Attachment 4: Web-based Survey Instrument – English

Page 2: Landing Page (Sample 1 & 2) Page 3: Language Selection (Sample 1 & 2) Page 4: Survey Code (Sample 1 & 2) Page 5: Information Page (Sample 1) Page 6: Information Page (Sample 2) Pages 7-8: Screening Questions (Sample 2) Page 9: Ineligibility Page (Sample 2) Pages 10-76: Survey Questionnaire (Sample 1 & 2)

Breast Cancer In Young Wo	men Survey		
	Form Approved OMB No. 0920-xxxx Exp. Date xx/xx/xxxx		
Breast Cancer in Young Women Survey			
(Encuesta de cáncer de mama en mujeres jóvenes)	(Encuesta de cáncer de mama en mujeres jóvenes)		
Public reporting of this collection of information is estimated to average 22 to 24 minutes per response, including the time for reviewing instructions 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 current 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 Reports Clearance Officer, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (XXX-XXXX).			
La carga pública de notificación para esta recolección de información se calcula que promedia los 22 al 24 minutos por respuesta, lo que incluye el tiempo que se toma en dar las instrucciones, hacer búsquedas en fuentes de datos, recolectar y mantener los datos necesarios, y completar y revisar la recopilación de información. Una agencia no puede llevar a cabo ni patrocinar un estudio de recopilación de información y las personas no están obligadas a responder, a menos que se presente un número de control de OMB válido y vigente. Envíe comentarios sobre este cálculo de tiempo o sobre cualquier otro aspecto de esta recolección de información, incluidas sugerencias para reducir esta carga, a CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-xxxx).			
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One moment please			
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Breast Cancer In Young Women Survey

Please select your language:

O English

O Spanish

Back Next

If participant enters a code here, she will automatically be placed in Sample 1, and is already eligible to take the survey. If left blank, the participant will be included with Sample 2 and her eligibility will be confirmed through the screener.

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	Breast Cancer In Young Women Survey		
	If you received a paper-version of the survey, please enter your survey code here. If not, leave blank and click continue.		
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If the survey code is entered on previous page, the participant will be directed to this information page for Sample 1:

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Breast Cancer In Young Women Survey

Breast Cancer in Young Women Survey

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

The Federal government is interested in research on breast cancer care and treatment for young women. The Centers for Disease Control and Prevention (CDC) has contracted with the non-profit research company RTI International to conduct a survey called Breast Cancer in Young Women Survey.

The survey has questions about your insurance coverage, employment status, copayments/deductibles, and the care that you received during your breast cancer treatment. Your survey participation will help policy makers to improve the care and policies for young women diagnosed with breast cancer such as yourself.

It is your choice whether or not to do the survey. Your decision will not affect any of your health care benefits or services. Some survey questions related to your breast cancer experience may cause you distress and you do not have to answer questions that make you feel uncomfortable.

There is a small potential risk of loss of privacy but we have made every effort to limit this risk as all your personal information is viewed only by authorized research staff and are stored in password protected folders. RTI will keep the information that you provide private and secure to the extent permitted by law. RTI will report the results of this survey to CDC in an aggregated format that will not identify any individuals.

We estimate that this survey will take about 22 minutes to complete.

If you have any questions or difficulty completing the survey, please call NAME toll-free at 1-877-XXX-XXX, anytime from 9am to 5pm Eastern Standard Time. If you have any questions about your rights as a survey respondent, you may call RTI's Office of Research Protection toll-free at 1-866-214-2043.

O Next

Back Next

If the survey code is left blank, the participant will be directed to this information page for Sample 2:

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Breast Cancer In Young Women Survey

Breast Cancer in Young Women Survey

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

The Federal government is interested in research on breast cancer care and treatment for young women. The Centers for Disease Control and Prevention (CDC) has contracted with the non-profit research company RTI International to conduct a survey called Breast Cancer in Young Women Survey. We have partnered with non-profit organizations, Living Beyond Breast Cancer and Young Survival Coalition to help finalize the survey questions and to reach out to potential participants.

