## **Attachment 3a**

# **Ovarian Cancer Survivorship Survey**

CDC estimates the average public reporting burden for this collection of information as 50 minutes per response, including the time for reviewing instructions, searching existing data/information sources, gathering and maintaining the data/information needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX).







### **INTRO**

This survey is specifically for women who have been diagnosed with ovarian cancer. In addition to ovarian cancer, this survey is also for women who have been diagnosed with cancer of the fallopian tubes, or cancer of the primary peritoneum. For simplicity, all three of these cancers will be referred to as ovarian cancer throughout the survey.

Some women who participate in this survey will be much closer to their diagnosis and still undergoing treatment, while others may have ended treatment several years ago. Several questions will ask you to think back to when you were first diagnosed with ovarian cancer, or when you were receiving treatment. If you are currently receiving treatment, please answer these questions to the best of your ability.

Your answers will help us better understand how to help women with ovarian, fallopian tube, and primary peritoneal cancer as they are diagnosed, receive treatment, and begin to recover. Please answer all of the following questions by choosing the option that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Your opinions are very important to us, and we appreciate your help.

SECTION A: SCI	REENER
SCREENER1	Are you at least 18 years old?  □ Yes □ No [GO TO INELIGIBLE]
SCREENER2	Have you ever been diagnosed with ovarian, fallopian tube, or primary peritoneal cancer?  □ Yes □ No [GO TO INELIGIBLE]
SCREENER3	Have you received any treatment for your ovarian cancer?  Yes [GO TO CONSENT]  No [GO TO INELIGIBLE]
INELIGIBLE	Thank you for your interest in this study. Unfortunately, you are not eligible to participate in the survey at this time. Thank you for your time.

#### **SECTION A1: INFORMED CONSENT**

#### CONSENT

NORC at the University of Chicago is conducting a survey sponsored by the Centers for Disease Control and Prevention. This survey is to learn about your experiences as an ovarian cancer survivor. By taking this survey, you will help us identify needs of ovarian cancer survivors in order to develop programs aimed at improving survivor health.

The survey will include questions related to your experiences, health, and well-being as an ovarian cancer survivor as well as general demographics and questions related to health and cancer in your family. The survey will take about 45 minutes to complete.

Taking the survey is your choice. Some questions may be sensitive to you. You may skip questions you do not want to answer and you can stop the survey at any time. Eligible participants will be mailed \$10 at the end of the survey.

Any information you provide will be maintained in a secure manner. No one will know how you answered the questions. Only project staff will have access to the study data. The data we collect from you will be combined with data from other participants.

If you have any questions about the survey, you can call the NORC IRB Administrator toll-free at: 866-309-0542.

I have read the above information. I consent voluntarily to be a participant in this study.

- € Yes [CONTINUE TO SECTION B]
- € No [END]

**END** Thank you for your interest. Have a nice day.

# **SECTION B: OVARIAN CANCER SYMPTOMS AND DIAGNOSIS**

INTRO2	type	questions in this survey will only indicate ovarian cancer, but are es (ovarian, fallopian tube, or primary peritoneal cancer). The follout your ovarian cancer symptoms and diagnosis.		
DIAG_A	GE	What was your age when you were <u>first</u> diagnosed with ovarian Years Old	cancer?	
DIAG_H	OW	<ul> <li>Which of the following best describes how you were first diagnocancer?</li> <li>I was diagnosed as part of a routine exam, check-up, or some substitution in the company of the c</li></ul>	screening	test.
SYMPTO	DM_x	Did you experience any of the following symptoms that were no weeks or month(s) leading up to your ovarian cancer diagnosis?	t normal t	for you in the
			Yes	No
	a.	Vaginal bleeding or discharge from your vagina that was not		_

		Yes	No
a.	Vaginal bleeding or discharge from your vagina that was not normal for you		_
b.	Pain or pressure in the pelvic or abdominal area (area between your stomach to between your hip bones)		_
c.	Lower back pain		
d.	Bloating or stomach swelling		
e.	Feeling full quickly or difficulty eating		
f.	Change in bathroom habits, such as more frequent or urgent need to urinate and/or constipation		

DIAG_TIME	How much time passed from when you started experiencing symptoms or knew
	something was wrong, to when you received an ovarian cancer diagnosis?

A week or les
2 weeks
3 weeks
A month

□ 2 months

 $\hfill\Box$  More than 2 months, but less than 6 months

□ More than 6 months

□ Didn't experience any symptoms

STAGE At what stage was you	ovarian cancer	diagnosed?
-----------------------------	----------------	------------

□ Stage 1

	□ Stage 2 □ Stage 3 □ Stage 4 □ Other, please spen □ Don't know	cify:	
DR_WHICH	<ul><li>Oncologist or can</li><li>Gynecological one</li><li>Surgeon</li></ul>	cologist (specialty oncologist) nternal medicine doctor st	
CANC_OTH	Other than your ovarian concer?  Property Yes  No [GO TO SECTION]	·	agnosed with any other kind of
CANC_xxxx	What type of cancer and I	how old were you were you v	vere diagnosed?
	CANC_TYPE  Cancer Typ	CANC_AGE Age	
SECTION C: OV	ARIAN CANCER TREATMEN	NT	
INTRO3	The following questions a ovarian cancer.	re about any treatment you i	may have received for your
SURGERY	Did you receive surgery as  Yes  No [GO TO TRTM	s part of your ovarian cancer	treatment?
DR_SURG	Which doctor performed  Oncologist  General Surgeon Gynecologist	your ovarian cancer surgery?	

