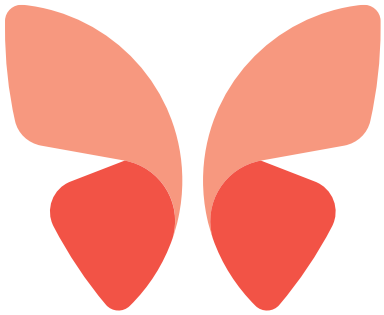

CAROLINA ENDOMETRIAL CANCER STUDY

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

MAIL-IN SURVEY

Printed Name of Study Participant: _____

Date Completed: ___ ___ / ___ ___ / ___ ___ ___ ___

SECTION A: INTRODUCTORY STATEMENT

Thank you for agreeing to be interviewed. The goal of this study is to collect information that may help us to better understand health and other concerns adults may have after an endometrial cancer diagnosis. There will be questions about a number of topics, including your family's history of cancer, your menstrual and pregnancy history, your medical history, and certain aspects of your daily life. Some of these questions ask you to think back to events that may have occurred many years ago. Although the answers may be hard to remember, please do the best you can. There are no right or wrong answers to any of these questions. You should just report what you have experienced in your life. We will send you a gift card for $40 within 4 weeks of completing this survey.

Before we start, we want to remind you that your participation in this study is voluntary, and all the information collected will be kept completely confidential. If there are any questions that you do not want to answer, you do not have to complete them.

SECTION B: BACKGROUND INFORMATION

This section asks about background information for you and your family.

B1. What is your date of birth?

____ ____ / ____ ____ / ____ ____ ____ ____
Month Day Year

B2. Where were you born?

_____,
City

_____ _____
State / Province / Territory Country

The next questions ask about history of other cancers.

B3a. Have you ever been diagnosed with skin cancer?

☐ Yes
☐ No ➔ **SKIP TO B4a**

B3b. What type(s) of skin cancer were you diagnosed with? Select all that apply:

- ■ Basal or Squamous cell carcinoma
- ■ Melanoma: Age at first diagnosis? ___ ___ years
- ■ Other, specify: _____

B4a. Have you ever been diagnosed with any other cancer? Please do not include uterine/endometrial cancer:

☐ Yes
☐ No ➔ **SKIP TO B5a**

B4b. What was the first type of other cancer you were diagnosed with?

First type of other cancer: _____

B4c. How old were you when you were diagnosed with this cancer?

____ ____ years

The next questions ask about family history of cancer.

B5a. Are you adopted?

☐ Yes
☐ No ➔ **SKIP TO B6a**

B5b. Do you know your biological family's cancer history?

☐ Yes
☐ No ➔ **SKIP TO B8a**

It is important for us to learn as much as possible about any history of cancer in your family, especially cancer of the uterus/endometrium. We are interested in living and deceased members of your family, but only if they are biological relatives.

B6a. Including living and deceased, were your biological aunt(s), mother, sister(s), or daughter(s), ever told by a health professional that they had uterine or endometrial cancer?

☐ Yes
☐ No ➔ **SKIP TO B7a**

B6b. Which of the following biological family members have been diagnosed with uterine/endometrial cancer? Select all that apply:

■ Mother
■ Sister(s)
■ Daughter(s)
■ Aunt(s) – father's side
■ Aunt(s) – mother's side
■ Other, specify: _____

B7a. Including living and deceased, have any of your biological aunt(s), uncle(s), parent(s), brother(s), sister(s), or children, ever been told by a health professional that they had cancer? Please do not include uterine/endometrial cancer:

- ☐ Yes
- ☐ No ➔ **SKIP TO B8a**
- ☐ Don't Know ➔ **SKIP TO B8a**

B7b. What type(s) of cancer did your biological family member(s) have?

Family Member's Relation to You:	Cancer Type(s):

The next questions ask about genetic testing. Some people with a strong family history of certain types of cancer, or who are diagnosed with cancer at young ages, may have genetic testing to see if they carry a gene mutation that increases risks of getting certain types of cancer.

B8a. Have you or a close biological family member, such as your mother, father, brother(s), sister(s), or children ever had a genetic test at a doctor's office or medical center to determine if you/they have a genetic risk for developing certain types of cancer?

- ☐ Yes
- ☐ No ➔ **SKIP TO B9**
- ☐ Don't Know ➔ **SKIP TO B9**

B8b. Please explain who had a genetic test at a doctor's office or medical center and any description of the test you'd like to provide:

Relation to You. This could include "Self":	Test description, if known:

B9. Some companies, such as 23andMe or Ancestry.com, offer genetic tests of your DNA that are advertised to improve your health and prevent disease. You can order these tests directly, without the involvement of a healthcare provider. Have you ever used any of these tests?

- ☐ Yes
- ☐ No
- ☐ Don't Know

B10a. Have you or any biological family members ever been told by a healthcare provider that you/they have a condition that causes a genetic risk for certain types of cancer? An example of this could include Lynch syndrome, also known as HPNCC or Cowden syndrome, among others:

- ☐ Yes
- ☐ No ➔ **SKIP TO Section C**
- ☐ Don't Know ➔ **SKIP TO Section C**

B10b. What condition(s) that cause a genetic risk for certain types of cancer were you or your biological family member(s) told you/they have?

Relation to You. This could include "Self":	Condition(s):

SECTION C: QUALITY OF LIFE

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

Again, to remind you, all of your answers are kept confidential and are combined with others so no one will be able to tell what your particular answers were. Even so, you don't have to answer any questions that you don't want to.

