CAROLINA ENDOMETRIAL CANCER STUDY

University of North Carolina at Chapel Hill
Lineberger Comprehensive Cancer Center – North
1700 Martin Luther King Jr Blvd
CB# 7294 | Room 323
Chapel Hill, NC 27599-7294

FOLLOW-UP #01

MAIL-IN SURVEY

SECTION A: INTRODUCTORY STATEMENT

Thank you for agreeing to share with us more about your endometrial cancer experience. All of the information you provide today will be kept confidential. You can choose not to answer any questions you do not want to answer. We will send you $40 within four weeks of completing this follow-up survey.

SECTION B: GIFT CARD / ADDRESS INFORMATION

First, I'd like to verify phone information so that we may process gift card payments and confirm any address changes since our last contact.

B1a. The preferred number we have recorded for you is **«primary_phone»**. Is this correct?

☐ Yes ➔ **SKIP TO B2a**
☐ No

B1b. What is your preferred phone number? ____ ____ ____ - ____ ____ ____ - ____ ____ ____ ____

B1c. Is this number a cell, home or work phone?

☐ Cell
☐ Home
☐ Work
☐ Other, specify: _____

B2a. The mailing address we have on file for you is:

«mail_addr1»
«mail_addr2»
«mail_city», «mail_state» «mail_zip»

Is this your preferred mailing address?

☐ Yes ➔ **SKIP TO B3a**
☐ No

B2b. What is your preferred mailing address?

_____
_____
_____

B3a. Is the address listed above your physical / residential address?

☐ Yes ➔ **SKIP TO B3c**
☐ No

B3b. What is your current physical / residential address?

_____

_____

_____

B3c. When did you begin living at this address?

____ ____ / ____ ____ ____ ____
Month Year

B4a. Have you lived at any other physical / residential addresses since you enrolled in the study?

☐ Yes

☐ No ➔ **SKIP TO Section C**

B4b. Please list any additional physical / residential addresses since you enrolled in the study:

Address 1:

_____

_____

_____

From: ____ ____ / ____ ____ ____ ____ To: ____ ____ / ____ ____ ____ ____
Month Year Month Year

Address 2:

_____

_____

_____

From: ____ ____ / ____ ____ ____ ____ To: ____ ____ / ____ ____ ____ ____
Month Year Month Year

Address 3:

_____

_____

_____

From: ____ ____ / ____ ____ ____ ____ To: ____ ____ / ____ ____ ____ ____
Month Year Month Year

SECTION C: TREATMENT / HEALTH CARE PROVIDER UPDATES

When you enrolled in this study, you were asked to provide information about any treatments you had for endometrial cancer up to that point in time. We would like to update your treatment information as of today.

[REDCap ONLY]:
[Health Care Provider information (Name, Facility, Address) piped in from baseline. For each provider, the following table appears]

# (ex. 1st) Health Care Provider Reported at Baseline	
Contact Info: «md_fname» «md_lname», «md_license_type» «md_mail_addr1» «md_mail_addr2», «md_mail_addr3» «md_mail_city», «md_mail_state» «md_mail_zip»	
Have you received additional treatment or follow-up care from this provider since our last interview?	**Treatment Info / Comments:** Include approximate date(s) and type(s) of treatment(s) received or planned to receive from this physician, if applicable
☐ Yes ☐ No ☐ Don't Know	

C1a. Since your diagnosis have you had a recurrence of your endometrial cancer? In other words, has your cancer come back in the same place or spread to another part of the body?

☐ Yes
☐ No ➔ **SKIP TO C2a**
☐ Don't Know ➔ **SKIP TO C2a**

C1b. When was the recurrence diagnosed?

____ ____ / ____ ____ ____ ____
Month Year

C1c. Please provide any information you can about the physician who first told you about the recurrence:

Name: _____

Practice/Clinic/Hospital Name: _____

Street Address: _____

City, State, Zip: _____

Telephone: ____ ____ ____ - ____ ____ ____ - ____ ____ ____ ____

C2a. Since our last contact, or within the last 12 months, are there any additional health care providers who have provided treatment or follow-up care for your endometrial cancer?

☐ Yes

☐ No ➔ **SKIP TO C3a**

C2b. Please provide any information you can about health care providers who have provided additional treatment or follow-up care for your endometrial cancer.

Physician 1 Information:

Name: _____

Practice/Clinic/Hospital Name: _____

Street Address: _____

City, State, Zip: _____

Telephone: ___ ___ ___ - ___ ___ ___ - ___ ___ ___ ___

What treatment did you receive from this provider?

Physician 2 Information (as needed):

Name: _____

Practice/Clinic/Hospital Name: _____

Street Address: _____

City, State, Zip: _____

Telephone: ___ ___ ___ - ___ ___ ___ - ___ ___ ___ ___

What treatment did you receive from this provider?

