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Outreach Contact Letter

Dear Cervical Cancer Survivor,

It's always a pleasure for me to share new ways in which you can be active in the Cervivor community.

Today I'd like to tell you about a study that The Centers for Disease Control and Prevention (CDC) is conducting about cervical cancer and a special invitation they have extended to the Cervivor network.

The CDC wants to help prevent women from developing cervical cancer. To do so, they are seeking to better understand women's screening and follow-up experiences prior to their being diagnosed with invasive cervical cancer. Cervical cancer survivors like you and me are invited to share our stories with them by taking an online survey. Results from the study would be used to recommend changes that could improve access to care for other women.

The survey will take about 15 minutes to complete.

The study will not collect any information that could personally identify you, including your name or e-mail address. All information that you share is confidential and will only be used for research purposes. www.Cervivor.org will not have access to your information.

I hope you will join me in completing the survey so that your personal impact story can make a difference.

If you would like to participate, please go to this link to complete the survey, [LINK TO WEB-SURVEY](#).

Thank you,

Tamika Felder

Chief Visionary

Cervivor

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You Are Not Alone: <http://bit.ly/1IQYEKR>

Web-based Survey, Landing Page



Form Approved
OMB No. 0920-1162
Exp. Date 02/28/2019

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[Returning?](#)



Case Investigation of Cervical Cancer Study

(Estudio de Investigación de Casos de Cáncer Cervical)

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Web-based Survey, Language Selection Page



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C&CC Study

Case Investigation of Cervical Cancer Study

Please select your language:

Por favor seleccione su idioma:

- English / Inglés Spanish / Español

reset

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Web-based Survey, Research Information Page



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C&CC Study

Case Investigation of Cervical Cancer Study

Case Investigation of Cervical Cancer (CICC) Study

Your participation in this survey is very important to us. Thank you for sharing your story.

The Centers for Disease Control and Prevention (CDC) wants to better understand women's screening and follow-up experiences prior to their being diagnosed with invasive cervical cancer. Results from the study would be used to recommend changes that could improve access to care for other women. CDC has contracted with the non-profit research institute Battelle to conduct the study.

The survey has questions about your cervical cancer screening history and follow-up of abnormal test results prior to your cancer diagnosis. **It is your choice whether to do the survey. There are no direct benefits to you from taking part in this research,** but your participation could help researchers improve access to cancer care for others by better understanding the experiences of cervical cancer survivors prior to diagnosis.

The study does not provide any medical treatment or care. Your decision to participate will not affect any of your health care benefits or services. Some survey questions related to your cervical cancer experience may cause you distress and you do not have to answer questions that make you feel uncomfortable.

We will not collect any information that could personally identify you, including your name or e-mail address. All information that you share with us is confidential and will only be used for research purposes. www.Cervivor.org will not have access to your information.

We estimate that this survey will take about **15 minutes** to complete.

If you have any questions or difficulty completing the survey, please call April Greek at (206) 528-3167. This survey has been reviewed and approved by the Battelle Institutional Review Board (IRB), a committee tasked to protect the rights, health, safety, and privacy of people who participate in research. If you have any questions about your rights as a survey respondent, you may call Battelle's IRB toll-free at 1-877-810-9530, Ext. 500.

Thank you for your participation.

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Web-based Survey, Screening Questions Page

If "Yes" to both questions, the potential participant is eligible and taken to the first question the survey.



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C&CC Study

Case Investigation of Cervical Cancer Study

Have you ever been diagnosed with invasive cervical cancer?

- Yes
 No

reset

Were you diagnosed at the age of 21 or older?

- Yes
 No

reset

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Submit

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Web-based Survey, Ineligibility Notification

If “No” to either of the screener questions, the potential participant is not eligible for the study.

INELIGIBLE IF:

(1) not diagnosed with invasive cervical cancer

Have you ever been diagnosed with invasive cervical cancer?

Yes

No

OR

(2) under the age of 21 years when diagnosed with invasive cervical cancer

Have you ever been diagnosed with invasive cervical cancer?