Below is a list of statements that other people with endometrial cancer have said are important. Please indicate how true each statement has been for you during the past 7 days:

PHYSICAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
C1.	I have a lack of energy.	☐	☐	☐	☐	☐
C2.	I have nausea.	☐	☐	☐	☐	☐
C3.	Because of my physical condition, I have trouble meeting the needs of my family.	☐	☐	☐	☐	☐
C4.	I have pain.	☐	☐	☐	☐	☐
C5.	I am bothered by side effects of treatment.	☐	☐	☐	☐	☐
C6.	I feel ill.	☐	☐	☐	☐	☐
C7.	I am forced to spend time in bed.	☐	☐	☐	☐	☐

Please indicate how true each statement has been for you during the past 7 days:

SOCIAL/FAMILY WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
C8.	I feel close to my friends.	☐	☐	☐	☐	☐
C9.	I get emotional support from my family.	☐	☐	☐	☐	☐
C10.	I get support from my friends.	☐	☐	☐	☐	☐
C11.	My family has accepted my illness.	☐	☐	☐	☐	☐
C12.	I am satisfied with family communication about my illness.	☐	☐	☐	☐	☐
C13.	I feel close to my partner or the person who is my main support.	☐	☐	☐	☐	☐
C14.	Regardless of your current level of sexual activity, please respond to the following statement. If you prefer not to answer it, please skip to C15:					
	I am satisfied with my sex life.	☐	☐	☐	☐	☐

Please indicate how true each statement has been for you during the past 7 days:

EMOTIONAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
C15.	I feel sad.	☐	☐	☐	☐	☐
C16.	I am satisfied with how I am coping with my illness.	☐	☐	☐	☐	☐
C17.	I am losing hope in the fight against my illness.	☐	☐	☐	☐	☐
C18.	I feel nervous.	☐	☐	☐	☐	☐
C19.	I worry about dying.	☐	☐	☐	☐	☐
C20.	I worry that my condition will get worse.	☐	☐	☐	☐	☐

Please indicate how true each statement has been for you during the past 7 days:

FUNCTIONAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
C21.	I am able to work. Include work at home.	☐	☐	☐	☐	☐
C22.	My work is fulfilling. Include work at home.	☐	☐	☐	☐	☐
C23.	I am able to enjoy life.	☐	☐	☐	☐	☐
C24.	I have accepted my illness.	☐	☐	☐	☐	☐
C25.	I am sleeping well.	☐	☐	☐	☐	☐
C26.	I am enjoying the things I usually do for fun.	☐	☐	☐	☐	☐
C27.	I am content with the quality of my life right now.	☐	☐	☐	☐	☐

Please indicate how true each statement has been for you during the past 7 days:

ADDITIONAL CONCERNS

		Not at all	A little bit	Some-what	Quite a bit	Very much
C28.	I have swelling in my stomach area.	☐	☐	☐	☐	☐
C29.	I have cramps in my stomach area.	☐	☐	☐	☐	☐
C30.	I have discomfort or pain in my stomach area.	☐	☐	☐	☐	☐
C31.	I have vaginal bleeding or spotting.	☐	☐	☐	☐	☐
C32.	I have vaginal discharge.	☐	☐	☐	☐	☐
C33.	I am unhappy about a change in my appearance.	☐	☐	☐	☐	☐
C34.	I have hot flashes/hot flushes.	☐	☐	☐	☐	☐
C35.	I have cold sweats.	☐	☐	☐	☐	☐

Please indicate how true each statement has been for you during the past 7 days:

ADDITIONAL CONCERNS (cont'd)		Not at all	A little bit	Some-what	Quite a bit	Very much
C36.	I have night sweats.	☐	☐	☐	☐	☐
C37.	I feel fatigued.	☐	☐	☐	☐	☐
C38.	I have pain or discomfort with intercourse.	☐	☐	☐	☐	☐
C39.	I have trouble digesting food.	☐	☐	☐	☐	☐
C40.	I have been short of breath.	☐	☐	☐	☐	☐
C41.	I am bothered by constipation.	☐	☐	☐	☐	☐
C42.	I urinate more frequently than usual.	☐	☐	☐	☐	☐
C43.	I have discomfort or pain in my pelvic area.	☐	☐	☐	☐	☐

SECTION D: PREGNANCY / HORMONE USE HISTORY

This section asks about history of pregnancies, use of talcum powder, douching, and hormone use.

D1a. How many biological children have you had?

____ ____ children If "00"**, SKIP TO D2a**

D1b. How old were you when your first biological child was born?

____ ____ years

D1c. How old were you when your last biological child was born?

____ ____ years

The next questions ask about use of talcum powder.

D2a. Have you ever applied talcum powder to a sanitary napkin, tampon, underwear, diaphragm, cervical cap, or directly to your vaginal area?

☐ Yes
☐ No ➔ **SKIP TO D3a**

D2b. How old were you when you first used talcum powder on or near your vaginal area?

____ ____ years

D2c. On average, how frequently did you use talcum powder on or near your vaginal area? Choose one:

☐ At least once a week
☐ Not every week, but at least once a month
☐ Not every month, but at least 2 times a year
☐ Once a year or less

D2d. Have you used talcum powder on or near your vaginal area in the past 12 months?

☐ Yes ➔ **SKIP TO D3a**
☐ No

D2e. How old were you when you last used talcum powder on or near your vaginal area?