Physician 3 Information (as needed):

Name: _____

Practice/Clinic/Hospital Name: _____

Street Address: _____

City, State, Zip: _____

Telephone: ___ ___ ___ - ___ ___ ___ - ___ ___ ___ ___

What treatment did you receive from this provider?

C3a. Since your diagnosis of endometrial cancer, have you been diagnosed with any other cancer?

☐ Yes
☐ No ➔ **SKIP TO C4**
☐ Don't Know ➔ **SKIP TO C4**

C3b. When was the cancer diagnosed?

___ ___ / ___ ___ ___ ___
Month Year

C3c. What type of cancer was diagnosed? _____

C3d. Please provide any information you can about the physician who first told you about the new cancer:

Name: _____

Practice/Clinic/Hospital Name: _____

Street Address: _____

City, State, Zip: _____

Telephone: ___ ___ ___ - ___ ___ ___ - ___ ___ ___ ___

C4. We may want to request updated copies of your medical records and/or obtain tumor tissue. To do so, we would need to obtain newly signed consents. Payment for receipt of newly signed consents is $15 for medical records and HIPAA authorizations and an additional $15 for tumor tissue consent. If we send you new consents and you complete them, do you grant permission for us to contact your providers for medical records and/or tumor tissue?

☐ Yes, you may contact all providers listed.

☐ No, you may not contact any of the providers listed.

☐ You may contact all but these providers. Specify: _____

_____

_____

SECTION D: MEDICAL HISTORY

This section asks about updates to your personal medical history.

Since your endometrial cancer diagnosis, have you been newly diagnosed by a medical provider as having:

D1.	Heart attack (myocardial infarction)?	☐ Yes	☐ No
D2.	Heart failure?	☐ Yes	☐ No
D3.	Peripheral vascular disease or deep vein thrombosis (blocked arteries/veins in your arms/legs)?	☐ Yes	☐ No
D4.	Chronic obstructive lung disease (COPD), or chronic bronchitis?	☐ Yes	☐ No
D5.	Emphysema?	☐ Yes	☐ No
D6.	Stomach ulcers proven by a test?	☐ Yes	☐ No
D7.	Liver disease?	☐ Yes	☐ No
D8.	A stroke/mini-stroke?	☐ Yes	☐ No
D9.	Hemiplegia (weakness/paralysis of arms/legs)?	☐ Yes	☐ No
D10.	Dementia (e.g. Alzheimer's)?	☐ Yes	☐ No
D11.	HIV/AIDS?	☐ Yes	☐ No
D12.	Hypertension/High blood pressure?	☐ Yes	☐ No
D13.	High Cholesterol?	☐ Yes	☐ No
D14.	Anxiety?	☐ Yes	☐ No
D15.	Depression?	☐ Yes	☐ No
D16a.	Serious kidney problems?	☐ Yes	☐ No
D16b.	If yes, have you ever required dialysis?	☐ Yes	☐ No
D17.	Rheumatoid arthritis?	☐ Yes	☐ No
D18a.	Other joint/bone problems?	☐ Yes	☐ No
D18b.	If yes, please specify: _____		
D19a.	Diabetes?	☐ Yes	☐ No
	If yes:		
D19b.	What type? ☐ Type I ☐ Type II ☐ Other/Don't Know		
D19c.	Have you ever had eye problems due to diabetes?	☐ Yes	☐ No
D19d.	Have you ever had kidney problems due to diabetes?	☐ Yes	☐ No
D20a.	Hepatitis?	☐ Yes	☐ No
D20b.	If yes, what type? ☐ A ☐ B ☐ C ☐ Other, specify: _____		

D21a. Are you taking any prescription medications for the conditions just reviewed?

☐ Yes
☐ No ➔ **SKIP TO D22**

D21b. Which of the newly diagnosed conditions listed below are you taking prescription medications for?
[REDCap ONLY]: List of Conditions marked "Yes" from D1-D20 followed by "Yes/No" response options

D22. Including any prescription medications you may be taking for other conditions, what is the total number of prescription medications you currently take?

____ ____ total prescription medications

SECTION E: LIFESTYLE

This section asks about sleep habits, physical activity, and height and weight measurements. The first questions ask about sleep habits and nighttime activities since your treatment of endometrial cancer.

E1. Since your treatment of endometrial cancer, how many hours of sleep do you usually get most days of the week?

____ ____ hours

E2.	Are you having problems falling asleep, staying asleep, or waking up too early?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
E3.	Have you experienced excessive sleepiness? For example, sleepiness or falling asleep in inappropriate situations or sleeping more during a 24-hour period than in the past:	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
E4.	Have you been told that you snore frequently or that you stop breathing during sleep?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
E5.	Have you experienced persistent fatigue despite a good night's sleep?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
E6.	Does fatigue interfere with your usual activities?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No

		None	**Mild**	**Moderate**	**Severe**	**Very severe**
E7.	In the past 7 days, how would you rate your fatigue on average?	☐	☐	☐	☐	☐

The next questions ask about your current physical activity.

