This study is about human papillomavirus (HPV), which has been linked to some Head & Neck (H&N) cancers. This study explores what H&N cancer survivors know about HPV. If you had a HPV-related cancer, this survey will ask about your experiences.

This survey is completely voluntary and all of the responses will be kept private and separate from any identifying information.

To answer a question, please enter a ☑ or a ☒ in the box next to your answer.
Were you diagnosed with a HPV-related head & neck cancer?
(Mark one and follow the instructions.)

☐ Yes ➔ (start on the next page)

☐ No ➔ (Please go directly to page 7)
SECTION ONE

The next questions help us learn about your experience with the diagnosis of HPV. Please answer the questions openly and truthfully.

Before your diagnosis of cancer, had you heard of HPV? (select the most correct statement)
- No, I had never heard of HPV.
- Yes, but did not know much about HPV.
- Yes, and I knew a lot about HPV.

When you were told that your cancer was related to HPV, were you taught about HPV?
- Yes
- No

At that time, how satisfied were you with the amount of information you received about HPV? (Choose one)
- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied

Did you seek more information about HPV?
- Yes
- No (If no, please check, then skip the next page and go to page 5).
Please mark where you FIRST looked for information about HPV. (Mark only ONE)
☐ Books
☐ Brochures, pamphlets
☐ Primary care provider (Family Doctor)
☐ Friends/family
☐ Internet
☐ Magazines
☐ Newspapers
☐ Complementary, alternative, or unconventional practitioner
☐ Other (________________________)

How helpful were the following sources of information about HPV?
(Mark one response for each)

<table>
<thead>
<tr>
<th></th>
<th>Not Used</th>
<th>Very helpful</th>
<th>Somewhat helpful</th>
<th>Not helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Books</td>
<td></td>
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<td>Brochures, pamphlets</td>
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<tr>
<td>Complementary, alternative, or unconventional practitioner</td>
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<tr>
<td>Other: (________________________)</td>
<td></td>
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</table>
SECTION TWO

For the following questions, please select how True or Untrue each statement is for you.

I know a lot about HPV.

☐ Very true
☐ Somewhat true
☐ A little true
☐ Not true at all

Knowing the facts about HPV is important to me.

☐ Very true
☐ Somewhat true
☐ A little true
☐ Not true at all

Because my cancer was HPV-related, not HPV-negative, I feel more optimistic about my future.

☐ Very true
☐ Somewhat true
☐ A little true
☐ Not true at all

HPV rarely crosses my mind.

☐ Very true
☐ Somewhat true
☐ A little true
☐ Not true at all

I am worried about spreading HPV to others.

☐ Very true
☐ Somewhat true
☐ A little true
☐ Not true at all

I feel embarrassed or ashamed because of HPV.

☐ Very true
☐ Somewhat true
☐ A little true
☐ Not true at all

Having HPV has hurt my relationship with my sexual partner(s).

☐ Very true
☐ Somewhat true
☐ A little true
☐ Not true at all
☐ Not applicable (no sexual partners since diagnosis)

I have told my sexual partner(s) about the HPV diagnosis.

☐ True
☐ False
☐ Not applicable (no sexual partners since diagnosis)
Because of my HPV, I have changed how often I engage in the following behaviors (select best answer for each behavior):

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Not applicable (not before or after)</th>
<th>More often</th>
<th>About the same</th>
<th>Less often</th>
<th>Completely stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kissing partner on the lips</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Oral sex – mouth on partner’s genitals</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
</tr>
<tr>
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<td>☐</td>
<td>☐</td>
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<td>☐</td>
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<tr>
<td>Vaginal sex</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
</tr>
<tr>
<td>Anal sex – penetration of anus by partner</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Anal sex – penetration of partner’s anus</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Use condoms</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</tbody>
</table>
SECTION THREE

The next questions are True/False and ask about your knowledge of HPV. If you do not know the answer, please mark "Uncertain."

Please answer the questions in order and do not go back to change answers.

HPV is a sexually transmitted infection.
  □ True
  □ False
  □ Uncertain

HPV can be spread through casual contact like holding hands or kissing the cheek or lips.
  □ True
  □ False
  □ Uncertain

There are many different types of HPV.
  □ True
  □ False
  □ Uncertain

Condom use decreases the risk of spreading HPV.
  □ True
  □ False
  □ Uncertain

HPV can be spread by oral sex.
  □ True
  □ False
  □ Uncertain

Genital warts are caused by HPV.
  □ True
  □ False
  □ Uncertain

HPV can cause an abnormal Pap tests in women.
  □ True
  □ False
  □ Uncertain
HPV and Head and Neck Cancer Survey

**HPV can be cured by antibiotic treatment.**
- True
- False
- Uncertain

**HPV is the most common sexually transmitted infection (STI or STD).**
- True
- False
- Uncertain

**HPV can cause herpes.**
- True
- False
- Uncertain

**In the United States, most tonsil and back of throat (oropharyngeal) cancers are caused by HPV.**
- True
- False
- Uncertain

**HPV infection usually causes some type of symptom(s).**
- True
- False
- Uncertain

**HPV can cause cervical cancer.**
- True
- False
- Uncertain

**Only women get symptoms from HPV.**
- True
- False
- Uncertain

**Usually HPV infections clear up (go away) without treatment.**
- True
- False
- Uncertain
The type of HPV that causes genital warts also can cause cancer.
- True
- False
- Uncertain

HPV can cause anal cancer.
- True
- False
- Uncertain

HPV screening is recommended for sexually active men.
- True
- False
- Uncertain

The HPV vaccine can cure HPV.
- True
- False
- Uncertain

The HPV vaccine is only recommended for females.
- True
- False
- Uncertain
HPV and Head and Neck Cancer Survey

SECTION FOUR

What is your age (in years)? _______

What is your gender?
☐ Male
☐ Female

What is your highest level of education completed? (please mark one)
☐ Grade school or less (K-8)
☐ Some high school
☐ High School Diploma /GED
☐ Some college, no degree
☐ Vocational or Technical School Completion
☐ Associates Degree (2 year college)
☐ Bachelor's Degree (4 Year College Degree)
☐ Advanced College Degree (beyond Bachelor's Degree)

What is your current employment level (mark all that apply)
☐ Full Time Employment
☐ Part Time Employment
☐ Retired
☐ Disability – Permanent
☐ Disability – Temporary
☐ Unemployed, not on disability
☐ Student
☐ Homemaker
☐ Self-employed

What is your marital status?
☐ Married or domestic union
☐ Separated/Divorced
☐ Never married
☐ Widowed

What is your current living situation?
☐ Living with spouse or domestic partner
☐ Not married, but living with romantic partner
☐ Living alone

What is your race or ethnicity? One or more categories may be selected
☐ White
☐ Black or African American
☐ American Indian or Alaska Native
☐ Hispanic, Latino/a, or Spanish origin
☐ Asian
☐ Other _____________________
If there is anything else you would like to share about HPV and head & neck cancer, please share in the space below.

Thank you for your time and thoughtful responses!

Once I receive this survey, I will send you a HPV Fact Sheet that includes information about HPV and how to learn more about HPV.

With great appreciation,

Sean Gallagher, RN, BSN, MA