The survey has questions about your insurance coverage, employment status, copayments/deductibles, and the care that you received during your breast cancer treatment. Your survey participation will help policy makers to improve the care and policies for young women diagnosed with breast cancer such as yourself.

It is your choice whether or not to do the survey. Your decision will not affect any of your health care benefits or services. Some survey questions related to your breast cancer experience may cause you distress and you do not have to answer questions that make you feel uncomfortable.

No information will be collected that could personally identify you, and RTI will report the results of this survey to CDC in an aggregated format.

We estimate that this survey will take about 24 minutes to complete. Prior to the survey, we will ask 4 questions to confirm your eligibility.

If you have any questions or difficulty completing the survey, please call NAME toll-free at 1-877-XXX-XXXX, anytime from 9am to 5pm Eastern Standard Time. If you have any questions about your rights as a survey respondent, you may call RTI's Office of Research Protection toll-free at 1-866-214-2043.

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Sample 2 then proceeds with 4 eligibility questions.

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Breast Cancer In Young Women Survey
S1. Are you a female? O Yes No Beck Next 76
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Breast Cancer In Young Women Survey

S2. Are you a breast cancer survivor who was diagnosed with ductal carcinoma in situ (DCIS) or invasive breast cancer (can include metastatic disease)?
O Yes

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Breast	Cancer In Young Women Survey
S3. Were you dia O Yes O No	gnosed between the ages 18-49?
	Back Next

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Breast Cancer In Young Women Survey	

S4. Do you live in North Carolina, California, Georgia, or Florida?

O Yes O No

Back Next

If a participant in Sample 2 responds "no" to any of S1-S3, or "yes" to S4, she will be ineligible to continue taking the survey.

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	Breast Cancer In Young Women Survey		
	Ineligible		
	Thank you for your response. Sony, but you are not eligible for this survey. At this time, we are seeking responses from female breast cancer survivors who were diagnosed with breast cancer between the ages of 18-49.		
	To avoid duplication of response, eligible residents of North Carolina, California, Georgia, and Florida have been contacted with a paper-version of the survey through mail. If you have received this, please enter the survey code on the initial screen.		
	○ Finish		
	Back Next		
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Sample 1 participants and eligible Sample 2 participants can proceed with the survey questionnaire.

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Breast Cancer In Young Women Survey		
A. Insurance Status		
This section asks about your health insurance status.		
A1. What type of medical insurance do you have now? Please mark ALL that apply.		
None and I do not receive charity care		
None and I receive charity care		
Insurance available through my employer or union (including HMO)		
Insurance available through my spouse's employer or union (including HMO)		
Insurance that I purchase with financial assistance (subsidy) from the state or federal government (Obamacare, Affordable Care Act)		
Insurance that I purchase myself, not through an employer		
Medicaid or other state insurance (including coverage by Medicaid authorized by Breast and Cervical Cancer Prevention and Treatment Act)		
Medicare		
CHAMPVA and TRICARE		
Indian Health Service		
Other - Write In		
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Breast Cancer In Young Women Survey

A2. What type of medical insurance did you have at the time of your initial breast cancer diagnosis? Please mark ALL that apply

None and I received charity care

Insurance available through my employer or union (including HMO)

Insurance available through my spouse's employer or union (including HMO)

Insurance that I purchased with financial assistance (subsidy) from the state or federal government (Obamacare, Affordable Care Act)

Insurance that I purchased myself, not through an employer

D Medicaid or other state insurance (including coverage by Medicaid authorized by Breast and Cervical Cancer Prevention and Treatment Act)

_		
1	Med	ic are

CHAMPVA and TRICARE

Indian Health Service

Other - Write In	

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Breast Cancer In Young Women Survey

A3. While you were receiving your initial breast cancer treatment including hormonal treatment, did you ever reach your insurance plans' treatment ceiling, which is the total amount that the insurance company will pay for your treatment?

O Yes O No

Back Next

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Breast Cancer In Young Women Survey

A4. Which best describes your insurance status over the past 12 months?