During a typical week, how many times on the average do you do the following kinds of exercise for more than 15 minutes during your free time? **Please do not include work or household activities:**

E8.	**Strenuous exercise** *- heart beats rapidly*	*e.g. running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling*	_____ time(s) per week _____ average minutes each time you exercised
E9.	**Moderate exercise** *- not exhausting*	*e.g. fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing*	_____ time(s) per week _____ average minutes each time you exercised
E10.	**Mild exercise** **-** *minimal effort*	*e.g. yoga, archery, fishing from river bank, bowling, horseshoes, golf, snowmobiling, easy walking*	_____ time(s) per week _____ average minutes each time you exercised

The next questions ask about height and weight.

E11. What is your current height? ____ feet ____ ____ inches

E12. What is your current weight? ____ ____ ____ pounds

E13. How many cups of fruits and/or vegetables do you eat each day? Please do not include white potatoes:

_____ cup(s) per day

E14a. Do you have concerns about your weight?

☐ Yes
☐ No ➔ **SKIP TO E15**

E14b. Have you discussed concerns about your weight with your health care team?

☐ Yes
☐ No

E15. Do you take vitamins or supplements?

☐ Yes
☐ No

SECTION F: PREVENTATIVE HEALTH CARE

This section asks about health care and wellness.

F1. Since your endometrial cancer diagnosis, have you:

Seen a regular doctor for a physical examination or check-up?	☐ Yes	☐ No
Had an eye exam to check your vision?	☐ Yes	☐ No
Seen a dentist or dental hygienist to check your teeth?	☐ Yes	☐ No
Had a Flu Vaccine?	☐ Yes	☐ No
Had a colonoscopy or sigmoidoscopy, that is, an examination with a lighted tube to check for signs of cancer in your rectum or colon?	☐ Yes	☐ No
Had a FIT (Fecal Immunochemical Test), that is, a test for blood in the stool to check for signs of cancer in your rectum or colon?	☐ Yes	☐ No
Had a mammogram, that is, an examination with an x-ray image to check for signs of cancer in your breasts?	☐ Yes	☐ No

SECTION G: COVID-19

This section asks about experiences related to the COVID-19 pandemic.

G1a. Have you had any test for COVID-19, including a test that collected a nasal swab, or blood sample, or a spit saliva sample?

- ☐ Yes
- ☐ No ➔ **SKIP TO G2a**

G1b. Have you ever tested positive for COVID-19?

- ☐ Yes
- ☐ No
- ☐ Waiting for results

G2a. Has anyone else in your household been tested for COVID-19?

- ☐ Yes
- ☐ No ➔ **SKIP TO G3a**
- ☐ Does not apply ➔ **SKIP TO G3a**

G2b. Has anyone else in your household tested positive for COVID-19?

- ☐ Yes
- ☐ No
- ☐ Waiting for results

G3a. Have you received a COVID-19 vaccine?

- ☐ Yes ➔ **SKIP TO G4a**
- ☐ No

G3b. Do you plan to have a COVID-19 vaccine in the future?

- ☐ Yes ➔ **SKIP TO G5**
- ☐ No

G3c. What is the primary reason you do not want to have a COVID-19 vaccine in the future?

_____

_____

_____

➔ **SKIP TO G5**

G4a. What type of COVID-19 vaccine did you receive or are you in the process of receiving?

☐ Johnson & Johnson →	How many doses?	☐ 1 dose	☐ 2 doses	☐ 3 doses	☐ 4 doses
☐ Moderna →	How many doses?	☐ 1 dose	☐ 2 doses	☐ 3 doses	☐ 4 doses
☐ Pfizer →	How many doses?	☐ 1 dose	☐ 2 doses	☐ 3 doses	☐ 4 doses
☐ Don't know →	How many doses?	☐ 1 dose	☐ 2 doses	☐ 3 doses	☐ 4 doses

☐ Other, specify: _____

_____

G4b. When did you first receive a COVID-19 vaccine?

____ ____ / ____ ____ ____ ____
Month Year

G5. Have you delayed your cancer care or had your treatment interrupted due to the COVID-19 pandemic? Select all that apply:

- ■ I chose to delay or postpone care/treatment due to COVID-19
- ■ Care/treatment was delayed because your hospital/provider did not allow it (or could not treat you) due to COVID-19 restrictions
- ■ Care/treatment was interrupted because of loss of income related to COVID-19
- ■ Care/treatment was delayed due to difficulty accessing medications or other medical care due to shelter in place or stay home orders
- ■ Care/treatment was interrupted because of loss of health insurance related to COVID-19
- ■ I did not experience any delay in treatment or interruption in care

SECTION H: SURVIVORSHIP CONCERNS

This section asks about things you may have experienced after your endometrial cancer treatment.