____ ____ years

The next questions ask about douching.

D3a. Have you ever douched, or used liquid to rinse your vaginal area?

☐ Yes
☐ No ➔ **SKIP TO D4a**

D3b. How old were you when you first douched?

____ ____ years

D3c. On average, how frequently did you douche? Choose one:

☐ At least once a week
☐ Not every week, but at least once a month
☐ Not every month, but at least 2 times a year
☐ Once a year or less

D3d. Have you douched in the past 12 months?

☐ Yes ➔ **SKIP TO D4a**
☐ No

D3e. How old were you when you last douched?

____ ____ years

The next questions ask about oral contraceptives and hormone therapy use.

D4a. Have you ever taken birth control pills for birth control or for any other reason?

☐ Yes
☐ No ➔ **SKIP TO D5a**

D4b. How old were you when you first took birth control pills?

____ ____ years

D4c. Are you still taking birth control pills?

☐ Yes ➔ **SKIP TO D5a**
☐ No

D4d. How old were you when you last took birth control pills?

____ ____ years

D5a. Have you ever had injections or implants for birth control such as DepoProvera or Nexplanon? These are medications in which a doctor gives you shots of hormones or puts long-acting hormones under your skin:

☐ Yes
☐ No ➔ **SKIP TO D6a**

D5b. How old were you when you first had hormone injections or implants for birth control?

____ ____ years

D5c. Are you still having hormone injections or implants for birth control?

☐ Yes ➔ **SKIP TO D6a**
☐ No

D5d. How old were you when you last had hormone injections or implants for birth control?

____ ____ years

D6a. Have you ever used an intrauterine device (IUD) for birth control or for any other reason?

☐ Yes
☐ No ➔ **SKIP TO D7a**

D6b. How old were you when you first used an IUD?

____ ____ years

D6c. Are you still using an IUD?

☐ Yes ➔ **SKIP TO D6e**
☐ No

D6d. How old were you when you last used an IUD?

____ ____ years

D6e. Some IUDs release the hormone progestin, and some do not. What type(s) of IUD(s) have you used? Choose one:

☐ Progesterone-releasing. For example, Liletta, Kyleena, Mirena, Skyla, etc.
☐ Hormone free. For example, ParaGard, Copper T, etc.
☐ Both progesterone-releasing and hormone free
☐ Don’t Know

The next questions ask about hormones that you may have taken for reasons other than birth control. Sometimes people take female hormones, such as estrogen, near menopause (the change of life) to treat hot flashes or other symptoms. We are interested in any hormone pills that you took that were not for birth control.

D7a. Have you ever taken estrogens or progestins, for reasons other than for birth control?

☐ Yes
☐ No ➔ **SKIP TO Section E**

D7b. Have you ever taken a combination estrogen/progestin pill such as Prempro, Premphase or FemHRT?

☐ Yes
☐ No ➔ **SKIP TO D8a**

D7c. Please specify the type/name of the combination estrogen/progestin pill(s) you took:

_____

_____

D7d. How old were you when you first took combination estrogen/progestin pills?

____ ____ years

D7e. Are you still taking combination estrogen/progestin pills?

☐ Yes ➔ **SKIP TO D8a**
☐ No

D7f. How old were you when you last took combination estrogen/progestin pills?

____ ____ years

D8a. Have you ever taken an estrogen-only pill such as Premarin or Estrace?

☐ Yes
☐ No ➔ **SKIP TO Section E**

D8b. Please specify the type/name of the estrogen-only pill(s) you took:

_____

_____

D8c. How old were you when you first took estrogen-only pills?

____ ____ years

D8d. Are you still taking estrogen-only pills?

☐ Yes ➔ **SKIP TO Section E**

☐ No

D8e. How old were you when you last took estrogen-only pills?

____ ____ years

SECTION E: MEDICAL HISTORY

This section asks about your personal medical history.

Have you ever been diagnosed by a medical professional as having:

E1.	Heart attack (myocardial infarction)?	☐ No	☐ Yes → Age at first diagnosis: _____
E2.	Heart failure?	☐ No	☐ Yes → Age at first diagnosis: _____
E3.	Peripheral vascular disease or deep vein thrombosis (blocked arteries/veins in your arms/legs)?	☐ No	☐ Yes → Age at first diagnosis: _____
E4.	Chronic obstructive lung disease (COPD), or chronic bronchitis?	☐ No	☐ Yes → Age at first diagnosis: _____
E5.	Emphysema?	☐ No	☐ Yes → Age at first diagnosis: _____
E6.	Stomach ulcers proven by a test?	☐ No	☐ Yes → Age at first diagnosis: _____
E7.	Liver disease?	☐ No	☐ Yes → Age at first diagnosis: _____
E8.	A stroke/mini-stroke?	☐ No	☐ Yes → Age at first diagnosis: _____
E9.	Hemiplegia (weakness/paralysis of arms/legs)?	☐ No	☐ Yes → Age at first diagnosis: _____
E10.	Dementia (e.g. Alzheimer's)?	☐ No	☐ Yes → Age at first diagnosis: _____
E11.	HIV/AIDS?	☐ No	☐ Yes → Age at first diagnosis: _____
E12.	Polycystic Ovarian Syndrome (PCOS)?	☐ No	☐ Yes → Age at first diagnosis: _____
E13.	Hypertension/High blood pressure?	☐ No	☐ Yes → Age at first diagnosis: _____
E14.	High Cholesterol?	☐ No	☐ Yes → Age at first diagnosis: _____
E15.	Anxiety?	☐ No	☐ Yes → Age at first diagnosis: _____
E16.	Depression?	☐ No	☐ Yes → Age at first diagnosis: _____
E17.	Uterine fibroids?	☐ No	☐ Yes → Age at first diagnosis: _____
E18a.	Serious kidney problems?	☐ No	☐ Yes → Age at first diagnosis: _____
E18b.	If yes, have you ever required dialysis?	☐ No	☐ Yes → Age at first diagnosis: _____
E19.	Rheumatoid arthritis?	☐ No	☐ Yes → Age at first diagnosis: _____
E20a.	Other joint/bone problems?	☐ No	☐ Yes → Age at first diagnosis: _____
E20b.	If yes, please specify: _____		
E21a.	Diabetes?	☐ No	☐ Yes → Age at first diagnosis: _____
	If yes:		
E21b.	What type? ☐ Type I ☐ Type II ☐ Other/Don't Know		
E21c.	Have you ever had eye problems due to diabetes?	☐ No	☐ Yes → Age at first diagnosis: _____
E21d.	Have you ever had kidney problems due to diabetes?	☐ No	☐ Yes → Age at first diagnosis: _____