	<ul><li>Other, please specify:</li><li>Don't know</li></ul>			
	proximately how long did you travel one-way to ceived surgery for your cancer?  Less than 30 minutes  Thirty minutes or more, but less than one One hour or more, but less than 2 hours Two or more hours		ital or facilit	ry where you
	d you receive any of the following cancer treatoretment?	ments as pa	art of your o	varian cancer
5. 3		Yes	No	Don't know
	therapy that was injected into a vein or n a port (also known as intravenous)			
	therapy that was injected into the abdominal also known as intraperitoneal)			
made ir	onal antibody therapy – uses antibodies n a laboratory from immune cells; given n an infusion			
d. Bevaciz	umab – antibody therapy used with herapy to treat ovarian cancer			
e. Poly po drugs tl	lymerase inhibitors, or PARP inhibitors – nat block DNA repair and may cause cancer die. Examples: Olaparib, Niraparib			
	olease specify:			
PROGRAMMER: IF TO CLINICTRIAL.	ANY OF ABOVE EQUAL '1' (YES), CONTINUE TO	O TRAVEL_	CHEMO. O	THERWISE, SK
TRAVEL_CHEMO	How long did you travel one-way to the hosp chemotherapy for your cancer?  Less than 30 minutes  Thirty minutes or more, but less than One hour or more, but less than 2 ho	n one hour		ou received

☐ Gynecologic Oncologist

CLINICTRIAL	Clinical trials are research studies that involve people. They are designed to test the safety and effectiveness of new treatments and to compare new treatments with standard care. Often, patients in clinical trials are not told what treatment they received until the trial is over.									
	Were you offered or did you seek out participation in a clinical trial as part of your ovarian cancer treatment? Only include clinical trials for drugs to treat cancer. Do not include trials for medications to treat cancer-related side effects, like nausea.  □ Yes □ No [GO TO RECENT]									
TRIAL_PART	Did you participate in a clinical trial as part of your cancer treatment?  □ Yes □ No									
NO_PART	Were you ever denied participation or decided not to participate in a clinical trial?  Pes  No [GO TO RECENT]									
REASON	What was the main reason you did not enter the clinical trial?  □ I did not meet the eligibility criteria. □ I refused the treatment protocol. □ I wanted to be treated elsewhere or by a different doctor. □ I wanted to know exactly what treatment I was receiving. □ Other, please specify:									
RECENT	How long ago was your most recent treatment for ovarian cancer?  Currently receiving treatment  Less than 12 months ago [GO TO ER_EVER]  At least a year ago, but less than 3 years ago [GO TO ER_EVER]  At least 3 years ago, but less than 5 years ago [GO TO ER_EVER]  At least 5 years ago, but less than 10 years ago [GO TO ER_EVER]  More than 10 years ago [GO TO ER_EVER]									
TRTMT_CURR	What treatment(s) are you currently receiving?									
ER_EVER	While undergoing cancer treatment, did you ever have to go to the emergency room (ER)?  □ Yes									

	Many cancer patients experience several different symptoms or si undergoing treatment. These side effects can vary from mild to se		
	of the following experiences while undergoing cancer treatment?	vere. D	na you nave
		Yes	No
	a. Had to interrupt or delay treatment		
	b. Had to stop or suspend treatment		
	c. Doctors prescribed medication to deal with side effects		
	d. Doctors changed treatment to deal with side effects		
	e. Refer you to specialists to help deal with side effects		
ECUR	Since you were first diagnosed with and treated for ovarian cancer told you that your ovarian cancer had come back, that is, that you recurrence?  Pes No [GO TO METASTASIS] Don't know [GO TO METASTASIS]		
ECUR_AGE	What was your age when your cancer came back, or recurred? Years Old		
METASTASIS	Since you were first diagnosed with and treated for ovarian cance other health professional told you that your ovarian cancer had spof your body, that is, that you had a metastasis?  — Yes — No [GO TO REMISSION]		
META_AGE	What was your age when you were diagnosed with a metastasis? Years Old		
EMISSION	To the best of your knowledge, are you now free of cancer or bee is in remission?  Pes No Don't know	n told t	hat your car

□ No

INTRO4 People who have received treatment for cancer often report that they continue experiencing a variety of symptoms or problems after, or even long after, they have

completed treatment. The following questions are about potential symptoms and side effects from your cancer treatment.

TXSYMPTO	M_x	Have you ever experienced any of the following symptoms <u>since you received</u> treatment for your cancer?									<u>ved</u>				
													Yes	No	
		 -						•			 				

		Yes	No
a.	Numbness, prickling or tingling in your hands or feet		
b.	Sharp, jabbing, throbbing, freezing or burning pain in your extremities		
c.	Extreme sensitivity to touch		
d.	Lack of coordination or falling		
e.	Muscle weakness in your arms and legs		

[PROGRAMMER: IF TXSYMPTOM\_A=1 OR TXSYMPTOM\_B=1 OR TXSYMPTOM\_C=1 OR TXSYMPTOM\_D=1 OR TXSYMPTOM\_E=1, CONTINUE. OTHERWISE, SKIP TO TREAT\_A.]