Yes

No

Were you diagnosed at the age of 21 or older?

Yes

No

If INELIGIBLE, the potential participant will see the following message:

Thank you for your interest. Unfortunately, we are unable to use your feedback at this time. We are currently seeking responses from cervical cancer survivors who were diagnosed with invasive cervical cancer at the age of 21 or older. If you are interested in alternative ways to support cervical cancer survivors, please return to www.Cervivor.org.

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Submit

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A. CERVICAL CANCER HISTORY

A1. When was the first time that a doctor or other health care professional told you that you had cervical cancer? (Year)

What was your age when you were told that you had cervical cancer?

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A2. Which of the following statements best describes how you were diagnosed with (invasive) cervical cancer for the first time? (Please mark only one.)

- I was diagnosed as part of routine exams (check-ups) or screening tests (NOT because of symptoms or problems I was having).
- I was diagnosed after seeking medical care to check on problems or symptoms I was having.
- Other:

reset

Specify:

Comments:

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Note: Question A2, "Other" option is selected to show the "Specify" response box.

The next questions will ask you about your Pap and HPV screening history. A Pap test checks your cervix for abnormal cells that could turn into cervical cancer.

During a Pap test, an instrument is inserted into the vagina. This widens the vagina so that the upper portion of the vagina and the entire cervix can be seen. Your doctor then uses a small spatula or brush to gently scrape the surface of the cervix to pick up cells which are then examined under the microscope.

An HPV test checks your cervix for the virus (HPV) that can cause abnormal cells and lead to cervical cancer. The HPV test can find the HPV virus by testing cells collected at the same time as a Pap test.

A3. Prior to your diagnosis, how often did you get cervical cancer screening (Pap test or HPV test) tests? (Please mark only one.)

- More than once a year
- Once a year
- Once every 2 or 3 years
- Every 3-5 years
- Less than every 5 years
- Not regularly screened
- No Pap test prior to cervical cancer diagnosis

reset

Comments:

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SKIP PATTERN:

If Question A4 is answered "No" survey proceeds to question A5.

If Question A4 is answered "Yes" survey skips to question A6.



Case Investigation of Cervical Cancer Study

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A4. In the five years prior to your cancer diagnosis, did you get any cervical cancer screening tests (excluding the test that led to your cervical cancer diagnosis)?

- Yes
- No

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Question A5 (continued), Response options “a” – “j”



Case Investigation of Cervical Cancer Study

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A5. We want to better understand why you may not have gotten screened within the 5 years prior to your diagnosis. There may have been a variety of reasons. Please answer *Agree, Disagree or I don't remember/I don't know* to the following statements. Remember that this question refers to **BEFORE your diagnosis with cervical cancer (not at the present time).**

In the 5 years prior to your diagnosis why DIDN'T you get screened?

	Agree	Disagree	I don't remember / I don't know	
a. I did not know what a cervical cancer screening test (Pap test or HPV test) was for	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
b. I never imagined that I would ever develop cervical cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
c. I thought screening tests were only for women who had symptoms of cervical cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
d. I was afraid that the screening test might cause cervical cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
e. I had been previously screened for cervical cancer and did not think I had to have this test again	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
f. I was scared it would hurt or be uncomfortable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
g. I felt embarrassed about the process of getting a screening test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
h. It was against my religious or cultural beliefs to get cervical cancer screening tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
i. I was afraid that I might be diagnosed with cervical cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset
j. I had other health concerns that were more important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
				reset

(survey “Page 5 of 19” is continued on the next page)

Question A5 (continued), Response options “k” – “z”

k. The clinic hours were inconvenient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
l. I just never got around to it. I was busy and didn't have the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
m. I needed someone else to go with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
n. I forgot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
o. My health care provider did not tell me that I needed a screening test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
p. I knew I needed a screening test but my health care provider did not do screening tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
q. I did not have a regular health care provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
r. I did not trust health care providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
s. I did not have health insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
t. I could not afford to be away from my job while getting a screening test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
u. The screening test was too costly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
v. Transportation to get to the screening test was too expensive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
w. I could not pay for child care in order to go to the clinic to get tested	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
x. I was afraid since I had a friend or family member who was diagnosed with cervical cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
y. I did not have a family history of cervical cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
z. I did not have a family history of cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

