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# HEAD AND NECK CANCER AND SEXUALITY: PATIENT PRIORITIES, PREFERENCES, AND EXISTING SELF-REPORT MEASURES

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# SEXUALITY AND HEAD AND NECK CANCER

**Sexuality is an important factor in patient QOL,  
but we do not fully understand the full impact  
HNC and its treatment has on sexuality**

# SEXUALITY AND HNC SURVIVORSHIP

- Changing demographics
  - Improved treatments have increased survival
  - HPV-related disease is related to increased survival
  - Earlier age of onset results in potentially longer survival at a younger age

# SEXUALITY AND HEAD AND NECK CANCER

## **Measuring sexuality as a part of QOL**

- There are a number of tools that measure sexual QOL, but none are tailored for HNC
- We do not know how these tools perform in relation to one another nor how well they may assess the needs of patients.
- We want to define the gap that exists in assessment of HNC impact on sexuality

- **Aim 1:** To examine the priorities and preferences of patients with head and neck cancer in regards to discussing and receiving information about sexuality from healthcare professionals
- **Aim 2:** To examine patient perceptions of existing self-report measures used to assess sexuality in patients with head and neck cancer

# WHO

- > 21 years of age
- Current or previous diagnosis of head and neck cancer
- Able to read and understand English
- Able to access web-based survey

# SURVEY CONTENT

- **Demographic Information Form**
- **Head and Neck Cancer History Form**
- **Priority and Preference for Receiving Sexuality Information Form**

# SURVEY CONTENT

- **General sexuality measures:**
  - **Modified Sexual Adjustment Questionnaire (7 items)**
    - quantifies the effects of cancer treatment on sexuality in the individual
  - **Derogatis Sexual Functioning Inventory – Sexual Satisfaction Scale (10 items)**
    - true-false items, each reflecting whether or not the respondent is satisfied with that specific aspect of his/her sexual functioning

# SURVEY CONTENT

- **Head and Neck Cancer specific quality of life measures:**
  - **Functional Assessment of Cancer Therapy – Head and Neck: Head and Neck (FACT-H&N) 27 items:**
    - assesses patient function in four domains: physical, social/family, emotional, and functional well-being
    - further supplemented by 12 site-specific items to assess for head and neck related symptoms.
  - **European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer Survey. ) 35 items:**
    - quality of life of head and neck cancer patients
    - contains one item that addresses being bothered by appearance and one item that addresses sexual enjoyment

# SURVEY CONTENT

- **Patient Perception of Self-Report Measure Questionnaires:**
  - **Patient Perception of the Modified Sexual Adjustment Questionnaire (4 items)**
  - **Patient Perception of the Derogatis Sexual Functioning Inventory – Sexual Satisfaction Scale (4 items)**
  - **Patient Perception of the Functional Assessment of Cancer Therapy – Head and Neck (4 items)**
  - **Patient Perception of the European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer Survey (4 items)**

# PATIENT PREFERENCE OF TIMING

[illegible]

# SURVEY CONTENT:

## MODIFIED SEXUAL ADJUSTMENT QUESTIONNAIRE

### Modified Sexual Adjustment Questionnaire

1. What is the importance of sexual activity in your life?

☐ Extremely important   ☐ Very important   ☐ Important   ☐ Slightly important   ☐ Of no importance

2. Do you enjoy sexual activity?

☐ Always   ☐ Almost always   ☐ Sometimes   ☐ Almost never   ☐ Never

3. Do you have a desire for sexual activity?

☐ Always   ☐ Almost always   ☐ Sometimes   ☐ Almost never   ☐ Never

4. Do you feel satisfied after sexual activity?

☐ Always   ☐ Almost always   ☐ Sometimes   ☐ Almost never   ☐ Never

5. How often do you have sexual activity?

☐ More than twice a week  
☐ 1-2 times a week  
☐ 1-3 times a month  
☐ Less than once a month  
☐ Not at all

6. Are you satisfied with the frequency of sexual activity in your life?

☐ Very satisfied   ☐ Somewhat satisfied   ☐ Neutral   ☐ Somewhat unsatisfied   ☐ Very unsatisfied

7. Have you been the one to initiate (start) sexual activity with your partner(s) since your last cancer treatment?

☐ Always   ☐ Almost always   ☐ Sometimes   ☐ Almost never   ☐ Never

Thank you for completing page 4 of 11 pages.

Please click "Submit" to move to the next page.

# PATIENT PERCEPTION: MODIFIED SEXUAL QDJUSTMENT QUESTIONNAIRE

Perception Questions: Modified Sexual Adjustment Questionnaire

Now that you have reviewed the Modified Sexual Adjustment Questionnaire, we would like you to answer the following questions. Keep in mind, the purpose of this tool is to capture information for research purposes regarding sexuality (sexual function and sexual wellbeing). We want to know if the Modified Sexual Adjustment Questionnaire captures the breadth of issues related to sexuality that you as a patient with head and neck cancer have experienced.

1. In your opinion, is the Modified Sexual Adjustment Questionnaire applicable for patients with head and neck cancer?

☐ Yes ☐ No ☐ Unsure

Comments:

2. In your opinion, does the Modified Sexual Adjustment Questionnaire adequately examine sexuality (sexual function and sexual wellbeing) for patients with head and neck cancer?