E22a. Hepatitis? ☐ No ☐ Yes → Age at first diagnosis: _____

E22b. If yes, what type? ☐ A ☐ B ☐ C ☐ Other, specify: _____

E23a. Are you taking any prescription medications for any of the conditions in questions **E1-E22**?

☐ Yes

☐ No ➔ **SKIP TO E24**

E23b. What prescription medications are you taking for the conditions in questions **E1-E22**?

Medication:	Condition(s):

E24. 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 F: MENSTRUATION / SYMPTOMS

This section asks about your menstrual periods and any problems you may have experienced before your diagnosis of endometrial cancer.

F1a. Have you ever had a menstrual period?

☐ Yes
☐ No ➔ **SKIP TO F4a**

F1b. How old were you when you had your first menstrual period?

____ ____ years

F2. At any time before your diagnosis of endometrial cancer, did you ever experience the following problems with menstrual periods:

		Did you experience the problem at least once within the 6 months before your diagnosis of endometrial cancer?	How long before your diagnosis of endometrial cancer did the problem start?	Did you seek care from a doctor or healthcare provider for the problem?
Irregular or unpredictable menstrual periods?	☐ No ☐ Yes ➔	☐ Yes ☐ No (Next)	☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year (Next)	☐ Yes ☐ No
Bleeding or spotting in between menstrual periods?	☐ No ☐ Yes ➔	☐ Yes ☐ No (Next)	☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year (Next)	☐ Yes ☐ No
Heavy menstrual periods?	☐ No ☐ Yes ➔	☐ Yes ☐ No (Next)	☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year (Next)	☐ Yes ☐ No
Prolonged menstrual periods lasting greater than 7 days?	☐ No ☐ Yes ➔	☐ Yes ☐ No (Next)	☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year (Next)	☐ Yes ☐ No

F3a. Are you still having menstrual periods?

☐ Yes ➔ **SKIP TO F4a**
☐ No

F3b. How old were you when you had your last menstrual period?

____ ____ years

F3c. What do you believe caused your periods to stop? Choose one:

☐ Menopause (change of life)
☐ Surgical removal of the uterus/womb or ovaries
☐ Chemotherapy or radiation treatment
☐ Another reason: _____

F4a. Have you had surgery to remove your uterus/womb (hysterectomy)?

☐ Yes
☐ No ➔ **SKIP TO F5a**

F4b. When was the operation to remove your uterus/womb (hysterectomy)?

__ __ / __ __ __ __
Month Year

F5a. Have you had surgery to remove one or both of your ovaries?

☐ Yes, both ovaries
☐ Yes, one ovary
☐ No ➔ **SKIP TO F6**

F5b. What was the date of the operation to remove your ovary/ovaries? If ovaries were removed on different dates, please only record the earlier date:

__ __ / __ __ __ __
Month Year

F6. At any time before your diagnosis of endometrial cancer, did you ever experience any of the following problems:

		Did you experience the problem at least once within the 6 months before your diagnosis of endometrial cancer?	How long before your diagnosis of endometrial cancer did the problem start?	Did you seek care from a doctor or healthcare provider for the problem?
Bleeding or spotting after sex?	☐ No ☐ Yes →	☐ Yes ☐ No	Next ☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year	Next ☐ Yes ☐ No
Pelvic pain?	☐ No ☐ Yes →	☐ Yes ☐ No	Next ☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year	Next ☐ Yes ☐ No
Pelvic or bladder pressure?	☐ No ☐ Yes →	☐ Yes ☐ No	Next ☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year	Next ☐ Yes ☐ No
Abdominal bloating or feeling full quickly?	☐ No ☐ Yes →	☐ Yes ☐ No	Next ☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year	Next ☐ Yes ☐ No
Change in urinary frequency or urgency?	☐ No ☐ Yes →	☐ Yes ☐ No	Next ☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year	Next ☐ Yes ☐ No
Change in bowel habit patterns?	☐ No ☐ Yes →	☐ Yes ☐ No	Next ☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year	Next ☐ Yes ☐ No

[**F6** continued…]