Since your endometrial cancer treatment:

H1.	Have you experienced shortness of breath or chest pain after physical activities, such as climbing stairs, or exercise?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
H2.	Have you experienced shortness of breath when lying flat, wake up at night needing to get air, or have persistent leg swelling?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
H3.	Has stress, worry, or being nervous, tense or irritable interfered with your life?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
H4.	Have you been bothered by hot flashes/night sweats?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
H5.	Have you been bothered by other hormone-related symptoms such as vaginal dryness or incontinence?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
H6a.	Do you have any concerns regarding your sexual function, sexual activity, sexual relationships, or sex life?	☐ Yes	☐ No
	If Yes:		
H6b.	Have you discussed this with your health care team?	☐ Yes	☐ No
H6c.	Are these concerns causing you distress?	☐ Yes	☐ No

The next questions ask about things you may have experienced more recently.

H7.	In the past two weeks, have you been bothered more than half the days by little interest or pleasure in doing things?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No
H8.	In the past two weeks, have you been bothered more than half the days by feeling down, depressed, or hopeless?	☐ Yes	☐ No
	If yes, have you discussed this with your health care team?	☐ Yes	☐ No

H9a. In the past 7 days, how would you rate your pain on average?

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No Pain										**Worst pain imaginable**

H9b. Have you discussed this pain with your health care team?

☐ Yes

☐ No

SECTION I: LOWER BODY SYMPTOMS

The following questions relate to symptoms you might have experienced in your foot, leg, hip, groin, or your lower body in the past 4 weeks.

I1. In the past 4 weeks, have you had limited movement of your:

Hip?	☐ Yes	☐ No
Knee?	☐ Yes	☐ No
Ankle?	☐ Yes	☐ No
Foot?	☐ Yes	☐ No
Toes?	☐ Yes	☐ No

I2. In the past 4 weeks, did your leg or foot feel weak?

☐ Yes
☐ No

I3. In the past 4 weeks, have you experienced any of the following in your foot, leg, hip, groin, or your lower body:

Tenderness?	☐ Yes	☐ No
Swelling?	☐ Yes	☐ No
Swelling with pitting? Pitting is when you press firmly on your skin and the dent stays long enough to feel it when you slide the pad of your finger across it.	☐ Yes	☐ No
Redness?	☐ Yes	☐ No
Blistering?	☐ Yes	☐ No
Firmness / Tightness?	☐ Yes	☐ No
Increased temperature in your leg?	☐ Yes	☐ No
Fatigue?	☐ Yes	☐ No
Heaviness?	☐ Yes	☐ No
Fullness?	☐ Yes	☐ No
Numbness?	☐ Yes	☐ No
Stiffness?	☐ Yes	☐ No
Aching?	☐ Yes	☐ No
Hip swelling?	☐ Yes	☐ No
Groin swelling? For example, genital or labia/vulvar swelling.	☐ Yes	☐ No
Pockets of fluid?	☐ Yes	☐ No

I4. Have you discussed these symptoms with your health care team? **[REDCap ONLY]:** Only shows if at least one condition above is marked “Yes”

- ☐ Yes
- ☐ No

SECTION J: QUALITY OF LIFE

This section asks about your physical well-being and quality of life since your diagnosis of endometrial cancer.

		Excellent	Very good	Good	Fair	Poor
J1.	In general, would you say your health is:	☐	☐	☐	☐	☐
J2.	In general, would you say your quality of life is:.....	☐	☐	☐	☐	☐
J3.	In general, how would you rate your physical health?	☐	☐	☐	☐	☐
J4.	In general, how would you rate your mental health, including your mood and your ability to think?	☐	☐	☐	☐	☐
J5.	In general, how would you rate your satisfaction with your social activities and relationships?	☐	☐	☐	☐	☐
J6.	In general, please rate how well you carry out your usual social activities and roles. This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.	☐	☐	☐	☐	☐

		Completely	Mostly	Moderately	A little	Not at all
J7.	To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	☐	☐	☐	☐	☐

		Never	Rarely	Some-times	Often	Always
J8.	**In the past 7 days,** how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	☐	☐	☐	☐	☐

SECTION K: OCCUPATIONAL HISTORY

This section asks about work since diagnosis of endometrial cancer. If you had more than one job, please use the job that you spent more hours at.

K1a. Have you left your job(s) or stopped working altogether since your diagnosis of endometrial cancer?