 \bigcirc Insured continuously by same insurance plan

 ${\ensuremath{\bigcirc}}$ Insured continuously but switched insurance plan

- O Uninsured for some months
- O Uninsured for all of the 12 months



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Breast Cancer In Young Women Survey

A5. Did you experience any of the following during the past 12 months? Please mark ALL that apply.

Lost your health insurance coverage

 $\hfill\square$ Paid a higher price than expected to obtain health insurance coverage

- Could not buy health insurance coverage because it was too expensive
- $\hfill\square$ Was turned down when you tried to buy health insurance coverage
- $\hfill\square$ Had a specific health condition excluded from the health insurance coverage
- Did not experience any of the above

Back	Next
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Breast Cancer In Young Women Survey

A6. In the past 12 months, have the costs of your prescription medicine(s) been Please mark ONE response.

- $O\ \ldots$ completely covered by health insurance (except for copayments or deductibles)?
- $O\ \ldots$ partially covered by health insurance (except for copayments or deductibles)?
- $\bigcirc\ldots$ not covered at all by health insurance (except for copayments or deductibles)?



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Breast Cancer In Young Women Survey

B. Financial Burden and Out of Pocket Costs

The next few questions are about the financial challenges you may have encountered following your breast cancer diagnosis.

B1. Due to your own personal medical expenses (including co-payments, deductibles, hospital bills, medication costs, and insurance premiums), did you or someone in your household in the past 12 months experience any of the following financial impacts? Please mark ALL that apply.

U Went without health insurance

Stopped working or lost job

 $\hfill\square$ Had utilities turned off because the bill was not paid

Cut down on spending for medication for my self

Had to move out of house or apartment because we could not afford to stay there

Had to declare bankruptcy or are in the process of declaring bankruptcy

Cut down on expenses in general such as food, recreational activities, educational activities

I took out a loan or borrowed against my car or home

My illness has had no impact on my household finances

Other - Write In

	Back	Next
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If an answer to B1 is "My illness has had no impact on my household finances" then survey will skip B2 and proceed to B3. (Please see mail-in survey instrument to clearly visualize the skip patterns).

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	Breast Cancer In Young Women Survey		
	B2. How much is the decline in financial situation due to your breast cancer and treatment?		
	O Not much at all		
	O A little		
	○ Somewhat		
	O Quite a bit		
	O Very much		
	Back Next		

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Breast Cancer In Young Women Survey

B3. How much money would you estimate you have paid out-of-pocket in the past 12 months for medical expenses related to your breast cancer including co-payments, hospital bills, deductibles, and medication costs— including hormonal therapy and other medications to help prevent cancer recurrence? For this question, please think of out-of-pocket money that you spent and not money provided by your insurance company.

O Less than \$500

- \$500-\$2,000
- O \$2,001-\$5,000
- O \$5,001-\$10,000
- O More than \$10,000

	Back	Next	
24%	6		

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Breast Cancer In Young Women Survey

B4. How did you pay for these out-of-pocket expenses including copayments, ho	ospital bills, deductibles,	and medication costs for medical s	ervices – including medications to help p	prevent cancer
recurrence?				

Please mark ALL that apply.

I used my personal / household income and/or savingsOption 1

I used funds from my Health Saving Account

I borrowed money from family or friends

🗌 I received support from a cancer support organization or other charities including online crowdsourcing – fundraising

I borrowed money against my house or other belongings (car).

I left some of my medical bills unpaid

I increased my credit card debt

I postponed payment of some bills including student loans, credit cards, utilities, etc.

I sold personal belongings (example: car, jewelry)

Other - Write In

	Back	Next
25%	6	

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Breast Cancer In Young Women Survey

B5. How much money would you estimate you have paid in the past 12 months for other expenses related to your breast cancer such as travel costs, parking, child/elderly care, etc?

- O Less than \$500
- O \$500-\$2,000
- \$2,001-\$5,000
- O \$5,001-\$10,000
- O More than \$10,000

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Breast Cancer In Young Women Survey

B6. How did you pay for these other expenses related to your breast cancer such as travel costs, parking, child/elderly care, etc? Please mark ALL that apply.

