Attachment 4a

CICC Survey, English

Form Approved
OMB No. 0920-xxxx
Exp. Date xx/xx/xxxx

Case Investigation of Cervical Cancer (CICC) Study

Sponsored by

The Centers for Disease Control and Prevention

Tips for Filling out the Survey

- Please share your honest opinions. All of your answers are kept private.
- Please use a **BLACK** or **DARK BLUE** ink pen to mark your answers.
- Be sure to read all of the answer choices before marking your answer.
- Sometimes the instruction will say to skip one or more questions. Look for notes telling you whether you should skip a question. If there is no note, go to the next question.
- Answer all questions by putting an "X" in the box next to your answer, like this:

Example

1. In the past month, did you have any headaches?

   ☒ Yes
   ☐ No → **Go to Question 3**
   ☐ Don't know → **Go to Question 3**

2. In the past month, how many times did you have a headache?

   ☒ 1-2 times
   ☐ 3-5 times
   ☐ 6 times or more
   ☐ Don't know

3.

Please select YES or NO for each item	1YES	2NO
Did you respond to this question?	☒	☐
Are you male?	☐	☒

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?

|__|__| / |__|__|__|__|

MONTH YEAR

A2. Which of the following statements best describes how you were diagnosed with (invasive) cervical cancer for the first time? (Select **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 (Specify):_____

Comments: _____

_____

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 in order 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? (Select **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

Comments: _____

_____

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)?

- ☐ No
- ☐ Yes ☐ **Go to Question A6 on Page 4**

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 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.	❑	❑	❑
b.	I never imagined that I would ever develop cervical cancer.	❑	❑	❑
c.	I thought screening tests were only for women who had symptoms of cervical cancer.	❑	❑	❑
d.	I was afraid that the screening test might cause cervical cancer.	❑	❑	❑
e.	I had been previously screened for cervical cancer and did not think I had to have this test again.	❑	❑	❑
f.	I was scared it would hurt or be uncomfortable.	❑	❑	❑
g.	I felt embarrassed about the process of getting a screening test.	❑	❑	❑
h.	It was against my religious or cultural beliefs to get cervical cancer screening tests.	❑	❑	❑
i.	I was afraid that I might be diagnosed with cervical cancer.	❑	❑	❑
j.	I had other health concerns that were more important.	❑	❑	❑
k.	The clinic hours were inconvenient.	❑	❑	❑
l.	I just never got around to it. I was busy and didn't have the time.	❑	❑	❑

	In the 5 years prior to diagnosis why DIDN'T you get screened?	Agree	Disagree	I don't remember/ I don't know
m.	I needed someone else to go with me.	❑	❑	❑
n.	I forgot.	❑	❑	❑
o.	My health care provider did not tell me that I needed a screening test.	❑	❑	❑
p.	I knew I needed a screening test but my health care provider did not do screening tests.	❑	❑	❑
q.	I did not have a regular health care provider.	❑	❑	❑
r.	I did not trust health care providers.	❑	❑	❑
s.	I did not have health insurance.	❑	❑	❑
t.	I could not afford to be away from my job while getting a screening test.	❑	❑	❑
u.	The screening test was too costly.	❑	❑	❑
v.	Transportation to get to the screening test was too expensive.	❑	❑	❑
w.	I could not pay for child care in order to go to the clinic to get tested.	❑	❑	❑
x.	I was afraid since I had a friend or family member who was diagnosed with cervical cancer.	❑	❑	❑
y.	I did not have a family history of cervical cancer.	❑	❑	❑
z.	I did not have a family history of cancer.	❑	❑	❑
aa.	I am not comfortable speaking English.	❑	❑	❑
bb.	I was no longer sexually active.	❑	❑	❑
cc.	I did not think I was due to come back.	❑	❑	❑
dd.	I did not want to be weighed at the doctor's office.	❑	❑	❑

Other Reasons or Comments:

_____

_____

Please go to Question A8 on Page 5

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 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.	❑	❑	❑
b.	I had a screening test previously and knew what to expect.	❑	❑	❑
c.	My health care provider told me that I needed a screening test.	❑	❑	❑
d.	A friend or family member recommended that I get a screening test.	❑	❑	❑
e.	I know a friend or family member who was diagnosed with cervical cancer.	❑	❑	❑
f.	I understood the importance of screening tests.	❑	❑	❑
g.	I wanted to take care of my body.	❑	❑	❑
h.	Screening tests were covered by my insurance (in part or all).	❑	❑	❑
i.	I had an abnormal test in the past.	❑	❑	❑

Other Reasons or Comments: _____

_____

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 (Select ONE)				**HPV Test Results (Select ONE)**			
Year	**Normal**	**Abnormal**	**Don't know**	**Year**	**Normal**	**Abnormal**	**Don't know**
	❑	❑	❑		❑	❑	❑
	❑	❑	❑		❑	❑	❑
	❑	❑	❑		❑	❑	❑
	❑	❑	❑		❑	❑	❑
	❑	❑	❑		❑	❑	❑

Comments: _____

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? (Select **ONE**)

- ☐ Yes, as recommended by my doctor ☐ **Go to Question A10 on Page 6**
- ☐ Yes, but I waited longer than recommended
- ☐ No, did not follow up
- ☐ I did not have an abnormal Pap or HPV test ☐ **Go to Question A10 on Page 6**

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 'don't remember/don't know' to the following statements.