(survey “Page 5 of 19” is continued on the next page)

Question A5 (continued), Response options "aa" - "dd" and "Other"

aa. I am not comfortable speaking English	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
bb. I was no longer sexually active	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
cc. I did not think I was due to come back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
dd. I did not want to be weighed at the doctor's office	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Other Reasons or Comments:

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20% Complete

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A6. We want to better understand why you did get screened within the 5 years prior to your diagnosis. There may have been a variety of reasons. Please answer *Agree, Disagree or I don't remember/I don't know* to the following statements. Remember that this question refers to **BEFORE your diagnosis with cervical cancer (not at the present time).**

In the 5 years prior to your diagnosis why DID you get screened?

	Agree	Disagree	I don't remember / I don't know	
a. I had cervical cancer screening tests (Pap test or HPV test) with my annual exam	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
b. I had a screening test previously and knew what to expect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
c. My health care provider told me that I needed a screening test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
d. A friend or family member recommended that I get a screening test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
e. I know a friend or family member who was diagnosed with cervical cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
f. I understood the importance of screening tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
g. I wanted to take care of my body.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
h. Screening tests were covered by my insurance (in part or all)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
i. I had an abnormal test in the past	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Other Reasons or Comments:

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Question A7, Pap Test Results with example response for year of first Pap test entered to show response options for test results



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A7. Please list the year of each Pap or HPV test you had in the 5 years prior to your cancer diagnosis and the test outcome (Normal, Abnormal, or Don't know).

Pap Test Results

No PAP test done in 5 years prior to diagnosis:

Pap #1, Year

Pap #1, Result

Normal Abnormal Don't know

[reset](#)

Pap #2, Year

Pap #3, Year

Pap #4, Year

Pap #5, Year

Pap #6, Year

Pap #7, Year

Pap #8, Year

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Question A7 (continued), HPV Test Results with example response for year of first HPV test entered to show response options for test results

HPV Test Results

No HPV test done in 5 years prior to diagnosis:

HPV #1, Year 2015

HPV #1, Result
 Normal Abnormal Don't know reset

HPV #2, Year

HPV #3, Year

HPV #4, Year

HPV #5, Year

HPV #6, Year

HPV #7, Year

HPV #8, Year

Comments:
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35% Complete

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SKIP PATTERN:

If “Yes, as recommended by my doctor” or “Yes, but I waited longer than recommended”, proceed to question A9.

Otherwise, skip to question A10.



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A8. If you had an abnormal Pap or HPV test result in the 5 years prior to or leading to your diagnosis, did you follow up with your doctor as recommended about this result? (Please mark only one.)

- Yes, as recommended by my doctor
- Yes, but I waited longer than recommended
- No, did not follow up
- I did not have an abnormal Pap or HPV test
- I have never had a Pap or HPV test

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Question A9, response options “a” - “n”



Case Investigation of Cervical Cancer Study

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A9. If you did not follow up with your doctor or waited longer than recommended after an abnormal test, please answer either Agree, Disagree or I don't remember/I don't know to the following statements.

If you had an abnormal test result, why DIDN'T you follow up with your doctor or waited longer than recommended?