I used my personal / household income and/or savings

I borrowed or received money from family or friends

🔲 I received support from a cancer support organization or other charities including online crowdsourcing – fundraising

 $\hfill\square$ I borrowed money against my house or other belongings (car)

I left some of my medical bills unpaid

I increased my credit card debt

I postponed payment of some bills including student loans, credit cards, utilities, etc

I sold personal belongings (example: car, jewelry)

Other - Write In

Back	Next
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reast Cancer In Young Wor	ne	n Sı	irvey
Because of your medical cost, did you have to… Please select YES or No for <u>each</u> item			
	YES	NO	
adelay or stop breast cancer treatment?	0	0	
bgo without any medication prescribed?	0	0	
ctake less than the fully prescribed amount of a prescription?	0	0	
dmiss a doctor's appointment?	0	0	
emiss a follow-up mammogram, MRI, or ultrasound?	0	0	
fdelay or did not receive breast reconstruction?	0	0	
gforgo fertility preservation?	0	0	
			Back Next
			28%

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Breast Cancer In Young Women Survey

B8. How would you describe your reaction to how your medical benefits (health insurance including Medicaid and Medicare) covered the cost of your cancer treatment?

The medical benefits contributed...

- O ...more money than I expected
- O ...about what I expected
- \bigcirc ...less money than I expected
- $O\ldots \mbox{Not}$ applicable as I did not have health coverage or insurance

	Back	Next
30%	6	

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Breast Cancer In Young Women Survey

B9. How would you describe your reaction to the money you spent for cancer treatment? I spent...

- $\bigcirc \dots$ more money than I expected
- O ...about what I expected
- O ...less than I expected

Back Next

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Breast Cancer In Young Women Survey			
B10. Did you ever discuss the cost of treatment for your cancer with your care team? O Yes O No			
Back Next			

Breast Cancer In Young Women Survey					
B11. When choosing a treatment course for your cancer, did you consider the costs of specific treatments?					
🔿 No, not at all					
O Yes, somewhat					
○ Yes, a great deal					
Back Next					
34%					

Breast Cancer In Young Women Survey				
C. Employment Status				
The next few questions are about the status of your employment.				
C1. At the time you were diagnosed with breast cancer, were you employed or working for pay? O Yes O No				
Back Next				
36%				

If the answer to C1 is "no", then survey will skip C2-C8 and will proceed with C9.

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Breast Cancer In Young Women Survey				
C2. Which of these best describes the job you held <u>at the time you were diagnosed</u> with breast cancer? C3. Employee of a PRIVATE or NONPROFIT company (working for pay) A FEDERAL government employee A STATE government employee A LOCAL government employee Worked for self (e.g. operated a business, professional practice or farm) Don't know				
Back Next				
37%				

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Breast Cancer In Young Women Survey

C3. On average, about how many hours per week did you work 1 month before your diagnosis?

- O 1 8 hours per week
- 🔿 9 16 hours per week
- 🔿 17 32 hours per week
- O 33 40 hours per week
- O More than 40 hours per week



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Breast Cancer In Young Women Survey

C4. Which of the following has been available to you during treatment for your initial breast cancer diagnosis (surgery, chemotherapy, radiation or targeted therapy) through your work? Please mark ALL that apply.

Medical insurance
Paid sick leave
Unpaid sick leave
Disability benefits
Flexible work schedule
Flexible work location (e.g., working from home)
None of the above
Other - Write In
Back Next
39%

Breast Cancer In Young Women Survey					
C5. In total, about how many days of work did you miss because of your breast cancer or its treatment?					
O I was not working					
O 0 days					
O 1 – 7 days					
🔘 8 – 14 days					
○ 15 – 21 days					
🔘 22 – 29 days					
O More than 30 days					
O I stopped working all together					
Back Next					

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Breast Cancer In Young Women Survey

C6.. As a result of your breast cancer or its treatment, did you have any of the following experiences? Please select YES or No for <u>each</u> item