EXPBEFORE	Had you ever experienced any of these symptoms before your cancer diagnosis and treatment?  □ Yes □ No
INTERFERE	How much have these symptoms interfered with your everyday activities, like getting dressed, working, participating in hobbies, doing usual household activities, or sleeping?  Uery much  Quite a bit  A little  Not at all
TALK_SYMP	Have you talked to a doctor or other health professional about these symptoms?  □ Yes □ No

**TREAT\_x** Have you used any of the following treatments to help you address your symptoms?

		Yes	No
a.	Over the counter pain relievers (like Tylenol, Aspirin, or Advil)		
b.	Prescription pain relievers		
c.	Other prescription drugs or medication		
d.	Electric nerve stimulation		
e.	Physical or Occupational therapy		
f.	Alternative treatments like acupuncture or herbal supplements		
g.	Other, please specify:		

NEUF	Since you received treatment for your cancer, has a doctor or any other heap provider told you that you have neuropathy? Neuropathy is pain numbness discomfort caused by damage to the nerves that brings signals to and from spinal cord to other parts of the body, such as the hands and feet. Some wo neuropathy after receiving treatment for cancer.    Yes   No   Don't know   Diagnosed before I had cancer	or the brair	n and		
SINCI	E_x Have you experienced any of the following <u>since you received treatment fo</u> cancer?	<u>r your</u>			
		Yes	No		
	Felt like you had to read something several times to understand it				
a. b.	Felt like your thinking was slow				
	· · · · · · · · · · · · · · · · · · ·				
C.	Felt like you had to work really hard to pay attention or you would make a mistake				
d.	Had difficulty concentrating				
e. f.	Had a hard time remembering things  Had a hard time reading and following complex instructions (e.g. directions for a	$\Box$			
1.	new medication)				
g.	Had difficulty planning for and keeping appointments that are not part of your				
	weekly routine (e.g. a therapy or doctor appointment, or a social gathering with friends and family)				
h.	Had trouble managing your time to do most of your daily activities				
i.	Had difficulty learning new tasks or instructions				
j.	Had trouble recalling the name of an object when talking to someone				
[PRO	treatment?	and			
	□ No				

**SYMPTALK** Have you talked to a doctor or other health professional about these symptoms?

How much have these symptoms interfered with your everyday activities, like doing your job, reading a book, participating in hobbies, or doing usual household activities?

**ACTIVITIES** 

Very muchQuite a bitA littleNot at all

	□ Yes □ No
COGNITIVE	Since you received treatment for your cancer, has a doctor or any other health care provider told you that you had chemo-brain, chemo-fog, or were suffering from cognitive issues due to chemotherapy?  □ Yes □ No
WGT_CHG	Did your weight change while you were undergoing cancer treatment?  Yes, lost weight  Yes, gained weight  No, weight was more or less the same
WGT_REC	Since being diagnosed with cancer, has a doctor or other health professional ever recommended that you gain or lose weight?  'Yes, recommended lose weight  Recommended gain weight  Recommended I maintain my weight  No, haven't received any weight-related recommendations
WEIGHT	About how much do you currently weigh without shoes? Pounds
HEIGHT_FT HEIGHT_IN	About how tall are you without shoes? Feet Inches
PSTWK_x	Please indicate the extent to which you have experienced these symptoms or problems during the past week.

During the PAST WEEK	Not at all	A little	Quite a bit	Very much
a. Did you have abdominal pain?				
b. Did you have a bloated feeling in your abdomen/stomach?				
c. Did you have problems with your clothes feeling too tight?				
d. Did you experience any change in bowel habits?				
e. Were you troubled by passing wind/gas/flatulence?				
f. Have you felt full too quickly after beginning to eat?				
g. Have you had indigestion or heartburn?				
h. Have you lost any hair?				
i. Did food and drink taste different than usual?				
j. Have you felt weak in your arms or legs?				

k.	Did you have aches and pains in your muscles or joints?					
I.	Did you have problems with hearing?					
m.	Did you urinate frequently?					
n.	Have you had skin problems (e.g. itchy, dry)?					
0.	Did you have hot flashes?					
p.	Did you have night sweats?					
-	Have you felt physically less attractive as a result of your disease or treatment?					
r.	Have you been dissatsified with your body?					
s.	How much has cancer been a burden to you?					
t.	How much has your treatment been a burden to you?					
u.	Were you worried about your future health?					
SECTION	ON E: YOUR FAMILY HISTORY OF CANCER  The following section will ask about your family h	istory of can	cer and ger	netic testing	<i>5</i> .	
RISK_TALK  Before you were diagnosed with ovarian cancer, had you ever talked to your doctor about your family history of cancer and what it might mean for your own health and cancer risk?  'Yes  No  FAM_OVAR  Have any other women in your family, that you are related to by blood, ever been diagnosed with ovarian cancer? This could include your mother, sisters, grandmothers, aunts, daughters, granddaughters, nieces, or cousins.  Yes  No [GO TO FAM_BREAST]  Don't know [GO TO FAM_BREAST]						
OVAR	OVAR_NUM How many women in your family, that you are <u>related to by blood</u> , have been diagnosed with ovarian cancer? This could include your mother, sisters, grandmothers, aunts, daughters, granddaughters, nieces, or cousins.  Number of relatives					
FAM_	BREAST Have any other women in your family, that you a diagnosed with breast cancer? This could include aunts, daughters, granddaughters, nieces, or could yes  No [GO TO MALE_BREAST]  Don't know [GO TO MALE_BREAST]	your mothei			5,	