	Agree	Disagree	I don't remember / I don't know	
a. I felt embarrassed about the abnormal result	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
b. I was scared to hear what the abnormal result meant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
c. I did not trust the abnormal test results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
d. I did not realize that the abnormal result could indicate cervical cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
e. My health care provider did not say I needed to follow up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
f. Clinic hours were inconvenient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
g. I wanted someone else to go with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
h. I did not have transportation to get to the clinic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
i. I forgot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
j. I was busy and didn't have the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
k. I was worried about the cost of the follow-up appointment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
l. I was worried about the cost of future treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
m. Transportation to get to the screening test was too expensive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
n. I could not pay for child care in order to go to the clinic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

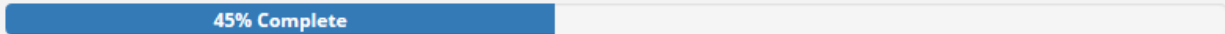
(survey “Page 9 of 19” is continued on the next page)

Question A9 (continued), response options “o” - “s” and “Other”

o. Being away from my job while getting a screening test was too expensive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
p. I did not have health insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
q. I did not have health insurance that covered the additional procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
r. I am not comfortable speaking English	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
s. I felt uncomfortable with my provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Comments:

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A10. In the five years prior to your cancer diagnosis, what other preventive care did you receive?

*** If you were not the appropriate age, please mark *Not needed / Not required*.**

	Yes	No	* Not needed / Not required
a. Colorectal exam (i.e., fecal occult blood test [FOBT], sigmoidoscopy, colonoscopy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Mammogram	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Flu shot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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reset

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49% Complete

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A11. Prior to your cancer diagnosis, did you have a tubal ligation or tubal sterilization (i.e., have both of your tubes tied, cut, or removed)?

- Yes
- No

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B. HEALTH INSURANCE

B1. At the time of your cancer diagnosis, which type of health insurance did you have? (Please mark all that apply.)

- Private insurance (Kaiser, Blue Cross, Aetna, work, group, etc.)
- Medicare (including Medicare managed care)
- Military or Veterans Administration
- Public insurance (Medicaid, other county or state public insurance)
- No insurance (Self-pay for all health care costs)
- Other:

Specify:

Expand

52% Complete

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Note: Question B1 response option "Other" is selected to show "Specify" text box.

B2. During the five years prior to your cervical cancer diagnosis, were you covered by health insurance that paid for all or part of your medical care?

- Yes
- No

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B2-b. During the five years prior to your cervical cancer diagnosis, was there ever a time when your health insurance did not provide adequate coverage for your medical needs?

- Yes
- No

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Note: Question B2 response option "Yes" is selected to show question B2-b.

B3. During the five years prior to your cervical cancer diagnosis, was there a particular doctor's office, clinic, health center, or other place that you usually went to if you were sick or needed care? (Please mark only one.)

- Yes, a doctor's office, clinic, or health center
- Yes, an urgent care clinic or ER
- No

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Question C1, options “a” - “m”.



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C. OTHER MEDICAL CONDITIONS

C1. Prior to your cervical cancer diagnosis, were you ever told by a doctor or health care professional that you had any of the following medical conditions?

	Yes	No	
a. Arthritis	<input type="radio"/>	<input type="radio"/>	reset
b. Asthma	<input type="radio"/>	<input type="radio"/>	reset
c. Diabetes	<input type="radio"/>	<input type="radio"/>	reset
d. Emphysema or Chronic Obstructive Pulmonary Disease (COPD)	<input type="radio"/>	<input type="radio"/>	reset
e. Kidney problems or failure	<input type="radio"/>	<input type="radio"/>	reset
f. Chronic liver condition	<input type="radio"/>	<input type="radio"/>	reset
g. Heart problems (heart attack, coronary artery/heart disease, stroke, irregular heartbeat, etc.)	<input type="radio"/>	<input type="radio"/>	reset
h. Hypertension or high blood pressure	<input type="radio"/>	<input type="radio"/>	reset
i. Depression (feeling sad) that required treatment	<input type="radio"/>	<input type="radio"/>	reset
j. Anxiety (nervousness) that required treatment	<input type="radio"/>	<input type="radio"/>	reset
k. Severe problems with memory or concentration	<input type="radio"/>	<input type="radio"/>	reset
l. Osteoporosis (fragile or soft bones)	<input type="radio"/>	<input type="radio"/>	reset
m. Stomach and/or intestinal problems (Crohn's disease, ulcers, inflammatory bowel disease, etc.)	<input type="radio"/>	<input type="radio"/>	reset