		Did you experience the problem at least once within the 6 months before your diagnosis of endometrial cancer?	How long before your diagnosis of endometrial cancer did the problem start?	Did you seek care from a doctor or healthcare provider for the problem?
Fatigue?	☐ No ☐ Yes →	☐ Yes ☐ No → Next	☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year → Next	☐ Yes ☐ No
Abnormal vaginal discharge?	☐ No ☐ Yes →	☐ Yes ☐ No → Next	☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year → Next	☐ Yes ☐ No
Bleeding or spotting after menopause? Please include any bleeding or spotting that occurred after you were no longer having menstrual cycles.	☐ No ☐ Yes → ☐ Does not apply **SKIP TO Section G**	☐ Yes ☐ No → Next	☐ Less than 6 months ☐ 6-12 months ☐ More than 1 year → Next	☐ Yes ☐ No

The next questions ask about bleeding or spotting after menopause. This refers to bleeding or spotting you may have experienced after you were no longer having menstrual cycles.

F7a. When was the first time you discussed bleeding or spotting after menopause with a doctor or healthcare provider?

☐ More than 1 year before diagnosis of endometrial cancer

☐ Between 6 months and 1 year before diagnosis of endometrial cancer

☐ Less than 6 months before diagnosis of endometrial cancer

☐ Did not ever discuss bleeding after menopause with a doctor or healthcare provider → **SKIP TO Section G**

F7b. What kind of doctor or healthcare provider did you first have this discussion with?

- ☐ Primary Care Provider - PCP
- ☐ Gynecologist – Ob/Gyn
- ☐ Urgent Care Physician
- ☐ Emergency Department Physician
- ☐ Other, specify: _____

F7c. Did you start the first conversation about bleeding or spotting after menopause or did your doctor/other healthcare provider ask you about it?

- ☐ I brought it up
- ☐ My doctor or other healthcare provider brought it up
- ☐ Don't Know

F7d. Before you discussed bleeding or spotting after menopause with a doctor or other healthcare provider, did you know endometrial cancer could cause this type of bleeding?

- ☐ Yes
- ☐ No

SECTION G: LIFESTYLE

This section asks about physical activity, alcoholic beverage history, tobacco use history, and your height and weight measurements. The first questions ask about your current leisure time 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:**

G1.	**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
G2.	**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
G3.	**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 alcoholic beverages that you may have consumed.

G4a. A year before your diagnosis of endometrial cancer, did you ever drink beer, wine or liquor on a regular basis, that is, four or more times per month?

☐ Yes
☐ No ➔ **SKIP TO G5a**

G4b. A year before your diagnosis of endometrial cancer, on average, how many days in a week did you have at least one beer, glass of wine, or shot of hard liquor?

____ day(s) per week

G4c. On a day that you drank, how many total bottles/cans of beer, glasses of wine, and/or shots of hard liquor did you usually have?

____ ____ drink(s) per day

The next questions ask about tobacco use including cigarettes and e-cigarettes.

G5a. Have you smoked at least 100 cigarettes in your entire life? Please do not include electronic or e-cigarettes:

☐ Yes
☐ No ➔ **SKIP TO G6a**

G5b. When you smoked cigarettes, how many did you usually smoke each day? One pack is equal to 20 cigarettes:

____ ____ ____ cigarettes per day

G5c. How old were you when you started smoking cigarettes?

____ ____ years

G5d. Do you still smoke cigarettes?

☐ Yes ➔ **SKIP TO G6a**
☐ No

G5e. How old were you when you stopped smoking cigarettes?

____ ____ years

G6a. Have you ever used an e-cigarette or other electronic "vaping" product?

☐ Yes
☐ No ➔ **SKIP TO G7**

G6b. At the time you were diagnosed with endometrial cancer, did you use e-cigarettes or other electronic "vaping" products every day, some days, or not at all?

☐ Every day
☐ Some days
☐ Not at all

G6c. Do you now use e-cigarettes or other electronic "vaping" products every day, some days, or not at all?

☐ Every day
☐ Some days
☐ Not at all

The next questions ask about height and weight at various times in your life.

G7. When you were 18 years old, what was your height? ____ feet ____ ____ inches

G8. When you were 18 years old, what was your weight? If you were pregnant when you were 18, please use your pre-pregnancy weight:

____ ____ ____ pounds

G9. One year before your diagnosis of endometrial cancer, what was your weight? If you were pregnant the year before your cancer diagnosis, please use your pre-pregnancy weight:

____ ____ ____ pounds

G10. What is your current height? ____ feet ____ ____ inches

G11. What is your current weight? If you are pregnant now, please use your pre-pregnancy weight:

____ ____ ____ pounds

SECTION H: OCCUPATIONAL HISTORY

This section asks about work at the time you were diagnosed with endometrial cancer. If you had more than one job, please use the job that you spent more hours at.

H1a. At the time you were diagnosed with endometrial cancer, which of the following best describes your employment status? Choose one:

- ☐ Employed full time
- ☐ Employed part time
- ☐ Not employed, but looking for work ➔ **SKIP TO H6**
- ☐ Not employed – not retired, disabled, or looking for work ➔ **SKIP TO H6**
- ☐ Retired ➔ **SKIP TO H6**
- ☐ Disabled, not able to work ➔ **SKIP TO H6**
- ☐ Other, specify: _____

H1b. At the time you were diagnosed with endometrial cancer, what was your job title?

_____

H1c. At the time you were diagnosed with endometrial cancer, what type of business or industry would you say best describes your workplace?