BREAST_NUM	with breast cancer? This could include your mother, sisters, grandmothers, aunts, daughters, granddaughters, nieces, or cousins.  Number of relatives
UNDER50	How many of them were diagnosed when they were younger than age 50?  Number of relatives
MALE_BREAST	Have any men in your family, that you are related to by blood, ever been diagnosed with breast cancer?  Pes No Don't know
GENETIC_REC	Genetic counseling involves an in-depth discussion with a trained genetic counselor, doctor, or nurse about your family's health history and your risk for having an inherited genetic mutation. Has a doctor or other health professional ever recommended or referred you for genetic counseling for breast or ovarian cancer?  □ Yes □ No
GENETIC_YN	Have you ever received genetic counseling for breast or ovarian cancer risk?  Yes  No [GO TO GENETIC_FAM]  Don't know [GO TO GENETIC_FAM]
GENETIC_WHE	<ul> <li>When did you receive genetic counseling? Please select all that apply.</li> <li>Before I was diagnosed</li> <li>At the same time I was diagnosed</li> <li>After I was diagnosed</li> </ul>
GENETIC_WHO	From whom did you receive genetic counseling? Please select all that apply.  Genetic counselor  My regular or primary care doctor  Nurse  Cancer doctor or oncologist  Gynecologist  Other  Don't know

**GENETIC\_FAM** As far as you know, have any of your blood relatives received genetic counseling for breast or ovarian cancer risk?

		□ Yes □ No		
BRCA_YN	ith the ris RCA1 and vide infor A2 genet	l BRCA2, mation		
BRCA_RE	SULT	S Did the results of your BRCA1/BRCA2 test indicate that you carry a mould put you at increased risk for cancer?  Yes  No [GO TO BRCA_FAM]  Inconclusive result (often called "Variant of Unknown Significe BRCA_FAM]  Don't know [GO TO BRCA_FAM]		
INFLUENC	E	Did the results of your genetic testing influence your cancer treatment following ways?	nt in any	of the
			Yes	No
	a.	Influenced surgery – had additional ovary or both ovaries removed		
	b.	Influenced surgery – had one or both breasts removed		
		(mastectomy)		
	c.	(mastectomy)  Took a PARP inhibitor (Poly polymerase inhibitors, or PARP inhibitors – drugs that block DNA repair and may cause cancer cells to die. Examples: Olaparib, Niraparib)		
	c.	Took a PARP inhibitor (Poly polymerase inhibitors, or PARP inhibitors – drugs that block DNA repair and may cause cancer cells		
PROGRAM NOTEST	d.	Took a PARP inhibitor (Poly polymerase inhibitors, or PARP inhibitors – drugs that block DNA repair and may cause cancer cells to die. Examples: Olaparib, Niraparib)		

E	RCA_FAM	As far as you know, have any of your blood mutations in BRCA1 or BRCA2 genes?      Yes     Don't know	relatives rec	eived genet	ic testing fo	or	
E	BRCA_DESCNT	Studies show that BRCA1 and BRCA2 are modescent. Most people of Ashkenazi descent Are you and your family of Ashkenazi Jewisl Yes  No Don't know	can trace th	-			
	ECTION F: INT NTRO6	Next, we will ask you some questions about medical system, while undergoing diagnosis doctors, nurses, and other hospital or healt	s and treatm	ent for cand	_		
S	IDEEFFECTS_x	ง How much do you agree or disagree with ea	ach of the fo	llowing state	ements?		
			Strongly Disagree	Disagree	Agree	Strongly Agree	Doesn't Apply
a.	-	alked to me about possible side effects ed my cancer treatment.					
b.	-	requently asked if I was experiencing side iated with my cancer treatment.					
c.	My doctors li side effects.	istened when I reported treatment-related					
d.	My doctors h treatment.	nelped me deal with side effects from my					
e.		gave me information on how I could tment related side effects at home.					
f.	My treatmen	nt-related side effects were well managed.					
g.		l with how my doctors managed my					

□ Insurance wouldn't cover it□ My doctor didn't think I needed it

□ Other reasons

□ I was afraid it would affect my health insurance coverage

h.	I had a hard time dealing with the side effects from my cancer treatment.			
i.	I looked for information online about how to manage my treatment-related side effects.			
j.	My doctors were not very helpful in dealing with the side effects from my cancer treatment(s).			
k.	I had all the support I needed in dealing with the side effects from my cancer treatment(s).			

# **SECTION G: SUPPORT AND COPING**

**INTRO7** The following questions are about psychological and emotional care you may have

received before, during, or after your cancer diagnosis and treatment.

**RELATIONS** During your cancer diagnosis and treatment, did your doctor, nurse, or other health

professional talk with you about how cancer may affect your emotions or relationships

with other people?

□ Yes

□ No

□ Don't know

SERVICES\_x During your cancer diagnosis and treatment, did you participate in or utilize any of the following services to help you cope psychologically or emotionally?