	YES	NO	
a. I changed jobs within the company to accommodate my breast cancer diagnosis	0	0	
b. I avoided changing jobs because I was worried about losing my health insurance			
c. I changed jobs and began working for a new company in order to get health insurance			
d. I took time off with pay	0	0	
e. I took time off without pay	0	0	
f. I quit my job			
g. I decided to retire early			
h. I lost (was fired from or was laid off) my job			
i. I had trouble doing my job well			
j. I decided to keep my job to avoid losing my health insurance			
k. I increased my work hours in order to cover my breast cancer related medical expenses			
Enter another option	0	0	



Breast Cancer In Young Women Survey					
C7. Overall, how supportive was your employer of you when you were being treated for breast cancer?					
O My employer did not know about my breast cancer diagnosis					
O Very supportive					
O Somewhat supportive					
O Neutral					
O Somewhat not supportive					
O Not supportive at all					
Back Next					

Breast Cancer In Young Women Survey			
C8. Please indicate if your employer did any of the things below to help you when you were being treated for breast cancer.			
My employer			
Please select YES or No for each item			
	YES	NO	
agave me permission to take the necessary time off for treatments	0	0	
ballowed me to have a flexible schedule so I could get treatments	0	0	
cpaid me for sick days	0	0	
dOther (please explain):	0	0	
Enter another option	0	0	
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Breast Cancer In Young Women Survey
C9. Are you currently working for pay?
O Yes
O Not now, but I plan to seek future employment
O Not now, nor in the foreseeable future
Back Next
47%

If answer to C9 is "Not now, but I plan to seek future employment" or "Not now, nor in the foreseeable future", then survey will skip C10, and proceed with C11. If answer to C9 is "Yes", survey will proceed with C10.

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	Breast Cancer In Young Women Survey
	C10. If you work for pay, are you self-employed or do you have an employer? O Self-employed O I have an employer
	Back Next
	48%

After answering to C10, survey will proceed with C12.

Breast Cancer In Young Women Survey
C11. How long has it been since you have worked for pay?
O 1 to 6 months
O 7 to 12 months
O 1 to 2 years
O More than 2 years but less than 5 years
○ 5 years or more
O I've never worked for pay or profit
Back Next

Breast Cancer In Young Women Survey
C12. How important is it for you to work for financial reasons?
○ Not at all important
O A little important
◯ Somewhat important
O Quite important
⊖ Very important
Back Next

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Breast Cancer In Young Women Survey

C13. How important is it for you to work for other non-financial reasons (for example, personal satisfaction, emotional well being)?

- O Not at all important
- O A little important
- O Somewhat important
- O Quite important
- O Very important



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	Breast Cancer In Young Women Survey
	D. Access to Cancer Treatment
	The next few questions are about your access to cancer treatments.
	D1. Indicate the type of breast cancer treatments or procedures you received? Please mark ALL that apply.
	Chemotherapy
	Radiation
	Surgery—Lumpectomy
	Surgery—Mastectomy
	Surgery—Oophorectomy
	Breast reconstruction
	Lymph node removal
	Hormonal Therapy [For example, Tamoxifen; Toremifene (Fareston®); Fulvestrant (Faslodex®); Leuprolide (Lupron ®); Goserelin (Zolade®); Triptorelin (Treistar®); Aromatase inhibitors - Letrozole (Femara ®), Anastrozole (Arimidex ®)]
	🗌 Immunotherapy [For example, Trastuzumab (Herceptin), Pertuzumab (Perjeta®), Bevacizumab (Avastin®)]
	🗌 Bone-directed Therapy [For example, Denosumab (Xgeva®, Prolia®), Pamidronate (Aredia®) and Zoledronic acid (Zometa)]
	Physical Therapy
	Complementary alternative medicine (CAM) treatments such as acupuncture, massage, nutrition counseling, etc.
	Fertility preservation procedures
	Genetic testing
	Other - Write In
	Back Next
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Breast Cancer In Young Women Survey

D2. At any time since you were first diagnosed with breast cancer, did you receive all of the medical care, tests, or treatments that your doctor believed was necessary?

O Yes

O No

	Back	Next	
559	6		

If answer to D2 was "Yes", then survey will skip D3 and proceed with D4.