_____

H1d. At the time you were diagnosed with endometrial cancer, what type of work schedule did 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: _____

H1e. At the time you were diagnosed with endometrial cancer, how many years had you worked in this job? If less than 1, enter 0:

____ ____ years

H1f. At the time you were diagnosed with endometrial cancer, on average, how many hours per week did you usually work in this job?

____ ____ ____ hours

H2a. Have you missed any days of work due to your diagnosis of endometrial cancer?

- ☐ Yes
- ☐ No ➔ **SKIP TO H3**

H2b. How much work have you missed due to your diagnosis of endometrial cancer?

- ☐ Less than 1 week
- ☐ 1-2 weeks
- ☐ 3-4 weeks
- ☐ 1-3 months
- ☐ More than 3 months

H3. Since your diagnosis of endometrial cancer, did you use any of the following during your absence(s) from work?

Paid sick leave?	☐ Yes	☐ No
Paid vacation leave?	☐ Yes	☐ No
Unpaid leave?	☐ Yes	☐ No
Family Medical Leave Act (FMLA)?	☐ Yes	☐ No
Short-term disability insurance?	☐ Yes	☐ No
Long-term disability insurance?	☐ Yes	☐ No
Other? Specify: _____	☐ Yes	☐ No

H4. Does/did your job offer paid time off or paid leave for you when you have/had to miss work?

- ☐ Yes
- ☐ No

H5a. Have you left your job(s) or stopped working altogether since your diagnosis of endometrial cancer?

- ☐ Yes
- ☐ No ➔ **SKIP TO H6**

H5b. What are the reason(s) you left your job(s) or stopped working altogether? Select all that apply:

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

H6. How much has the COVID-19 coronavirus pandemic been harmful to your employment status?

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

SECTION I: DEMOGRAPHIC FACTORS

This section will give us a little more background information about you.

I1. Would you describe yourself as Hispanic, Latina, or Spanish origin?

- ☐ Yes
- ☐ No

I2. Which one or more of the following would you say is your race? Select all that apply:

- ■ White
- ■ Black or African American
- ■ American Indian or Alaskan Native
- ■ Asian
- ■ Native Hawaiian or Other Pacific Islander
- ■ Other, specify: _____

I3. How do you describe yourself?

- ☐ Female
- ☐ Male
- ☐ Transgender
- ☐ Do not identify as female, male, or transgender

I4. Which of the following best represents how you think of yourself?

- ☐ Gay or Lesbian
- ☐ Straight, that is not gay, lesbian, or bisexual
- ☐ Bisexual
- ☐ Something else

The next questions ask about education and household status.

I5. What is the highest level of school you have completed? Choose one:

- ☐ 0-8 years
- ☐ 9-12 years, but not a high school graduate
- ☐ High school graduate or GED
- ☐ Technical or Associates Degree
- ☐ Some college
- ☐ College graduate
- ☐ Post-graduate or professional degree

I6a. What is your present marital status?

- ☐ Never married or partnered ➔ **SKIP TO I7**
- ☐ Married or partnered
- ☐ Widowed
- ☐ Separated, divorced, or no longer partnered ➔ **SKIP TO I7**

I6b. What is the highest level of school completed by your spouse/partner? Choose one:

- ☐ 0-8 years
- ☐ 9-12 years, but not a high school graduate
- ☐ High school graduate or GED
- ☐ Technical or Associates Degree
- ☐ Some college
- ☐ College graduate
- ☐ Post-graduate or professional degree

I7. Last year, what was 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

I8. How many people, of all ages, live in your household? ____ ____ person/people

The next questions ask about caregivers, meaning friends or family members who may have provided help with getting to the doctor, going to appointments with you, making decisions about treatment, or providing other types of care and support during or after cancer treatment.

I9a. Since your diagnosis of endometrial cancer, has any friend or family member provided these types of care to you during your cancer treatment?

- ☐ Yes
- ☐ No ➔ **SKIP TO Section J**
- ☐ Have not had treatment since diagnosis ➔ **SKIP TO Section J**

I9b. Who was your caregiver? Select all that apply:

- ■ Spouse/Partner
- ■ Child
- ■ Sibling
- ■ Parent-in-law
- ■ Parent
- ■ Other relative
- ■ Friend
- ■ Other

SECTION J: ACCESS TO MEDICAL CARE / FINANCIAL SITUATION

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

J1a. At the time you were diagnosed with endometrial cancer, did you have health insurance coverage?

☐ Yes
☐ No ➔ **SKIP TO J2a**

J1b. At the time you were diagnosed with endometrial cancer, what type(s) of health insurance did you have? Select all that apply:

- ■ 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:

_____

J2a. Since your diagnosis of endometrial cancer, have there been any changes to the type(s) of health insurance coverage you have?