	SERVICES			If Yes, How	HELPFUL				
	SERVICES			helpful did	How helpful did you find this resource to be				
		Yes	No	you find this	Very	Somewhat	A Little	Not At All	
		163	INO	resource to	Helpful	Helpful	Helpful	Helpful	
a.	Support Group			be?					
b.	Professional Counseling								
c.	Talk to religious leaders or members of spiritual community								
d.	Talk to doctors, nurses, or other health professionals								
e.	Talk to friends and family								
f.	Yoga or other exercise								
g.	Meditation								
h.	Stress reduction or management techniques								

					Ехр. Ба	IE XX/ XX/ XXXX	i.	
i.	Social worker							
j.	The internet to get cancer education or support, like in an online community or forum							
k.	Camps, retreats, adventure programs or social activities that offer cancer education or support							
1.	Other, please specify:							
	NOSUPPORT  Do any of the following reasons apply to why you didn't utilize any support services?  Please select all that apply.  I didn't know these services were available.  I didn't want to participate in these services or activities.  I didn't have a way of getting to these activities or services.  I didn't think I needed to participate in these activities.  I couldn't afford to participate in these activities.  RELY_x  During cancer diagnosis and treatment, did you have people you were able to rely on to							
			None of	A little of	Some of	Most of	All of the	
	a Damaind on holy you take madications?		the time	the time	the time	the time	time	
	a. Remind or help you take medications?							
	b. Help you cook meals?							
	c. Help you complete household chores?							
	d. Help you run errands?							
	e. Provide transportation?							
	f. Help take care of children or pets?							

Help with your caregiving responsibilities, like

having someone take care of a sick friend or

relative that you normally care for?

bills?

k. Help you financially?

h. Accompany you to doctor's appointments?

Help you complete work responsibilities?

Help take care of important duties, such as pay

l.	Confide in or talk to about how you were feeling or doing?						
m.	Provide com	fort or s	upport in a time of need?				
n.	Share your worries or fear with?						
o.	Help you tak	e your m	nind off things?				
p.	Have a good with?	time or	do something enjoyable				
S	ECTION H: YO	UR HEA	LTH INSURANCE				
INTRO8 The following questions are about y diagnosis and treatment.			our health in	surance covera	ge during yo	our cancer	
	nsure_yn	tests, c	u have any form of health ins or cancer treatments? Yes No		·	·	
11	NSURE_TYPE	and tre	eatment? Please select all the Health insurance through y Private health insurance, in Medicare Medi-Gap Medicaid SCHIP (State Children's Health insurance) Health care (e.g. TRI Indian Health Service State-sponsored health plaid Other government program Single service plan (e.g. der No coverage of any type [Gill Don't know [GO TO STAYJO]]	at apply. our (or your sour (or your sour (or your sour sour sour sour sour sour sour s	spouse's) emplo rchased Program) HAMP-VA)		er diagnosis
INSREF_APPT Was there ever a time when health for your cancer with the doctor or to Yes  No Doesn't applyDon't know Does not apply						a medical ap	pointment
II	INSRFF OPIN Was there ever a time when healt!			insurance re	fused to cover :	a second oni	nion about

your cancer?

	□ Yes
	□ No
	□ Don't know
	□ Does not apply
INSREF_TEST	Was there ever a time when health insurance refused to cover a test or procedure recommended by your doctors for your cancer care and treatment?
	□ Yes
	□ No
	□ Don't know
	☐ Does not apply
INSREF_MED	Was there ever a time when health insurance refused to cover a medication prescribed for your cancer care?
	, □ Yes
	□ No
	□ Don't know
	☐ Does not apply
STAYJOB	During your cancer diagnosis and treatment, did you ever stay at a job in part because you were concerned about losing your health insurance?  — Yes
	□ No
	□ Don't know
	□ Does not apply
LOSE_CANC	Were you ever concerned about losing your health insurance because of your cancer?
	□ Yes
	□ No
	□ Does not apply
UNINSURED	At any point during your cancer diagnosis or treatment, were you uninsured or did you lose your health insurance coverage?
	□ Yes
	□ No
	□ Don't know
	☐ Does not apply
DENY_INS	Were you ever denied health insurance coverage because of your cancer?
	□ Yes
	□ No
	□ Don't know

☐ Does not apply

INTRO9	the following questions are about your occupational status and experiences with work before, during, and after your cancer treatment.					
EMPLOY	At the time of your ovarian cancer diagnosis, what was your employment status?    Employed full-time   Employed part-time   Self-employed   Unemployed and looking for work [GO TO SECTION J]   Unemployed and not looking for work [GO TO SECTION J]   Homemaker [GO TO SECTION J]   Retired [GO TO SECTION J]   On disability [GO TO SECTION J]					
EMP_TYPE	What kind of work were you doing at the time of you cancer diagnosis? For example: teacher, nurse, lawyer, etc.					
LEAVE_YN	Did you take any leave or time off from work for any of your cancer treatment and/or recovery?					
	□ No [GO TO WORKAFTER_YN]					
LEAVE_TYPE	What kind of leave or time off did you take during your treatment and/or recovery?  Please select all that apply.  Paid sick leave  Unpaid sick leave  Other paid time off  Family Medical Leave Act (FMLA)  Disability leave  There was no time off  Quit job  Other, please specify:					
WORKAFTER_	YN After your treatment and recovery, did you continue working for pay?  □ Yes □ No [GO TO TRTMNT AFTER]					