- ☐ Yes
- ☐ No ➔ **SKIP TO K2a**
- ☐ Did not have a job at the time of or since diagnosis ➔ **SKIP TO K2a**

K1b. What are the reason(s) you left your job(s) or stopped working altogether? Select all that apply:

- ■ Retired early
- ■ Retired as planned
- ■ Was laid off or let go
- ■ Changed jobs or careers
- ■ Work was too demanding/difficult after cancer
- ■ Other, specify: _____

K2a. Which of the following best describes your current employment status? Choose one:

- ☐ Employed full time
- ☐ Employed part time
- ☐ Not employed, but looking for work ➔ **SKIP TO K3**
- ☐ Not employed – not retired, disabled, or looking for work ➔ **SKIP TO K3**
- ☐ Retired ➔ **SKIP TO K3**
- ☐ Disabled, not able to work ➔ **SKIP TO K3**
- ☐ Other, specify: _____

K2b. What is your current job title?

_____

K2c. What type of business or industry would you say best describes your current workplace?

_____

K2d. What type of work schedule do you have? Choose one:

- ☐ Regular hours, starting and stopping work at about the same time every day you worked
- ☐ Rotating shifts or irregular/varying hours
- ☐ Other, specify: _____

K2e. How many years have you worked in this job? If less than 1, enter 0:

____ ____ years

K2f. On average, how many hours per week do you usually work in this job?

____ ____ ____ hours

K3. What is your present marital status?

- ☐ Never married or partnered
- ☐ Married or partnered
- ☐ Widowed
- ☐ Separated, divorced, or no longer partnered

K4. This year, what will be your total household income range, before taxes? Choose one:

- ☐ Less than $5,000
- ☐ $5,000 to $10,000
- ☐ $10,001 to $20,000
- ☐ $20,001 to $30,000
- ☐ $30,001 to $40,000
- ☐ $40,001 to $50,000
- ☐ $50,001 to $100,000
- ☐ $100,001 or more
- ☐ Prefer not to answer

SECTION L: ACCESS TO MEDICAL CARE / FINANCIAL SITUATION

This section asks about access to medical care and how you feel about your financial situation.

L1. What type(s) of health insurance do you have now? Select all that apply:

- ■ None
- ■ Private health insurance through your employer or your partner's employer
- ■ Private health insurance purchased by yourself or your partner, such as through a healthcare market exchange
- ■ Medicaid
- ■ Medicare
- ■ Tricare or other military health insurance, including VA healthcare
- ■ Any other insurance that covers part of your medical bills, please specify:

_____

L2. Have concerns about losing your health insurance kept you in a job since your diagnosis of endometrial cancer?

- ☐ Yes
- ☐ No
- ☐ Have not had a job since diagnosis

L3. On a scale of 1 to 10 with 1 being "No Confidence" and 10 being "High Confidence", how confident are you that you could find the money to pay for a financial emergency that costs about $1,000?

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

L4. On a scale of 1 to 10 with 1 being "Always" and 10 being "Never", how frequently do you find yourself "just getting by" financially or living paycheck to paycheck?

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

L5. On a scale of 1 to 10 with 1 being "Always Hard" and 10 being "Never Hard", how hard is it for you to pay for the very basics, like food, housing, medical care, and heating?

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

The next questions ask how you feel about your financial situation as it relates to your endometrial cancer care.

Please answer the following statements with your response as it applies to the past 7 days:

		Not at all	A little bit	Some-what	Quite a bit	Very much
L6.	I know that I have enough money in savings, retirement, or assets to cover the cost of my treatment.	☐	☐	☐	☐	☐
L7.	My out-of-pocket medical expenses are more than I thought they would be.	☐	☐	☐	☐	☐
L8.	I worry about the financial problems I will have in the future as a result of my illness or treatment.	☐	☐	☐	☐	☐
L9.	I feel I have no choice about the amount of money I spend on care.	☐	☐	☐	☐	☐
L10.	I am frustrated that I cannot work or contribute as much as I usually do.	☐	☐	☐	☐	☐
L11.	I am satisfied with my current financial situation.	☐	☐	☐	☐	☐
L12.	I am able to meet my monthly expenses.	☐	☐	☐	☐	☐
L13.	I feel financially stressed.	☐	☐	☐	☐	☐
L14.	I am concerned about keeping my job and income, including my work at home.	☐	☐	☐	☐	☐
L15.	My cancer or treatment has reduced my satisfaction with my current financial situation.	☐	☐	☐	☐	☐
L16.	I feel in control of my financial situation.	☐	☐	☐	☐	☐
L17.	I have been distressed by not knowing what my cancer care would cost.	☐	☐	☐	☐	☐
L18.	I am worried about the financial stress on my family as a result of my cancer.	☐	☐	☐	☐	☐

L19. Since your diagnosis of endometrial cancer, was there a time you wanted to see a doctor, but could not because of transportation issues?

☐ Yes

☐ No

L20. Since your diagnosis of endometrial cancer, have you ever stopped or refused a treatment related to your cancer because it cost too much?

☐ Yes

☐ No

L21. Since your diagnosis of endometrial cancer, have you ever been contacted by a collection agency as a result of your cancer care?