☐ Yes ☐ No ☐ Unsure

Comments:

3. In your opinion, are there issues related to sexuality (sexual function and sexual wellbeing) that are not adequately captured in the Modified Sexual Adjustment Questionnaire?

☐ Yes ☐ No ☐ Unsure

What are those issues?

Comments:

4. Please share your general comments about the Modified Sexual Adjustment Questionnaire.

# SURVEY CONTENT:

## DEROGATIS SEXUAL FUNCTIONING INVENTORY

Derogatis Sexual Functioning Inventory - Sexual Satisfaction Scale		
Below are some statements about sexual satisfaction. Please indicate whether each statement is true of you by checking either true or false for each statement.		
	True	False
1. Usually, I am satisfied with my sexual partner	<input type="radio"/>	<input type="radio"/>
2. I feel I do not have sex frequently enough	<input type="radio"/>	<input type="radio"/>
3. There is not enough variety in my sex life	<input type="radio"/>	<input type="radio"/>
4. Usually, after sex I feel relaxed and fulfilled	<input type="radio"/>	<input type="radio"/>
5. Usually, sex does not last long enough	<input type="radio"/>	<input type="radio"/>
6. I am not very interested in sex	<input type="radio"/>	<input type="radio"/>
7. Usually, I have a satisfying orgasm with sex	<input type="radio"/>	<input type="radio"/>
8. Foreplay before intercourse is usually very arousing for me	<input type="radio"/>	<input type="radio"/>
9. Often, I worry about my sexual performance	<input type="radio"/>	<input type="radio"/>
10. Usually, my partner and I have good communication about sex	<input type="radio"/>	<input type="radio"/>

# PATIENT PERCEPTION: DEROGATIS SEXUAL FUNCTIONING INVENTORY

## Perception Questions: Derogatis Sexual Functioning Inventory - Sexual Satisfaction Scale

Now that you have reviewed the Derogatis Sexual Functioning Inventory - Sexual Satisfaction Scale, we would like you to answer the following questions. Keep in mind, the purpose of this tool is to capture information for research purposes regarding sexuality (sexual function and sexual wellbeing). We want to know if the Derogatis Sexual Functioning Inventory - Sexual Satisfaction Scale captures the breadth of issues related to sexuality that you as a patient with head and neck cancer have experienced.

1. In your opinion, is the Derogatis Sexual Functioning Inventory - Sexual Satisfaction Scale applicable for patients with head and neck cancer? ☐ Yes ☐ No ☐ Unsure

Comments:

2. In your opinion, does the Derogatis Sexual Functioning Inventory - Sexual Satisfaction Scale adequately examine sexuality (sexual function and sexual wellbeing) for patients with head and neck cancer? ☐ Yes ☐ No ☐ Unsure

Comments:

3. In your opinion, are there issues related to sexuality (sexual function and sexual wellbeing) that are not adequately captured in the Derogatis Sexual Functioning Inventory - Sexual Satisfaction Scale? ☐ Yes ☐ No ☐ Unsure

What are those issues?

Comments:

4. Please share your general comments about Derogatis Sexual Functioning Inventory - Sexual Satisfaction Scale.

SURVEY  
CONTENT:

FACT-H&N  
1

FACT-H&N (Version 4)

Below is a list of statements that other people with your illness have said are important.  
Please choose one button per line to indicate your response as it applies to the past 7 days.

PHYSICAL WELL-BEING

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have nausea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my physical condition, I have troublemeeting the needs of my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am bothered by side effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am forced to spend time in bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# SURVEY CONTENT:

## FACT-H&N 2

SOCIAL/FAMILY WELL-BEING					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get emotional support from my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get support from my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My family has accepted my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with family communication about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel close to my partner (or the person who is my main support)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Regardless of your current level of sexual activity, please answer the following question. ☐ I prefer not to answer

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am satisfied with my sex life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SURVEY  
CONTENT:

FACT-H&N  
3

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

**EMOTIONAL WELL-BEING**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with how I am coping with my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am losing hope in the fight against my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry that my condition will get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# SURVEY CONTENT:

## FACT-H&N 4

FUNCTIONAL WELL-BEING					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work (include work at home)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My work (include work at home) is fulfilling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to enjoy life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have accepted my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am sleeping well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am enjoying the things I usually do for fun	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am content with the quality of my life right now	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# SURVEY CONTENT:

## FACT-H&N 5

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.					
ADDITIONAL CONCERNS					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to eat the foods that I like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My mouth is dry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have trouble breathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My voice has its usual quality and strength	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to eat as much food as I want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am unhappy with how my face and neck look	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can swallow naturally and easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I smoke cigarettes or other tobacco products	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I drink alcohol (e.g. beer, wine, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to communicate with others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I can eat solid foods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have pain in my mouth, throat or neck	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# PATIENT PERCEPTION: FACT-H&N

## Perception Questions: Functional Assessment of Cancer Therapy - Head and Neck

Now that you have reviewed the Functional Assessment of Cancer Therapy - Head and Neck survey, we would like you to answer the following questions. We want to know if the Functional Assessment of Cancer Therapy - Head and Neck survey captures the breadth of issues related to sexuality that you as a patient with head and neck cancer have experienced.