	If you had an abnormal test result, why <u>DIDN'T</u> 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.	❑	❑	❑
b.	I was scared to hear what the abnormal result meant.	❑	❑	❑
c.	I did not trust the abnormal test results.	❑	❑	❑
d.	I did not realize that the abnormal result could indicate cervical cancer.	❑	❑	❑
e.	My health care provider did not say I needed to follow up.	❑	❑	❑
f.	Clinic hours were inconvenient.	❑	❑	❑
g.	I wanted someone else to go with me.	❑	❑	❑
h.	I did not have transportation to get to the clinic.	❑	❑	❑
i.	I forgot.	❑	❑	❑
j.	I was busy and didn't have the time.	❑	❑	❑
k.	I was worried about the cost of the follow-up appointment.	❑	❑	❑
l.	I was worried about the cost of future treatment.	❑	❑	❑

m.	Transportation to get to the screening test was too expensive.	❑	❑	❑

	If you had an abnormal test result, why <u>DIDN'T</u> you follow up with your doctor or wait longer than recommended?	**Agree**	**Disagree**	**I don't remember/ I don't know**
n.	I could not pay for child care in order to go to the clinic.	❑	❑	❑
o.	Being away from my job while getting a screening test was too expensive.	❑	❑	❑
p.	I did not have health insurance.	❑	❑	❑
q.	I did not have health insurance that covered the additional procedures.	❑	❑	❑
r.	I am not comfortable speaking English.	❑	❑	❑
s.	I felt uncomfortable with my provider.	❑	❑	❑

Other Reasons or Comments:_____

_____

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

		Yes	**No**	*** Not needed/required**
a.	Colorectal exam (i.e., fecal occult blood test [FOBT], sigmoidoscopy, colonoscopy)	❑	❑	❑
b.	Mammogram	❑	❑	❑
c.	Flu shot	❑	❑	❑

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

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

B. HEALTH INSURANCE

B1. At the time of your cancer diagnosis, which type of health insurance did you have? (Select 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): _____

B2. a. 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 ☐ **Go to Question B3 below**

B2b. 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

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

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

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?

	Diagnosis	Yes	No	If Yes, year of diagnosis
a.	Arthritis	❑	❑	_____
b.	Asthma	❑	❑	_____
c.	Diabetes	❑	❑	_____
d.	Emphysema or Chronic Obstructive Pulmonary Disease (COPD)	❑	❑	_____
e.	Kidney problems or failure	❑	❑	_____
f.	Chronic liver condition	❑	❑	_____
g.	Heart problems (heart attack, coronary artery/heart disease, stroke, irregular heartbeat, etc.)	❑	❑	_____
h.	Hypertension or high blood pressure	❑	❑	_____
i.	Depression (feeling sad) that required treatment	❑	❑	_____
j.	Anxiety (nervousness) that required treatment	❑	❑	_____
k.	Severe problems with memory or concentration	❑	❑	_____
l.	Osteoporosis (fragile or soft bones)	❑	❑	_____
m.	Stomach and/or intestinal problems (Crohn's disease, ulcers, inflammatory bowel disease, etc.)	❑	❑	_____
n.	Other (Specify): _____ _____	❑	❑	_____
o.	Other (Specify): _____ _____	❑	❑	_____
p.	Other (Specify): _____ _____	❑	❑	_____

D. DEMOGRAPHICS

D1. Are you of Hispanic or Latina origin?

- ☐ Yes
- ☐ No

D2. What is your race or racial heritage? Please select 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 select **ONE**.

- ☐ Married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated
- ☐ Never married
- ☐ Living with partner

D4. At the time of your cervical cancer diagnosis, which of the following categories best described your annual household income?

- ☐ 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

D4b. At the time of your cervical cancer diagnosis, how many people were supported by the total income for your household, including yourself? (Select **ONE**)

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

D5. Were you born on the island of Puerto Rico, in the United States, or in another country?

- ☐ USA → **Go to Question D7**
- ☐ Puerto Rico
- ☐ Other (Specify): _____

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

|___|___| Years

D7. Are you comfortable speaking English?

- ☐ Yes
- ☐ No

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

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

- ☐ Yes
- ☐ No
- ☐ I'm not sure

E3a. 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

Go to Question E4

- ☐ I do not have children, or they were not eligible. **Go to Question E3b**

E3b. If you had children, would you have him/her vaccinated for HPV?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

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

- ☐ Yes
- ☐ No
- ☐ I'm not sure

Thank you for completing the survey.

If you would like to share your story, or have any additional thoughts or information, please use the space on the next page.

Please place the survey in the self-addressed, stamped envelope.