WORKTX_AFTE	After your treatment and recovery, did you Please select all that apply.  Continue at the same job you had before your cancer diagnosis  Have a different job than the one you had before your cancer diagnosis  Go part-time or worked fewer hours at the same job  Have different duties or responsibilities at the same job  Decided not to pursue a promotion
PROGRAMMER	IF WORKTX_AFTER NOT MISSING, GO TO DISCRIM.
TRTMNT_AFTE	After your treatment and recovery, did you  Retire Go on disability Quit working Lose your job or get fired Continue looking for work Other
DISCRIM	Did you ever feel like you were experiencing discrimination in your workplace resulting from your cancer diagnosis, treatment, and its lasting effects?  □ Yes □ No
SECTION J: FINA	NCIAL IMPACT
INTRO10	Next, we will ask about the possible financial impact cancer has had on your life.
FINANCES	To what degree has cancer caused financial problems for you and your family?  □ A lot □ Some □ A little □ None at all
BORROW	Have you or has anyone in your family had to borrow money or go into debt because of your cancer or its treatment?  □ Yes □ No
BANKRUPT	Did you or your family ever file for bankruptcy because of your cancer or its treatment?  □ Yes □ No

SACRIFICE	Have you or your family ever had to make other kinds of financial sacrifices because of your cancer or its treatment?  Yes Please describe what kind of financial sacrifices:  No
MEDBILLS	Have you ever worried about having to pay large medical bills related to your cancer?  U Yes  No
UNABLE	Keeping in mind medical visits for your cancer, its treatment, or the lasting effects of that treatment, have you ever been unable to cover your share of the costs of those visits?  □ Yes □ No
OUTOFPOCKET	Overall, how much do you think you or your family spent out-of-pocket on co-pays, medical bills, and other expenses related to your cancer, its treatment, and/or the lasting effects of that treatment?  □ Less than \$2,000  □ Between \$2,000 and \$5,000  □ Between \$5,001 and \$10,000  □ Between \$10,001 and \$25,000  □ More than \$25,000

# **SECTION K: OTHER MEDICAL CONDITIONS**

INTRO11

We are also interested in learning about other medical conditions, aside from cancer, that you may have and any medications, either prescription or over-the-counter, you may be taking to address health issues.

OTHMED\_x, DIAG\_x Have you <u>ever</u> been diagnosed with any of the following medical conditions? Please select all the apply.

					If Yes, Were you diagnosed with	Diagnosis before or after ovarian cancer treatment		
		Yes	No	Don't Know	this condition before or after you	Before	After	
a.	Hypertenion (High blood pressure)				received treatment for ovarian cancer?			
b.	High cholesterol							
c.	Heart problems (such as heart attack, coronary artery disease, cogestive heart failure, irregular heartbeat, etc.)							
d.	Stroke, including mini-strokes or blood clots in the brain							
e.	Diabetes, high blood sugar, or sugar in the urine							
f.	Arthritis							
g.	Osteoprosis or Osteopenia (loss of bone mass, fragile or soft bones)							
h.	Asthma							
i.	Emphysema, chronic bronchitis, or chronic obstructive pulmonary disease (COPD)							
j.	Kidney disease							
k.	Stomach and/or intestinal problems, such as Crohn's disease, ulcers, or inflammatory bowel disease							
I.	Anemia							
m.	Other, please specify:							

**DEPRESS** 

Have you ever taken any prescription medication for depression? *Examples include Zoloft, Prozac, Sarafem, Lexapro, Celexa, Paxil, Effexor, Cymbalta, or Wellbutrin.* 

□ Yes

	<ul><li>□ No [GO TO ANXIETY]</li><li>□ Don't know [GO TO ANXIETY]</li></ul>
DEPRESS_BDA	Did you take this medication before, during, or after your cancer diagnosis and treatment? Please select all that apply.  □ Took medication BEFORE cancer diagnosis and treatment □ Took medication DURING cancer diagnosis and treatment □ Took medication AFTER cancer diagnosis and treatment
DEPRESS_CURF	Are you currently taking medication for depression?
	□ Yes □ No □ Don't know
DEPRESS_RX	Who wrote the prescription for your anti-depressant medication?  Primary care doctor  Oncologist  Psychiatrist  Other, please specify:
ANXIETY	Have you ever taken prescription medication for anxiety or for feeling worried, anxious or nervous? Examples include Xanax, Niravam, Klonopin, Ativan, Valium, Vanspar, or a beta-blocker like Bevibloc or propranolol.  □ Yes □ No [GO TO PAIN_OTC] □ Don't know [GO TO PAIN_OTC]
ANXIETY_BDA	Did you take this medication before, during, or after your cancer diagnosis and treatment? Please select all that apply.  □ Took medication BEFORE cancer diagnosis and treatment □ Took medication DURING cancer diagnosis and treatment □ Took medication AFTER cancer diagnosis and treatment
ANXIETY_CURR	Are you currently taking medication for depression?  Pes  Don't know
ANXIETY_RX	Who wrote the prescription for your anti-depressant medication?  Primary care doctor  Oncologist  Psychiatrist  Other, please specify:

PAIN_OTC	Are you currently taking any over-the-counter, or non-prescription, medication to help you deal with pain? Examples include Advil, Tylenol, or Motrin.  □ Yes □ No
PAINMED	Are you currently taking any <i>prescription</i> medications to help you deal with pain?  Examples include Hydrocodone, Percocet, or Vicodin.  □ Yes □ No [GO TO CHOLEST]
PAINMED_WH	<ul> <li>Is the pain for which you take these medications for due to your cancer, its treatment, or its late and long-term side effects?</li> <li>□ Yes</li> <li>□ No</li> </ul>
PAINMED_BDA	Did you start taking prescription pain medication before, during, or after your ovarian cancer diagnosis and treatment? Please select all that apply.  Took medication BEFORE ovarian cancer diagnosis and treatment Took medication DURING ovarian cancer diagnosis and treatment Took medication AFTER ovarian cancer diagnosis and treatment
CHOLEST	Have you ever taken prescription medication to lower your cholesterol? These medications are usually called statins. Examples include Zocor, Lipitor, Crestor, or Pravachol/Prevastin.  Pes No [GO TO BP_EVER] Don't know [GO TO BP_EVER]
CHOLEST_BDA	Did you take this medication before, during, or after your cancer diagnosis and treatment? Please select all that apply.  □ Took medication BEFORE cancer diagnosis and treatment □ Took medication DURING cancer diagnosis and treatment □ Took medication AFTER cancer diagnosis and treatment
CHOLES_CURR	Are you <u>currently</u> taking medications to help lower your cholesterol?  □ Yes □ No □ Don't know

BP_EVER	Have you ever taken prescription medication to help lower your blood pressure?  Examples include Lisinopril or Prinivil, Amoldipine or Norvasc, Metoprolol or Toprol, and Losartan or Cozaar.  Yes  No [GO TO INSULIN]  Don't know [GO TO INSULIN]
BP_BDA	Did you take this medication before, during, or after your cancer diagnosis and treatment? Please select all that apply.  □ Took medication BEFORE cancer diagnosis and treatment □ Took medication DURING cancer diagnosis and treatment □ Took medication AFTER cancer diagnosis and treatment
BP_CURR	Are you <u>currently</u> taking medication to help lower your blood pressure?  Pes Don't know
INSULIN	Have you ever taken insulin by injection or an oral prescription medication for diabetes?  Examples of oral medications include Metformin or Glucophage, Actos, Januvia, or Invokana.  Pes No [GO TO SLEEP] Don't know [GO TO SLEEP]
INSULIN_BDA	Did you take this medication before, during, or after your cancer diagnosis and treatment? Please select all that apply.  □ Took medication BEFORE cancer diagnosis and treatment □ Took medication DURING cancer diagnosis and treatment □ Took medication AFTER cancer diagnosis and treatment
INSULIN_CURR	Are you <u>currently</u> taking medication for diabetes?  Pres  No  Don't know
SLEEP	Have you <u>ever</u> taken a prescription medication to help you sleep? Examples include Silenor, Lunesta, Ambien, or Restoril  Yes  No [GO TO SECTION L]  Don't know [GO TO SECTION L]
SLEEP_BDA	Did you take this medication before, during, or after your cancer diagnosis and treatment? <i>Please select all that apply.</i> □ Took medication BEFORE cancer diagnosis and treatment

	<ul><li>Took medication DURING cancer diagnosis</li><li>Took medication AFTER cancer diagnosis a</li></ul>					
SLEEP_CURI	R Are you <u>currently</u> taking medication to help you slo	eep?				
INTRO12	The following questions are about your current he	alth and well	-being.			
GLOBAL_xx	Please respond to each item by marking <u>one box p</u>	er row.				1
<u>Variable</u> <u>name</u>		Excellent	Very Good	Good	Fair	Poor
GLOBAL01	In general, would you say your health is:					$\perp$
GLOBAL02	In general, would you say your quality of life is:					
GLOBAL02 GLOBAL03	In general, how woud you rate your physical health?					
GLOBAL03 GLOBAL04	In general, how would you rate your mental health,					
323 <i>D</i> , 123 .	including your mood and your ability to think?					
GLOBAL05	In general, how would you rate your satisfaction					
	with your social activities and relationships?					
GLOBAL09	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.)					
GLOBAL06	To what extent are you able to carry out your ever walking, climbing stairs, carrying groceries, or mov  Completely Mostly Moderately A little Not at all		l activities su	uch as		
GLOBAL10	In the past 7 days, how often have you been bothe feeling anxious, depressed, or irritable?	red by emoti	onal proble	ms such as	;	

□ Never

		Sometimes							
		Often							
		Always							
GLOBAL08	In the	past 7 days, how would you	ı rate your fa	atigue on avera	age?				
		None							
		Mild							
		Moderate							
		Severe							
		Very severe							
GLOBAL07	In the	past 7 days, how would you	ı rate your pa	ain on average	?				
		0 No Pain							
		1							
		2							
		3							
		4							
		5							
		6							
		7							
		8							
		9							
		10 Worst Pain Imaginable							
SLEEP_SATIS	How sa	How satisfied are you with the sleep you are getting?							
		Very satisfied							
		Somewhat satisfied							
		Neither satisfied nor dissa	itisfied						
		A little satisfied							
		Not at all satisfied							
PAST4_x	In the	past <u>4 weeks</u>	1	1	1		1		
			All of the	Most of	Some of the	A little of	None of		
			time	the time	time	the time	the time		
<ul><li>a. About how good reaso</li></ul>		you feel tired for no							
		you feel nervous?							
c. About how	often did	you feel so nervous that							
nothing cou	ıld calm v	ou down?							