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Breast Cancer In Young Women Survey

D3. Which of the following are reasons you did not receive all of the medical care, tests, or treatments you or a doctor believed you needed?

Please select YES or No for each item

	YES	NO
a. Couldn't afford it	0	0
b. Insurance company wouldn't approve or pay for it	0	0
c. Doctor did not accept your insurance	0	0
d. Had transportation problems getting to the doctor's office	0	0
e. Had problems other than transportation challenges getting to the doctor's office	0	0
f. Couldn't get time off from work	0	0
g. Didn't know where to go to get care/treatment	0	0
h. Couldn't get child care/adult care	0	0
i. Didn't have time as care/test/treatment took too long	0	0
j. I was afraid of the treatment's side effects	0	0
k. I wanted to preserve my fertility	0	0
Other	0	0
Enter another option	0	0



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Breast Cancer In Young Women Survey

D4. How much of a problem if any, was it to get the breast cancer care that you or a doctor believed was necessary (for example, reaction to the treatments or had transportation issues or financial problems)?

O Not a problem

O A small problem

O A large problem

Back Next

Breast Cancer In Young Women Survey
D5. How often did you have to wait longer than you wanted to get an appointment with your doctor?
O Never
O Sometimes
O Usually
O Always
Back Next

ccess, place your bookmarks here on the bookmarks bar. Import bookmarks now...

Breast Cancer In Young Women Survey

D6. When you went to see your doctor for breast cancer care, how long did you typically wait in the office to see the doctor?

- O 0-15 minutes
- O 16-30 minutes
- O 31-45 minutes
- O 46-60 minutes
- O More than 60 minutes



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Breast Cancer In Young Women Survey

D7. During the past 12 months, was hormonal therapy recommended to you to treat your breast cancer? Hormonal therapy includes the use of Tamoxifen; Toremifene (Fareston®); Fulvestrant (Faslodex®); Luteinizing hormone-releasing hormone (LHRH) agonists – Leuprolide (Lupron ®), Goserelin (Zolade®), Triptorelin (Trelstar®); Aromatase inhibitors - Letrozole (Femara ®); Anastrozole (Arimidex ®).

O Yes O No



If answer to D7 is "No", then survey will skip D8-D10 and proceed with Section E.

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B	reast Cancer In Young Women Survey	
	Did you begin hormonal therapy or did you receive LHRH agonists during the past 12 months? O Yes, hormonal therapy alone O Yes, hormonal therapy with LHRH agonist	
	O Yes, LHRH agonist alone⊡ O No	
	Back Next	
	63%	

If answer to D8 is "Yes", then survey will skip D9 and proceed with D10.

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Breast Cancer In Young Women Survey		
D9. Indicate the reason you decided not to initiate or continue with hormonal therapy or LHRH agonist as recommended. Please select YES or No for <u>each</u> item		
	YES NO	
a. Copayment for the therapy was high	0 0	
b. Insurance wouldn't cover the therapy	0 0	
c. Potential side effects or experienced side effects	0 0	
d. Wanted to get pregnant	0 0	
e. Other (please explain):	0 0	
Enter another option	0 0	
	Back Next	

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Breast Cancer In Young Women Survey

D10. If you began hormonal therapy or LHRH agonist during the past 12 months, did you do any of the following to save money related to your hormonal therapy?

Please select YES, NO, Refused, or Don't Know for each item

	YES	NO	Refused	Don't Know
a. You skipped doses of hormonal therapy or LHRH agonist for treating your breast cancer to save money	0	0	0	0
b. You took fewer doses of your hormonal therapy for treating your breast cancer to save money	0	0	0	0
c. You delayed receiving hormonal therapy to treat your breast cancer to save money	0	0	0	0
d. You asked your doctor for a lower cost hormonal therapy to treat your breast cancer to save money	0	0	0	0
e. You bought breast cancer hormonal therapy from another country to save money	0	0	0	0
f. You used other therapies to avoid purchasing breast cancer hormonal therapy to save money	0	0	0	0

