eating Out	Daily	4-5 times a week	2-3 times a week	Once a week	Rarely
159. How often do you eat out for breakfast?	0	0	0	0	0
160. How often do you eat out for lunch?	0	0	0	0	0
161. How often do you eat out for dinner?	0	0	0	0	0

If you answered at least once per week for any of the questions above, then please answer the following questions.

	Daily	4-5 times a week	2-3 times a week	Once a week	Rarely
162. How often do you eat at buffets?	0	0	0	0	0
163. How often do you eat at "fast food chains"?	0	0	0	0	0
164. How often do you eat at a "sit down" restaurant?	0	0	0	0	0

165. Please name the fast food chain you visit most frequently:

166. Please name the sit down restaurant you visit most frequently:

Food Frequency	Daily	4-5 times a week	2-3 times a week	Once a week	Rarely
167. How often do you eat dairy products? (milk, cheese, etc)	0	0	0	0	0
168. How often do you eat fruits? (fresh or canned)	0	0	0	0	0
169. How often do you eat vegetables or salad?	0	0	0	0	0
170. How often do you eat desserts/sweets? (cake, candy, cookies, etc)	0	0	0	0	0

Beverage Frequency	4 or more	3	2	1	None
171. How many carbonated beverages do you drink per day?	0	0	0	0	0
172. How many caffeinated beverages do you drink per day?	0	0	0	0	0
173. How many alcoholic beverages do you drink per day?	0	0	0	0	0
Eating Habits				Yes	No
174. Do you eat while watching television or doin	g work act	ivities?		0	0
175. Do you pay attention or monitor your portion	n sizes?			0	0
176. How long does it take for you to eat a typica	l meal?				minutes
177. Do you snack?				0	0
If you answered yes to snacking, please answer	the followi	ng questior	1S.		

 178. What time of day do you usually snack?

 179. What do you usually select for a snack?

About your feelings and emotions since being diagnosed with cancer

These items deal with ways you've been coping with the stress in your life <u>since being diagnosed</u> <u>with cancer.</u> Using these response choices, try to rate each item separately in your mind from the others. Make your answers as true *for you* as you can.

		Not at all	A little bit	A medium amount	A lot
180.	I've been turning to work or other activities to take my mind off things.	0	0	0	0
181.	I've been concentrating my efforts on doing something about the situation I'm in.	0	0	0	0
182.	I've been saying to myself "this isn't real."	0	0	0	0
183.	I've been using alcohol or other drugs to make myself feel better.	0	0	0	0
184.	I've been getting emotional support from others.	0	0	0	0
185.	I've been giving up trying to deal with it.	0	0	0	0
186.	I've been taking action to try to make the situation better.	0	0	0	0
187.	I've been refusing to believe that it has happened.	0	0	0	0
188.	I've been saying things to let my unpleasant feelings escape.	0	0	0	0
189.	I've been getting help and advice from other people.	0	0	0	0
190.	I've been using alcohol or other drugs to help me get through it.	0	0	0	0
191.	I've been trying to see it in a different light, to make it seem more positive.	0	0	0	0
192.	I've been criticizing myself.	0	0	0	0
193.	I've been trying to come up with a strategy about what to do.	0	0	0	0
194.	I've been getting comfort and understanding from someone.	0	0	0	0
195.	I've been giving up the attempt to cope.	0	0	0	0

		Not at all	A little bit	A medium amount	A lot
196.	I've been looking for something good in what is happening.	0	0	0	0
197.	I've been making jokes about it.	0	0	0	0
198.	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	0	0	0	0
199.	I've been accepting the reality of the fact that it has happened.	0	0	0	0
200.	I've been expressing my negative feelings.	0	0	0	0
201.	I've been trying to find comfort in my religion or spiritual beliefs.	0	0	0	0
202.	I've been trying to get advice or help from other people about what to do.	0	0	0	0
203.	I've been learning to live with it.	0	0	0	0
204.	I've been thinking hard about what steps to take.	0	0	0	0
205.	I've been blaming myself for things that happened.	0	0	0	0
206.	I've been praying or meditating.	0	0	0	0
207.	I've been making fun of the situation.	0	0	0	0

About the support you receive from other people

People sometimes look to others for companionship, assistance, or other types of support. <u>How</u> <u>often</u> is each of the following kinds of support available to you if you need it? *Choose one option on each line.*

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
208.	Someone you can count on to listen to you when you need to talk	0	0	0	0	0
209.	Someone to give you information to help you understand a situation	0	0	0	0	0
210.	Someone to give you good advice about a crisis	0	0	0	0	0
211.	Someone to confide in or talk to about yourself or your problems	0	0	0	0	0
212.	Someone whose advice you really want	0	0	0	0	0
213.	Someone to share your most private worries and fears with	0	0	0	0	0
214.	Someone to turn to for suggestions about how to deal with a personal problem	0	0	0	0	0
215.	Someone who understands your problems	0	0	0	0	0
216.	Someone to help you if you were confined to bed	0	0	0	0	0
217.	Someone to take you to the doctor if you needed it	0	0	0	0	0
218.	Someone to prepare your meals if you were unable to do it yourself	0	0	0	0	0
219.	Someone to help with daily chores if you were sick	0	0	0	0	0

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
220.	Someone who shows you love and affection	0	0	0	0	0
221.	Someone to love and make you feel wanted	0	0	0	0	0
222.	Someone who hugs you	0	0	0	0	0
223.	Someone to have a good time with	0	0	0	0	0
224.	Someone to get together with for relaxation	0	0	0	0	0
225.	Someone to do something enjoyable with	0	0	0	0	0
226.	Someone to do things with to help you get your mind off things	0	0	0	0	0

About your confidence at the present time

We would like to know *how confident* you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly <u>at the present time</u>.

227. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

Not at all	0	0	0	0	0	0	0	0	0	0	
confident	1	2	3	4	5	6	7	8	9	10	confident

228. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

Not at all	0	0	0	0	0	0	0	0	0	0	Totally
confident	1	2	3	4	5	6	7	8	9	10	confident

229. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

Not at all	0	0	0	0	0	0	0	0	0	0	Totally
confident	1	2	3	4	5	6	7	8	9	10	confident

230. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

Not at all confident	O	O	O	O	O	O	O	O	O	O	Totally
	1	2	3	4	5	6	7	8	9	10	confident
231. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?											
Not at all	O	O	O	O	O	O	O	O	O	O	Totally
confident	1	2	3	4	5	6	7	8	9	10	confident
232. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?											
Not at all confident	O	O	O	O	O	O	O	O	O	O	Totally
	1	2	3	4	5	6	7	8	9	10	confident

Thank you very much for completing the survey! We appreciate your input!