☐ Yes
☐ No ➔ **SKIP TO J3**

J2b. 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:

_____

J3. 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

J4. 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
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

J5. 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
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

J6. 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
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

J7. During the 5 years before your diagnosis of endometrial cancer, which of the following types of health insurance did you have? 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:

_____

J8. During the 5 years before your diagnosis of endometrial cancer, who did you usually see when you were sick or needed advice about your health? Choose one:

- ☐ Did not have a usual source of care
- ☐ General practitioner / family doctor / regular doctor
- ☐ Women's health specialist or OB/GYN
- ☐ Other specialist such as heart, lung, or kidney doctor. For example, Cardiologist, Pulmonologist, Nephrologist, or other specialist.
- ☐ Emergency room or urgent care doctor
- ☐ Local health department doctor or health advisor
- ☐ Other, specify: _____

J9. During the 5 years before your diagnosis of endometrial cancer, did you:

See a regular doctor for a physical examination or check-up?	☐ Yes	☐ No
Have an eye exam to check your vision?	☐ Yes	☐ No
See a dentist or dental hygienist to check your teeth?	☐ Yes	☐ No
Have a Flu Vaccine?	☐ Yes	☐ No
Have 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
Have a pap smear or pap test, that is, an examination to check for signs of cancer in your cervix?	☐ Yes	☐ No
Have a mammogram, that is, an examination with an x-ray image to check for signs of cancer in your breasts?	☐ Yes	☐ No

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
J10.	I know that I have enough money in savings, retirement, or assets to cover the cost of my treatment.	☐	☐	☐	☐	☐
J11.	My out-of-pocket medical expenses are more than I thought they would be.	☐	☐	☐	☐	☐
J12.	I worry about the financial problems I will have in the future as a result of my illness or treatment.	☐	☐	☐	☐	☐
J13.	I feel I have no choice about the amount of money I spend on 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
J14.	I am frustrated that I cannot work or contribute as much as I usually do.	☐	☐	☐	☐	☐
J15.	I am satisfied with my current financial situation.	☐	☐	☐	☐	☐
J16.	I am able to meet my monthly expenses.	☐	☐	☐	☐	☐
J17.	I feel financially stressed.	☐	☐	☐	☐	☐
J18.	I am concerned about keeping my job and income, including my work at home.	☐	☐	☐	☐	☐
J19.	My cancer or treatment has reduced my satisfaction with my current financial situation.	☐	☐	☐	☐	☐
J20.	I feel in control of my financial situation.	☐	☐	☐	☐	☐
J21.	I have been distressed by not knowing what my cancer care would cost.	☐	☐	☐	☐	☐
J22.	I am worried about the financial stress on my family as a result of my cancer.	☐	☐	☐	☐	☐

J23. 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

J24. 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

J25. Since your diagnosis of endometrial cancer, has there ever been a time you could not see your cancer doctor because of the COVID-19 coronavirus pandemic?

☐ Yes
☐ No

J26. Since your diagnosis of endometrial cancer, has there ever been a time you had to delay or stop your cancer treatment because of the COVID-19 coronavirus pandemic?

☐ Yes
☐ No

J27. Since your diagnosis of endometrial cancer, have you ever been contacted by a collection agency as a result of your cancer care?

☐ Yes

☐ No

J28. 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 K: COVID-19 CORONAVIRUS

This section asks about exposure to the COVID-19 coronavirus.

K1. Have you ever been exposed to someone with documented or suspected COVID-19 coronavirus infection, such as co-workers, family members, or others?

- ☐ Yes, documented COVID-19 coronavirus case(s) only
- ☐ Yes, suspected COVID-19 coronavirus case(s) only
- ☐ Yes, both documented and suspected COVID-19 coronavirus cases
- ☐ Not that I know of

K2a. Have you had any test for COVID-19 coronavirus, including a test that collected a nasal swab, or blood sample, or a spit saliva sample?

- ☐ Yes
- ☐ No ➔ **SKIP TO K3**

K2b. Did you test positive for COVID-19 coronavirus?

- ☐ Yes
- ☐ No
- ☐ Waiting for results

K3. Do you think you have already had COVID-19 coronavirus, but were not tested?

- ☐ Yes
- ☐ No

SECTION L: PERSPECTIVES ON DISCRIMINATION, RACE, AND HEALTHCARE

We are interested in the experiences of endometrial cancer survivors across different parts of their lives. In your day-to-day life, how often do any of the following things happen 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
L1.	You are treated with less courtesy than other people are.	☐	☐	☐	☐	☐	☐
L2.	You are treated with less respect than other people are.	☐	☐	☐	☐	☐	☐
L3.	You receive poorer service than other people at restaurants or stores.	☐	☐	☐	☐	☐	☐
L4.	People act as if they think you are not smart.	☐	☐	☐	☐	☐	☐
L5.	People act as if they are afraid of you.	☐	☐	☐	☐	☐	☐
L6.	People act as if they think you are dishonest.	☐	☐	☐	☐	☐	☐
L7.	People act as if they're better than you are.	☐	☐	☐	☐	☐	☐
L8.	You are called names or insulted.	☐	☐	☐	☐	☐	☐
L9.	You are threatened or harassed.	☐	☐	☐	☐	☐	☐

L10. 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

The next questions ask how you feel about parts of healthcare organizations.

Please answer the following statements with your level of agreement:

		Strongly Disagree	Disagree	Agree	Strongly Agree
L11.	You should be cautious when dealing with healthcare organizations.	☐	☐	☐	☐
L12.	Patients have sometimes been deceived or misled by healthcare organizations.	☐	☐	☐	☐
L13.	When healthcare organizations make mistakes they usually cover it up.	☐	☐	☐	☐
L14.	Healthcare organizations have sometimes done harmful experiments on patients without their knowledge.	☐	☐	☐	☐
L15.	Healthcare organizations don't always keep your information totally private.	☐	☐	☐	☐
L16.	Sometimes I wonder if healthcare organizations really know what they are doing.	☐	☐	☐	☐
L17.	Mistakes are common in healthcare organizations.	☐	☐	☐	☐

People interact with doctors and hospitals when a cancer diagnosis occurs and also for many other reasons not related to cancer. The next questions ask about your perspective on race and interactions with healthcare organizations.