☐ Yes

☐ No

L22. Since your diagnosis of endometrial cancer, which of the following have you done to manage your cancer care cost?

Skipped a vacation or other activity due to cost?	☐ Yes	☐ No
Borrowed money from friends, family, a bank, or another source?	☐ Yes	☐ No
Taken money from a savings or retirement account?	☐ Yes	☐ No
Filed for bankruptcy?	☐ Yes	☐ No
Filed for disability?	☐ Yes	☐ No
Avoided treatment for another medical problem other than your cancer?	☐ Yes	☐ No
Skipped paying non-medical bills, like rent, credit cards, or other necessities?	☐ Yes	☐ No
Applied for financial assistance?	☐ Yes	☐ No
Received financial assistance?	☐ Yes	☐ No

SECTION M: PERSPECTIVES ON DISCRIMINATION

We are interested in the experiences of endometrial cancer survivors across different parts of their lives. Since your endometrial cancer diagnosis, in your day-to-day life, how often have any of the following things happened to you?

Please answer the following statements with your level of agreement:

		Almost every day	At least once a week	A few times a month	A few times a year	Less than once a year	Never
M1.	You are treated with less courtesy than other people are.	☐	☐	☐	☐	☐	☐
M2.	You are treated with less respect than other people are.	☐	☐	☐	☐	☐	☐
M3.	You receive poorer service than other people at restaurants or stores.	☐	☐	☐	☐	☐	☐
M4.	People act as if they think you are not smart.	☐	☐	☐	☐	☐	☐
M5.	People act as if they are afraid of you.	☐	☐	☐	☐	☐	☐
M6.	People act as if they think you are dishonest.	☐	☐	☐	☐	☐	☐
M7.	People act as if they're better than you are.	☐	☐	☐	☐	☐	☐
M8.	You are called names or insulted.	☐	☐	☐	☐	☐	☐
M9.	You are threatened or harassed.	☐	☐	☐	☐	☐	☐

M10. If you answered "A few times a year" or more frequently to any of the 9 statements above, what do you think is the main reason for these experiences?

- ☐ Did not answer "A few times a year" or more frequently to any of the 9 statements above
- ☐ Your ancestry or national origins
- ☐ Your gender
- ☐ Your race
- ☐ Your age
- ☐ Your religion
- ☐ Your height
- ☐ Your weight
- ☐ Some other aspect of your physical appearance
- ☐ Your sexual orientation
- ☐ Your education or income level
- ☐ Other

[REDCap ONLY – Only visible in Form View – Not visible in Survey Mode]:

The next section asks more detailed questions about sexual function, bowel function, and bladder function and takes approximately 15 minutes to complete. We can continue and complete these questions on the phone. Or, if you would feel more comfortable, we can send the questions as a paper survey if you prefer. Would you like to complete the questions on the phone?

☐ Yes - Phone

☐ No - Paper/Hard Copy ➔ **SKIP TO Section P**

SECTION N: SEXUAL FUNCTION QUESTIONNAIRE

Physical contact and sexual relations can be an important part of many people's lives. People who suffer from illnesses involving their pelvic region may experience changes in their sex life. The questions below refer to this. The information you provide will remain strictly confidential.

Part 1:

N1. During the past month, have you been interested in close physical contact? For example, a kiss and a cuddle:

Not at all	A little	Quite a bit	Very much
☐	☐	☐	☐

N2. During the past month, have you had close physical contact with your family and close friends?

Not at all	A little	Quite a bit	Very much
☐	☐	☐	☐

N3. During the past month, have you had any interest in sexual relations?

Not at all	A little	Quite a bit	Very much
☐	☐	☐	☐

N4. During the past month, have you had sexual relations?

No	Yes, 1-2 times a month	Yes, 3-4 times a month	Yes, 1-2 times a week	Yes, more than twice a week
☐	☐	☐	☐	☐

N5. During the past month, has your sex life or lack of sex life made you worry?

Not at all	A little	Quite a bit	Very much
☐	☐	☐	☐

N6. During the past month, have you had a partner? **If not**, please mark "**No**" and **SKIP to question N10**.

Yes	No
☐	☐

N7. During the past month, has your partner wanted to have sexual relations?

Not at all	A little	Quite a bit	Very much
☐	☐	☐	☐

N8. Is your partner male? **If not**, please mark "**No**" and **SKIP to question N10**.

Yes	No
☐	☐

N9. During the past month, did your partner have difficulty achieving an erection?

Not at all	A little	Quite a bit	Very much
☐	☐	☐	☐

For the following questions, **please mark the number between 1 and 7 that best applies to you.**

N10. During the past month, how satisfied or dissatisfied have you been with your sex life or lack of sex life?

Very dissatisfied						Very satisfied
1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

N11. During the past month, how satisfied or dissatisfied have you been with your appearance?