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Breast Cancer In Young Women Survey
E. Quality and Coordination of Care and Treatment
For the next series of questions, we will be asking about the care you received from doctors, nurses, and other health care professionals involved in your breast cancer care and treatment.
E1. Which type of provider has been most involved in directing your care and treatment for your breast cancer in the past 12 months? Please select one only.
O Primary care doctor or family doctor or nurse practitioner
O Medical oncologist or nurse oncologist
O Breast surgeon
O Other - Write In
Back Next
67%

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E2. In your opinion, how often did your doctor, the nurses, and other staff at your doctor's office or clinic work well together in providing your medical care? Never Sometimes Usually Atways 			
Back Next			

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Breast Cancer In Young Women Survey

E3. On a scale of 0 to 10, where 0 means the worst doctor possible and 10 means the best doctor possible, how would you rate the provider *most involved* in directing your care for your breast cancer? Would you say...

0 = (Worst doctor possible)
1
2
3
4
5
6
7
8
9
10 = (Best doctor possible)

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Breast Cancer In Young Women Survey

E4.	Based on your interactions with your doctor, nurses, and other staff, how would you rate the quality of care you received from the office of the provider most involved in directing your care
for y	vour breast cancer?

O Poor

O Fair

O Good

O Very good

O Excellent

Back	Next

Breast Cancer In Young Women Survey		
E5. How often did the provider most involved in directing your care for your breast cancer explain things in a way you could understand?		
O Never		
O Sometimes		
O Usually		
O Always		
Back Next		
72%		

Breast Cancer In Young Women Survey		
 E6. How often did the provider <i>most involved</i> in directing your care for your breast cancer spend enough time with you? Never Sometimes Usually Always 		
Back Next		

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Breast Cancer In Young Women Survey

E7. How would you describe the knowledge of your relevant medical history by the provider most involved in directing your breast cancer treatment?

- O Poor
- O Fair

O Good

O Very good

O Excellent



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Breast Cancer In Young Women Survey

F. Disease-specific symptom index

The next set of questions is about symptoms you might be experiencing.

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F1. Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I have a lack of energy	0	0	0	0	0
b. I have pain	0	0	0	0	0
c. I have nausea	0	0	0	0	0
d. I have certain parts of my body where I experience pain	0	0	0	0	0
e. I have been short of breath	0	0	0	0	0
f. I worry that my condition will get worse	0	0	0	0	0
g. I am content with the quality of my life right now	0	0	0	0	0
h. Because of my physical condition, I have trouble meeting the needs of my family	0	0	0	0	0

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Breast Cancer In Young Women Survey

G. Cancer History

The next few questions are about the history of your cancer

G1. Please select one or more of the following types of breast cancers you have had.

Endocrine receptor (estrogen or progesterone receptor) positive

HER2 positive

Triple negative, not positive to receptors for estrogen, progesterone, or HER2

 $\hfill\square$ Triple positive, positive for estrogen receptors, progesterone receptors and HER2

Inflammatory breast cancer

Don't know

	Back	Next	
78%	6		

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Breast Cancer In Young Women Survey	
G2. Select the one response that best describes your breast cancer stage at diagnosis.	
○ Stage 0	
O Stage I	
⊖ Stage II	
○ Stage III	
⊖ Stage IV	
O Don't Know	
Back Next	

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Breast Cancer In Young Women Survey

G3. Have you experienced a recurrence or been diagnosed with another cancer since your initial breast cancer diagnosis?

O Recurrence of breast cancer -- non-metastatic

O Recurrence of breast cancer – metastatic

O Diagnosed with another type of cancer

O Neither

Back	Next

Breast Cancer In Young Women Survey	
G4. About how long ago did you receive your last cancer treatment (chemotherapy, radiation, surgery, hormonal therapy)?	
○ I am still receiving treatment	
O Less than 1 year ago	
O 1 year ago to less than 3 years ago	
igodot 3 years ago to less than 5 years ago	
\bigcirc 5 years ago to less than 10 years ago	
O 10 years ago to 20 years ago	
O More than 20 years ago	
O I have not been treated for cancer	
Back Next	

