

DEPARTMENTS OF RADIATION ONCOLOGY AND OTOLARYNGOLOGY

Survey on Surveillance for Head and Neck Cancer

Background

- You are invited to participate in a survey to help us understand your feelings toward the surveillance, or follow-up, of your cancer after treatment.
- This information will help us determine the best way to follow patients after completion of treatment for head and neck cancer
- This survey is for patients with HPV-related head and neck cancer, which is also sometimes called viral-associated or p16 positive cancer

Survey Information

- This survey should take approximately 15 minutes to complete
- Your participation is completely voluntary
- By completing and returning this survey, you are giving your consent to participate in this survey study

Ple	ease fill out today's date:
	est, we're going to ask you some questions about your cancer type and your concerns ated to cancer. Please check the boxes to answer each question.
1.	When did you finish treatment for cancer?
	☐ Less than 2 months ago
	\square 2 to 5 months ago
	☐ 6 months ago or more
2.	Rate your agreement with the following statement: The HPV virus caused my cancer.
	☐ Disagree
	☐ Agree
3.	Rate your agreement with the following statement: Most people with cancer like me will not have their cancer come back.
	☐ Disagree
	☐ Agree
4.	After receiving all of the planned treatments, do you consider the chance of your cancer coming back IN THE HEAD AND NECK AREA to be (please select one):
	☐ Very low
	□ Low
	☐ Moderate
	☐ High
	☐ Very high
5.	After receiving all of the planned treatments, do you consider the chance of your cancer spreading TO OTHER PARTS OF YOUR BODY to be:
	☐ Very low
	□ Low
	☐ Moderate
	☐ High
	☐ Very high

6.	If my cancer	comes ba	ck, it is	likely to	come l	back in	my THF	ROAT.		
		Disagree	;							
		Agree								
7.	If my cancer	comes ba	ck, it is	likely to	come l	oack EL	SEWH	ERE IN	MY B	BODY.
		Disagree)							
		Agree								
8.	To what exte and activities		•	•		•		rude in	nto you	ur other thoughts
	0 1 Not at all	2	3	4	5	6	7	8	9	10 A great deal
9.	How often hat treatment? P						cancer	might	come	back after
	0	1			2		3	}		4
No	one of the time	Rai	ely	0	ccasion	ally	Off	en		All the time

10. We want to make sure we understand your concerns. For each of the following, please rate how important it is for you to discuss each concern with your provider at your follow up visits.

My cancer coming back (recurring)	Not at all	Somewhat	Very much
My mortality (surviving)	Not at all	Somewhat	Very much
My physical quality of life	Not at all	Somewhat	Very much
My mental quality of life	Not at all	Somewhat	Very much
Transmission of HPV to my spouse	Not at all	Somewhat	Very much
Transmission of HPV to my family	Not at all	Somewhat	Very much
Financial concerns	Not at all	Somewhat	Very much
Continuing to work	Not at all	Somewhat	Very much
Change in my mood	Not at all	Somewhat	Very much
Understanding why/how I got this cancer	Not at all	Somewhat	Very much
Intimacy with my partner/sexual life	Not at all	Somewhat	Very much

11. Now, we'd like you to imagine a scenario. Imagine you are at your regular follow up visit, and your provider has just finished examining you, including looking at your throat with a scope (camera down your nose). When you're finished talking about how you're doing, your doctor says to you: "You're doing great. If you want, instead of coming in every three months to see a provider and have a scope down your nose like we originally discussed, your treatment team would like to give you the option of coming back in six to twelve months." Would you be interested?

0	1	2	3	4	5
Not at all					Definitely

12. Imagine that your doctor now tells you, "People with your cancer do very well, and you are unlikely to have this cancer come back. In the very rare cases where it comes back, it is very unlikely that I would catch it during one of our regular visits. Instead, in these rare cases, patients usually notice an issue and call us to be seen. So instead of coming in every three months for an in person visit with a scope down your nose, your treatment team would like to give you the option of coming back in six to twelve months." Would you be interested?

0	1	2	3	4	5
Not at all					Definitely

13. There are some things that can be done to monitor cancer remotely even if they are not being seen by their providers. Which of these would make you feel most comfortable about coming in to see your provider in six to twelve months instead of every three months?
Please pick the option you are MOST INTERESTED IN DOING.
☐ Blood samples
☐ Urine samples
$\hfill\Box$ Surveys about your symptoms and how you're feeling by email or online (that will b reviewed by your healthcare provider)
 Expedited appointment with a specialist for side effects of treatment (e.g. swallow specialist)
14. There are some things that can be done to monitor cancer remotely even if they are not being seen by their providers. Which of these would make you feel most comfortable about coming in to see your provider in six to twelve months instead of every three months?
Please pick ANY of the options you would be WILLING TO DO. You can check as many a you could like.
☐ Blood samples
☐ Urine samples
$\hfill\Box$ Surveys about your symptoms and how you're feeling by email or online (that will b reviewed by your healthcare provider)
☐ Expedited appointment with a specialist for side effects of treatment (e.g. swallow specialist)
15. In general, how would you rate your physical health?
☐ Excellent
☐ Very Good
☐ Good
☐ Fair
□ Poor