Very dissatisfied						Very satisfied
1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

Part 2: Please complete this section **if you have been sexually active during the past month**. If you have not been sexually active during the past month, please go on to part 3. [REDCap – only visible if N4 <> "No"]

During the past month:	Not at all	A little bit	Quite a bit	Very much
N12a. Did you feel that your vagina was dry during intercourse?	☐	☐	☐	☐
N12b. If yes, has it bothered you?	☐	☐	☐	☐
N13a. Have you had any pain during intercourse?	☐	☐	☐	☐
N13b. If yes, has it bothered you?	☐	☐	☐	☐
N14a. Have you experienced bleeding during intercourse?	☐	☐	☐	☐
N14b. If yes, has it bothered you?	☐	☐	☐	☐
N15. Did you feel that intercourse was bothersome because your vagina felt too small?	☐	☐	☐	☐

During the past month:	Never	Occasionally	Often	Always
N16. Were you able to complete sexual intercourse?	☐	☐	☐	☐
N17. Have you reached orgasm?	☐	☐	☐	☐

During the past month:	Not at all	A little bit	Quite a bit	Very much
N18. Did you feel relaxed after sex?	☐	☐	☐	☐

Part 3: The following questions are about possible changes since your cancer diagnosis.

N19. Has your interest in close physical contact changed since you were diagnosed with cancer?

I am less interested now	It is unchanged	I am more interested now
☐	☐	☐

N20. How much close physical contact do you have with your family and close friends compared to before you were diagnosed with cancer?

I have less than before	It is unchanged	I have more than before
☐	☐	☐

N21. Has your interest in sexual relations changed since you were diagnosed with cancer?

I am less interested now	It is unchanged	I am more interested now
☐	☐	☐

The following question applies only **if you have a partner.** [REDCap – only visible if N6 "Yes"]

N22. Has your partner's interest in sexual relations changed since you were diagnosed with cancer?

My partner is less interested now	It is unchanged	My partner is more interested now
☐	☐	☐

The following questions apply to you only **if you are sexually active.** [REDCap – only visible if N4 <> "No"]

N23. Has the dryness of your vagina changed compared to before you were diagnosed with cancer?

It is less dry now	It is unchanged	It is dryer now
☐	☐	☐

N24. Do you feel that the size of your vagina has changed since you were diagnosed with cancer?

It is smaller now	It is unchanged	It is larger now
☐	☐	☐

The following question applies to you only **if you have experienced pain during intercourse.**
[REDCap – only visible if N13a <> ”Not at all”]

N25. Has the pain you experience during intercourse changed since you were diagnosed with cancer?

I have less pain now	It is unchanged	I have more pain now
☐	☐	☐

SECTION O: BOWEL AND BLADDER FUNCTION QUESTIONNAIRE

The following questions ask if you have certain bowel or bladder symptoms and, if you do, **how much they bother you**. While answering these questions, please consider your symptoms **over the last 3 months**.

Over the last 3 months:		**NO**		**If YES, how much has it bothered you?**			
				Not at all	**Somewhat**	**Moderately**	**Quite a bit**
O1.	Do you feel you need to strain too hard to have a bowel movement?	☐	or	☐	☐	☐	☐
O2.	Do you feel you have not completely emptied your bowels at the end of a bowel movement?	☐	or	☐	☐	☐	☐
O3.	Do you usually lose stool beyond your control if your stool is well formed?	☐	or	☐	☐	☐	☐
O4.	Do you usually lose stool beyond your control if your stool is loose?	☐	or	☐	☐	☐	☐
O5.	Do you usually lose gas from the rectum beyond your control?	☐	or	☐	☐	☐	☐
O6.	Do you usually have pain when you pass your stool?	☐	or	☐	☐	☐	☐
O7.	Do you experience a strong sense of urgency and have to rush to the bathroom to have a bowel movement?	☐	or	☐	☐	☐	☐
O8.	Does part of your bowel ever pass through the rectum and bulge outside during or after a bowel movement?	☐	or	☐	☐	☐	☐
O9.	Do you usually experience frequent urination?	☐	or	☐	☐	☐	☐
O10.	Do you usually experience urine leakage associated with a feeling of urgency, that is, as strong sensation of needing to go to the bathroom?	☐	or	☐	☐	☐	☐
O11.	Do you usually experience urine leakage related to coughing, sneezing, or laughing?	☐	or	☐	☐	☐	☐
O12.	Do you usually experience small amounts of urine leakage? That is, drops of urine.	☐	or	☐	☐	☐	☐
O13.	Do you usually experience difficulty emptying your bladder?	☐	or	☐	☐	☐	☐
O14.	Do you usually experience pain or discomfort in the lower abdomen or genital region?	☐	or	☐	☐	☐	☐

SECTION P: FUTURE CONTACT / CLOSING COMMENTS

Thank you again for your participation in this follow-up survey. We greatly appreciate your willingness to provide this updated information.