□ Rarely

d. About how often did you feel hopeless?e. About how often did you feel restless or

f. About how often did you feel so restless you

fidgety?

could not sit still?

g. About how	often did you feel depress	ed?			
h. About how o	often did you feel that eve t?	erything			
i. About how	often did you feel so sad t	nat			
nothing cou	d cheer you up?				
j. About how	often did you feel worthle	ss?			
SECTION M: A	BOUT YOU				
INTRO13	The final set of question	s is about you.			
SCHOOL	What is the highest grad		g you complete	ed?	
	□ Grade 11 or less				
	<ul><li>Completed high</li></ul>	school			
	<ul><li>Post high schoo</li></ul>	l training other than c	ollege (vocatio	nal or technical	)
	□ Some college				
	<ul> <li>College graduat</li> </ul>	e			
	<ul> <li>Postgraduate</li> </ul>				
MARITAL	What is your marital sta	tus?			
	□ Married				
	□ Living as marrie	d			
	□ Divorced/Separ				
	□ Widowed				
	□ Single, never be	en married			
ETHNICITY	Are you of Hispanic, Lat	ino/a, or Spanish origi	n?		
	□ Yes				
	□ No [GO TO RAC	E]			
ETH_GROUP	Which group are you fro	om?			
_		an American, Chicano	/a		
	□ Puerto Rican	·			
	□ Cuban				
	□ Dominican				
	□ Central or South	n American			
		Latino/a, or Spanish o	origin		
		, ,	J		
<b>RACE</b> What	s your race? You may sele	ect multiple categories	<b>5.</b>		
	□ White				

Black or African American

Asian

	Native Hawaiian or Pacific Islander American Indian or Alaska Native				
EMPLOY_CURR	What is your <u>current</u> occupational status?    Employed (full-time, part-time, or self-employed)   What kind of work are you currently doing? For example: teacher, postal worker, nurse, etc   Unemployed   Homemaker   Student   Retired   Disabled   Other, please specify:				
HI_TYPE	What kind of health insurance do you have? Please select all that apply.    Health insurance through your (or your spouse's) employer    Private health insurance, individually purchased    Medicare    Medi-Gap    Medicaid    SCHIP    Military health care (TRICARE/VA/CHAMP-VA)    Indian Health Service    State-sponsored health plan    Other government program    Single service plan (e.g. dental, vision, prescription)    No coverage of any type [GO TO CHILDREN]    Don't know [GO TO CHILDREN]				
NOHI_12MOS	In the past 12 months, was there any time when you did not have any health insurance coverage?  □ Yes				

	□ No □ Don't know
CHILDREN	Do you have any children?  □ Yes □ No [GO TO INCOME]
CHILD_NUM	How many children to you have? Number of children
UNDER18	How many are under age 18? Number of children under 18
INCOME	Thinking about all the members of your family living in your household, what is your combined annual income, meaning the total pre-tax income from all sources earned in the past year?  Less than \$20,000  \$21,000 to \$49,999  \$50,000 to \$74,999  \$75,000 to \$99,999  \$100,000 to \$199,999  \$200,000 or more  Don't know
STATE	What state do you live in?
ZIP_CODE	What zip code to you live in?
[INCENT2] Cornumber:	ngratulations, you are eligible for a \$10 Amazon gift code. Below is your gift code [GIFTCODE DISPLAYED HERE]
	I you like us to email or mail the above giftcode number to you?  € Email only → GO TO WEBINEM1 & WEBINEM2  € Mail only → GO TO INC_ADDRESS  € I do not want the giftcode sent to me → GO TO SOCIAL NETWORK QUESTIONS
[WEBINEM1] I	Please enter your email address:

[WEBINEM2] Please reenter your email address:						
[INC_ADDRESS Street: Apartm City: State: Zip Cod						
	Social Network Questions					
Social Network Questions  [SECTION NOTE: Seventeen (17) respondents from both the registry sample and the social-media sample will be selected randomly as seeds. In respondent-driven sampling (RDS), a seed is an individual who uses her network to recruit other participants into the study. The seventeen seeds will complete an additional section of the survey, including social network questions as listed below.]						
NETWORK1	Are there any other women you know that have been diagnosed with cancer of the ovary, fallopian tube, or peritoneum who may be interested in participating in this study?  Yes No Don't know Prefer not to answer					
NETWORK2	Are these women who are:					

have been diagnosed with ovarian, fallopian tube, or primary peritoneal cancer,

• at least 18 years of age,

□ Yes

and have undergone some form of treatment?

		No				
		Don't know Prefer not to an	answer			
NETWORKS	_					
NETWORK3	On the next screen, we will ask for the names and contact information for up to three other women that you know who may be interested in participation.  □ CONTINUE					
NETWORK4	Please enter the name and contact information for the women that you know will be selected at random for participation. You will receive an additional \$1 women you refer who also participates.					
Woman 1						
Name:						
Address:		<del> </del>				
City:	State:	Zip:				
Email address:						
Woman 2						
Name:			_			
Address:						
City:	State:	Zip:				
Email address:						
Woman 3						
Address:						
		Zip:				

Email address: _		
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THANKYOU

Thank you for your time and your effort completing this survey. We appreciate your assistance with this important study.