(survey “Page 15 of 19” is continued on the next page)

Question C1 (continued)

n. Cancer (other than cervical cancer)	<input checked="" type="radio"/>	<input type="radio"/>	reset
Other (Specify)	<input checked="" type="radio"/>	<input type="radio"/>	reset
Other (Specify)	<input type="radio"/>	<input type="radio"/>	reset
Cancer (other than cervical cancer), <u>year of diagnosis:</u>	<input type="text" value="2012"/> <input type="button" value="v"/>		
Other Medical Condition 1:	<input type="text" value="gout"/>		
gout, <u>year of diagnosis:</u>	<input type="text"/> <input type="button" value="v"/>		
<div style="background-color: #0070C0; color: white; padding: 5px; text-align: center;">70% Complete</div>			
<input type="button" value=" << Previous Page"/>		<input type="button" value=" Next Page >>"/>	

Note: Options "n" and "Other" have example answers to display follow up response options.

D. DEMOGRAPHICS

D1. Are you of Hispanic or Latina origin?

Yes

No

[reset](#)

D2. What is your race or racial heritage? (Please mark all that apply.)

White or Caucasian

Black or African American

Asian

American Indian or Alaska Native

Native Hawaiian or other Pacific Islander

D3. At the time of your cervical cancer diagnosis, what was your marital status? (Please mark only one.)

Married

Widowed

Divorced

Separated

Never married

Living with partner

[reset](#)

D4. a. At the time of your cervical cancer diagnosis, which of the following categories best described your annual household income? (Please mark only one.)

Less than \$10,000

\$10,000 to \$19,999

\$20,000 to \$29,999

\$30,000 to \$39,999

\$40,000 to \$49,999

\$50,000 to \$69,999

\$70,000 to \$89,999

\$90,000 or more

I don't know

[reset](#)

(survey "Page 16 of 19" is continued on the next page)

b. At the time of your cervical cancer diagnosis, how many people were supported by the total income for your household, including yourself? (Please mark only one.)

- 1 (just you)
- 2
- 3
- 4 or more

[reset](#)

D5. In what country were you born?

- USA
- Other

[reset](#)

Please specify the name of the country:

D6. How many years have you lived in the United States continuously?

Years

D7. Are you comfortable speaking English?

- Yes
- No

[reset](#)

D8. What is your age in years?

Years

85% Complete

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Note: Question D5 response option "Other" is selected to display follow up questions.

E. SELF-SAMPLING and HPV VACCINATION

E1. Tests will soon be available that would allow a woman to collect a sample to test for cervical cancer at home or at a health care clinic—a procedure called self-sampling. Prior to your cervical cancer diagnosis, would you have been willing to self-sample if you were given instructions about how to collect the sample?

- Yes
- No
- I'm not sure

reset

E2. Have you received the cervical cancer vaccine (HPV vaccine)?

- Yes
- No
- I'm not sure

reset

E3. If you have children who were eligible for the HPV vaccine, did you have them vaccinated?

- Yes, all eligible children were vaccinated.
- Yes, some but not all eligible children were vaccinated.
- No
- I'm not sure
- I do not have children, or they were not eligible.

reset

If you had children, would you have him/her vaccinated for HPV?

- Yes
- No
- I'm not sure

reset

Note: Question E3 response option "I do not have children..." is selected to display follow up question.

(survey "Page 17 of 19" is continued on the next page)

E4. Prior to your cancer diagnosis were you aware of HPV?

- Yes
- No
- I'm not sure

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95% Complete

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If you would like to share your story, or have additional thoughts or information, please use this page.

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**Thank you for completing the survey.
Please select the submit button below to finalize your responses.**

100% Complete

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Submit

Two new questions in the web-based survey

This information is provided by the cancer registries for the other sample.

#1. On page 1 of 19 in the web-based survey:

What was your age when you were told that you had cervical cancer? (years)

#2. On page 16 of 19 in the web-based survey:

What is your age in years?