P1. We plan to contact you again in about a year with a newsletter and to check in with how you are doing. You may have previously provided us with the contact info for a friend or relative we could reach out to in the event we were unable to reach you, would you like to add to or update that contact information now?

☐ Yes
☐ No ➔ **SKIP TO P2**

1st Contact:

Name: _____ Relationship: _____

Phone 1: _____

Phone 2: _____

Email: _____

2nd Contact:

Name: _____ Relationship: _____

Phone 1: _____

Phone 2: _____

Email: _____

P2. Before we complete this survey, do you have any questions or comments to share?

_____

_____

_____

_____

_____

_____

P3. [REDCap ONLY]:

Please tell us what kind of device you used to complete this survey. This will help us improve the survey formatting for any follow ups:

- ☐ Computer using a web browser (Mac, Windows, other)
- ☐ Computer tablet (iPad, Surface, Galaxy or other)
- ☐ Phone (iPhone, Samsung or other)
- ☐ Other, specify: _____

_____

Thank You for completing this survey.
You should be receiving a mailing from us within 4 weeks, including payment for $40 to thank you for taking the time to complete this survey.

Question D1-D20b Charleston Comorbidity Index (CCI)

Habbous S, Chu KP, Harland LTG, et al. Validation of a one-page patient-reported Charlson comorbidity index questionnaire for upper aerodigestive tract cancer patients. Oral Oncology. 2013;49(5):407-412. doi:10.1016/j.oraloncology.2012.11.010

Question E8-E10 Godin-Shephard Leisure-Time Physical Activity Questionnaire

Amireault, S., & Godin, G. (2015). The Godin-Shephard Leisure-Time Physical Activity Questionnaire: Validity evidence supporting its use for classifying healthy adults into active and insufficiently active categories. *Perceptual and Motor Skills, 120*(2), 604–622.

Question E2-10, E13, E14a, E15, F1, H1-9a, I3 NCCN Guideline Version 2.2019 Survivorship Assessment

Sanft T, Denlinger CS, Armenian S, et al. NCCN Guidelines Insights: Survivorship, Version 2.2019. J Natl Compr Canc Netw. 2019;17(7):784-794. doi:10.6004/jnccn.2019.0034

Question I1-I4 Gynecologic Cancer Lymphedema Questionnaire

Kim SI, Kim N, Lee S, et al. Development of the short version of the Gynecologic Cancer Lymphedema Questionnaire: GCLQ-7. J Gynecol Oncol. 2017;28(2):e9. doi:10.3802/jgo.2017.28.e9

Question J1-J8 Patient Reported Outcome Measurement Information System Global Health (PROMIS 10)

Hays, R. D., Bjorner, J., Revicki, R. A., Spritzer, K. L., & Cella, D. (2009). Development of physical and mental health summary scores from the Patient Reported Outcomes Measurement Information System (PROMIS) global items. Quality of Life Research, 18(7), 873-80.

Question L6-L18 COST: A FACIT Measure of Financial Toxicity (FACIT-COST) V.2

De Souza JA, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the Comprehensive Score for financial Toxicity (Cost): Measuring Financial Toxicity. Cancer. 2017;123(3):476-484. doi:10.1002/cncr.30369

Question M1-M10 Everyday Discrimination Scale

Williams, D. R., Yu, Y., Jackson, J., & Anderson, N. (1997). Racial Differences in Physical and Mental Health: Socioeconomic Status, Stress, and Discrimination. Journal of Health Psychology, 2, 335-351. http://dx.doi.org/10.1177/135910539700200305

Question N1-N25 Sexual Function-Vaginal Changes Questionnaire (SVQ extended)

Jensen, P.T., Klee, M.C., Thranov, I. and Groenvold, M. (2004), Validation of a questionnaire for self-assessment of sexual function and vaginal changes after gynaecological cancer. Psycho-Oncology, 13: 577-592. https://doi.org/10.1002/pon.757

Question O1-O8 Colorectal-Anal Distress Inventory 8 (CRADI-8)

Barber MD, Walters MD, Bump RC. Short forms of two condition-specific quality-of-life questionnaires for women with pelvic floor disorders (PFDI-20 and PFIQ-7). Am J Obstet Gynecol. 2005 Jul;193(1):103-13. doi: 10.1016/j.ajog.2004.12.025. PMID: 16021067.

Question O9-O14 Urinary Distress Inventory 6 (UDI-6)

Uebersax JS, Wyman JF, Shumaker SA, McClish DK, Fantl JA. Short forms to assess life quality and symptom distress for urinary incontinence in women: the Incontinence Impact Questionnaire and the Urogenital Distress Inventory. Continence Program for Women Research Group. Neurourol Urodyn. 1995;14(2):131-9. doi: 10.1002/nau.1930140206. PMID: 7780440.