1. In your opinion, is the Functional Assessment of Cancer Therapy - Head and Neck survey applicable for patients with head and neck cancer? ☐ Yes ☐ No ☐ Unsure

Comments

2. In your opinion, does the Functional Assessment of Cancer Therapy - Head and Neck survey adequately examine sexuality (sexual function and sexual wellbeing) for patients with head and neck cancer? ☐ Yes ☐ No ☐ Unsure

Comments

3. In your opinion, are there issues related to sexuality (sexual function and sexual wellbeing) that are not adequately captured in the Functional Assessment of Cancer Therapy - Head and Neck survey? ☐ Yes ☐ No ☐ Unsure

What are those issues?

Comments

4. Please share your general comments about the Functional Assessment of Cancer Therapy - Head and Neck survey.

# SURVEY CONTENT:

## EORTC HN-35

1

### EORTC QLQ - H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you. During the past week:

	Not at all	A little	Quite a bit	Very much
Have you had pain in your mouth?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had pain in your jaw?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had soreness in your mouth?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had a painful throat?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had problems swallowing liquids?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had problems swallowing pureed food?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had problems swallowing solid food?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you choked when swallowing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had problems with your teeth?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had problems opening your mouth wide?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had a dry mouth?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had sticky saliva?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had problems with your sense of smell?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had problems with your sense of taste?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you coughed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been hoarse?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt ill?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has your appearance bothered you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# SURVEY CONTENT:

## EORTC HN-35 2

During the past week:	Not at all	A little	Quite a bit	Very much
Have you had trouble eating?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble eating in front of your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble eating in front of other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble enjoying your meals?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble talking to other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble talking on the telephone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble having social contact with your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble having social contact with friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble going out in public?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble having physical contact with family or friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt less interest in sex?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt less sexual enjoyment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# SURVEY CONTENT:

## EORTC HN-35

3

During the past week:		
	No	Yes
Have you used pain-killers?	<input type="radio"/>	<input type="radio"/>
Have you taken any nutritional supplements (excluding vitamins)?	<input type="radio"/>	<input type="radio"/>
Have you used a feeding tube?	<input type="radio"/>	<input type="radio"/>
Have you lost weight?	<input type="radio"/>	<input type="radio"/>
Have you gained weight?	<input type="radio"/>	<input type="radio"/>

# PATIENT PERCEPTION: EORTC HN-35

## Perception Questions: European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer

Now that you have reviewed the European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer survey, we would like you to answer the following questions. We want to know if the European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer survey captures the breadth of issues related to sexuality that you as a patient with head and neck cancer have experienced.

1. In your opinion, is the European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer survey applicable for patients with head and neck cancer? ☐ Yes ☐ No ☐ Unsure

Comments:

2. In your opinion, does the European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer survey adequately examine sexuality (sexual function and sexual wellbeing) for patients with head and neck cancer? ☐ Yes ☐ No ☐ Unsure

Comments:

3. In your opinion, are there issues related to sexuality (sexual function and sexual wellbeing) that are not adequately captured in the European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer survey? ☐ Yes ☐ No ☐ Unsure

What are those issues?

Comments:

4. Please share your general comments about European Organization for Research and Treatment of Cancer Quality of Life for Head and Neck Cancer survey.

# OVERALL STUDY GOALS

- 1) Support the timing and manner of patient-centered discussions around sexuality**
- 2) Support the development of a HNC-specific sexuality self-report measure**
- 3) Provide information that may assist in informing the timing of interventions aimed at improving issues related to sexuality in survivors of HNC**

# HOW TO PARTICIPATE

- Location: Web-based survey
- Time commitment: 20-30 minutes
- Access study via

- Web address:

<https://redcap.vanderbilt.edu/surveys/?s=HYLHYHRN79>

- QR code:



**HAVE YOU EVER HAD HEAD AND NECK CANCER?**

IF SO, WE WANT TO HEAR FROM YOU!

**HEAD AND NECK CANCER AND SEXUALITY RESEARCH STUDY**

If you are over the age of 21 and have access to a computer, you may be eligible to participate.

Participation will require filling out online surveys. We hope the results from this study will help to create resources about sexuality (sexual function and sexual wellbeing) for future patients with head and neck cancer.

IF YOU ARE INTERESTED IN PARTICIPATING, PLEASE GO TO:  
[HTTPS://REDCAP.VANDERBILT.EDU/SURVEYS/?S=HYLHYHRN79](https://redcap.vanderbilt.edu/surveys/?s=HYLHYHRN79)  
OR SCAN THE QR CODE:



You can also call 615-343-1838, toll free 1-833-402-8664 or email Dr. Bethany Rhoten and her research team ([vusnoncresearch@vanderbilt.edu](mailto:vusnoncresearch@vanderbilt.edu)) with any questions you may have about this research study.

Date of IRB Approval: 03/27/2018

Institutional Review Board