16. During your last app you saw or spoke to		l you have confi	dence and trus	t in the health	care provider
☐ Yes, definitel	y				
☐ Yes, to some	extent				
☐ No, not at all					
☐ Don't know /	can't say				
17. The role you play in us how you could lik				nt. The next q	uestion will tell
Please choose one decision to be made		ng statements th	nat best descrik	es how you o	could like the
☐ I prefer to ma	ıke the final t	reatment decision	on		
☐ I prefer to ma doctor's opini		reatment decision	on after serious	ly considering	g my
☐ I prefer that n is best.	ny doctor and	d I share respon	sibility for decid	ding which tre	atment
☐ I prefer that n considers my	•	kes the final trea	atment decisior	n, but seriousl	У
☐ I prefer to lea	ve all treatm	ent decisions to	my doctor.		
18. Next, we'd like to un is less clear.	derstand wh	at you prefer to	do in situations	where the tre	eatment choice
Sometimes, medical Other times, reason needed. In situations you lean towards wat to be.	able people o s where it's n	differ in their beli ot clear, do you	efs about whet tend to learn to	her medical a owards taking	action is
1 I lean toward waiting and seeing	2	3	4	5	6 I lean toward taking action

Next, we're going to ask you some questions about yourself. Please check the boxes to answer each question.

1.	Did your treatment for cancer include surgery? ☐ Yes ☐ No
2.	Did your treatment for cancer include radiation? ☐ Yes ☐ No
3.	Did your treatment from cancer include chemotherapy? ☐ Yes ☐ No
4.	Age:
5.	Gender: Male Female Other
.	Race/Ethnicity: Non-Hispanic White / Caucasian Black or African American Native American or American Indian Asian / Pacific Islander Hispanic Other
	☐ I prefer not to answer

7.	Education: What is the highest degree or level of school you have completed?
	☐ Less than a high school diploma
	☐ High school degree or equivalent (e.g. GED)
	☐ Some college, no degree
	☐ Trade school or Associate degree (e.g. AA, AS)
	☐ Bachelor's degree (e.g. BA, BS)
	☐ Master's degree (e.g. MA, MS, MEd)
	☐ Professional degree (e.g. MD, DDS, DVM)
	☐ Doctorate (e.g. PhD, EdD)
	☐ I prefer not to answer
8.	Are you in a long-term relationship?
	□ Yes
	□ No
9.	Employment status: Are you currently?
	☐ Working full time
	☐ Working part time
	☐ Not working
	☐ I prefer not to answer
10.	If you take time off of work to come to your appointments, how do you get time off?
	□ FMLA
	☐ Vacation days
	☐ Sick days
	☐ Unpaid time off
	☐ Other
	☐ Not applicable—do not take time off work
11.	How much time do you allot to come to each follow up visit?
	☐ Less than half a day
	☐ Half day
	☐ Full day
12.	☐ More than a full day Do you have health insurance?

☐ Yes
□ No
☐ Unsure
13. How much of a co-pay or out of pocket expense do you pay for each doctor follow up visit?
☐ I pay a co-pay of approximately this amount each time: \$
☐ I do NOT pay a co-pay
☐ I don't know
14. How much money do you spend out of pocket for travel expenses (food, lodging, gas, transportation) to come to each doctor follow-up visit?
\$
15. How do you travel to follow-up appointments?
☐ I provide my own transportation (Travel in your own automobile)
☐ Ask a friend or family for a ride
☐ Transportation provided by volunteer
☐ Bus or public transportation (including Uber or Lyft)
☐ Other
☐ I prefer not to answer
16. How easy or difficult is it for you to travel to your follow-up appointments?
□ Very easy
☐ Somewhat easy
☐ Somewhat difficult
☐ Very difficult
17. How many people live at home with you?
□ 0
□ 1
□ 2-3
☐ 4 or more
☐ I prefer not to answer

18. How many financial dependents do you have?
□ 0
□ 1
□ 2-3
☐ 4 or more
☐ I prefer not to answer
19. How confident are you filling out forms by yourself?
☐ All of the time
☐ Most of the time
☐ Some of the time
☐ A little of the time
☐ None of the time
20. Household Income:
☐ Less than \$20,000
□ \$20,000 to \$34,999
□ \$35,000 to \$49,999
□ \$50,000 to \$74,999
□ \$75,000 to \$99,999
□ \$100,000 to \$149,999
□ \$150,000 to \$199,999
☐ \$200,000 or more
☐ I prefer not to answer

Thank you kindly for participating in this survey!