Please answer the following statements with your level of agreement:

		Strongly Disagree	Disagree	Agree	Strongly Agree
L18.	Doctors treat Black and White people the same.	☐	☐	☐	☐
L19.	Racial discrimination in a doctor's office is common.	☐	☐	☐	☐
L20.	In most hospitals, Black and White people receive the same kind of care.	☐	☐	☐	☐
L21.	Black people can receive the care they want as equally as White people can.	☐	☐	☐	☐

SECTION M: HOME VISIT

As we near the end of the survey, we'd like to ask about your willingness to participate in a home visit by a nurse-interviewer to collect additional information on medications, blood pressure, and body measurements such as leg circumference. This will help us better understand health experiences after endometrial cancer. Not all participants who agree to participate in a home visit will be scheduled for one.

Due to the COVID-19 coronavirus pandemic, scheduling of visits will not begin until approved by the UNC System's Office of Human Research Ethics which is based on the guidance of state and local public health officials. If you agree and are selected to participate, we will schedule a 1-hour appointment for a trained nurse-interviewer to complete standardized body and blood pressure measurements, record medication use information, and sign consents in your home. For your participation, we will send you $40 within 4 weeks of completing the home visit.

M1. Are you willing to participate in the home visit, if selected?

☐ Yes
☐ No ➔ **SKIP TO Section N**

Thank you. As part of the home visit, there is an additional research effort to understand how cancer treatment may affect the microbiome, and the potential consequences for sexual or bowel function. The microbiome describes all the bacteria and other organisms that live inside the human body, some of which are beneficial, and some not.

For this part of the study, we would mail you a kit with information on how you can collect samples of the gut and vaginal microbiome to complete in the privacy of your home. The nurse-interviewer would pick up the samples during the home visit. For your participation in the microbiome sample collection, we will send you $50 within 4 weeks of completing the home visit.

M2a. Are you willing to receive the gut and vaginal microbiome sample collection kits?

☐ Yes ➔ **SKIP TO Section N**
☐ No

M2b. It will help us to know why you are not interested in participating in the microbiome study. Please select the reason that best describes why you have chosen not to participate:

☐ I am not comfortable with providing microbiome sample(s)
☐ I am too busy and do not have enough time to complete this
☐ I am too ill or busy with my cancer treatment to complete this
☐ The payment is not enough for me to be willing to participate
☐ Other, specify: _____

_____

SECTION N: OTHER CONTACTS

As we mention in our study newsletter and consent to participate in research, we plan to follow up with you every year or so for approximately 5 years.

N1. In case we can't reach you, are you willing to provide contact information of a friend or relative that might be able to assist us in reaching you?

☐ Yes

☐ No ➔ **SKIP TO Section O**

1st Contact:

Name: _____ Relationship: _____

Phone 1: _____

Phone 2: _____

Email: _____

2nd Contact:

Name: _____ Relationship: _____

Phone 1: _____

Phone 2: _____

Email: _____

SECTION O: CLOSING COMMENTS

Thank you for answering these questions.

O1. Before we end the survey, is there any other information or anything you would like to add that was not asked?

Again, thank you very much for your help with this study.

Annotations

C1-43: Functional Assessment of Cancer Therapy – Endometrial (FACT-En) (Version 4)
Bonomi, A.E., Cella, D.D., Hahn, E.A., Bjordal, K., Sperner, B., Gangeri, L., Bergman, B., Willems, J., Hanquet, P., & Zittoun, R. Multilingual translation of the Functional Assessment of Cancer Therapy (FACT) quality of life measurement system. Quality of Life Research 1996; 5: 309-320

E1-22: Charlson Comorbidity Index
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

F2 and 6 Adapted from: Pakish, J. B., Lu, K. H., Sun, C. C., Burzawa, J. K., Greisinger, A., Smith, F. A., Fellman, B., Urbauer, D. L., & Soliman, P. T. (2016). Endometrial Cancer Associated Symptoms: A Case-Control Study. *Journal of women's health (2002)*, *25*(11), 1187–1192. https://doi.org/10.1089/jwh.2015.5657

G1-3: Godin-Shepard Leisure-time Physical Activity Godin G. The godin-shephard leisure-time physical activity questionnaire. The Health & Fitness Journal of Canada. 2011. Accessed August 14, 2023. https://doi.org/10.14288/hfjc.v4i1.82.

I9a and b: Caregiving from MEPS (2018) Medical Expenditure Panel Survey (MEPS). Content last reviewed March 2023. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/data/meps.html

J10-22: 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

L1-10: Everyday Discrimination Scale
Williams DR, Yan Yu, Jackson JS, Anderson NB. Racial differences in physical and mental health: socio-economic status, stress and discrimination. J Health Psychol. 1997;2(3):335-351. doi:10.1177/135910539700200305

L11-17: Medical Mistrust Index
LaVeist, T. A., Isaac, L. A., & Williams, K. P. (2009). Mistrust of health care organizations is associated with underutilization of health services. Health services research, 44(6), 2093–2105. https://doi.org/10.1111/j.1475-6773.2009.01017.x

L18-21: Perceived Racism Index
LaVeist, T. A., Nickerson, K. J., & Bowie, J. V. (2000). Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients. *Medical care research and review : MCRR*, *57 Suppl 1*, 146–161. https://doi.org/10.1177/1077558700057001S07