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Breast Cancer In Young Women Survey

G5. In addition to breast cancer, what other conditions have caused you problems? Select ALL that apply

noot nee that apply

a. Vision/problem seeing

- b. Hearing problem
- C. Arthritis/rheumatism
- d. Back or neck problem

e. Fracture, bone/joint injury

f. Other injury

🗌 g. Heart problem

h. Stroke problem

i. Hypertension/high blood pressure

j. Diabetes

k. Lung/breathing problem (for example, asthma and emphysema)

I. Cancers other than breast cancer

🗌 m. Birth defect

- n. Intellectual disability, also known as mental retardation
- o. Other developmental problem (for example, cerebral palsy)
- Depression/anxiety/emotional problem
- 🗌 q. Senility
- C r. Weight problem
- S. Missing limbs (fingers, toes or digits), amputee

L Kidney, bladder or renal problems

u. Circulation problems (including blood clots)

V. Benign Tumors, Cysts

- w. Fibromyalgia, lupus
- 🗌 x. Osteoporosis, tendinitis

Scroll down

z. Multiple Sclerosis (MS), Muscular Dystrophy (MD)

🗌 aa. Polio (myelitis), paralysis, para/quadriplegia

bb. Parkinson's disease, other tremors

C. Other nerve damage, including carpal tunnel syndrome

🗌 dd. Hemia

🗌 ee. Ulcer

ff. Varicose veins, hemorrhoids

🔲 gg. Thyroid problems, Grave's disease, gout

hh. Knee problems (not arthritis (c.), not joint injury (e.))

☐ ii. Migraine headaches (not just headaches)

☐ jj. Other impairment/problem

kk. Other impairment/problem

II. Other impairment/problem

mm. None of the above

nn. Don't know/Not sure



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Breast Cancer In Young Women Survey

H. Demographics
The last few questions are about you.

- H1. What is your age?
 - 18–24 years old
 - O 25-29 years old
 - O 30-34 years old
 - O 35-39 years old
 - O 40-44 years old
 - O 45-49 years old
 - 50-54 years old

 - O 55-59 years old
 - O 60-64 years old
 - O 65 years old or older

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Breast Cancer In Young Women Survey
H2. What was your age when you were initially diagnosed with breast cancer?
○ 18–24 years old
O 25–29 years old
○ 30–34 years old
O 35–39 years old
○ 40-44 years old
O 45-49 years old
Back Next
86%

Breast Cancer In Young Women Survey
H3. What is the highest level of education you have completed?
O Less than High School
O High School Graduate or G.E.D.
O Some College or Technical School
O College Graduate (Bachelor's Degree)
○ Graduate Degree
H4. Are you of Hispanic or Latino origin or descent?
O Yes, Hispanic or Latino
O No, not Hispanic or Latino
Back Next 87%

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	Breast Cancer In Young Women Survey		
	H5. What is your race? Please mark ALL that apply.		
	White		
	Black or African American		
	Asian		
	Native Hawaiian or Other Pacific Islander		
	American Indian or Alaska Native		
	Beck Next		
	88%		

Breast Cancer In Young Women Survey	
H6. When you were diagnosed with breast cancer, what was your marital status?	
Please mark ONE.	
O Married	
O Separated	
O Never married	
O Living with your partner	
O Do not want to report	
Back Next	

Breast Cancer In Young Women Survey	
H7. What is your current marital status? Please mark ONE.	
O Married	
O Widowed	
O Separated	
O Never married	
O Living with your partner	
O Do not want to report	
Back Next	
91%	

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H9. When you were initially diagnosed with breast cancer, how many children under 18 years old did you have living at your home? None 1 - 3 children 2 - 6 children 1 0 or more children

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H9. How would you describe yourself? Please mark ALL that apply.

- \bigcirc I work full time or part time
- \bigcirc I am unemployed
- O I am a homemaker
- O I am a student
- O I am retired



Breast Cancer In Young Women Survey	
H10. When you were diagnosed with breast cancer, what was the total yearly income of your entire household, before tax deductions, from all sources? Please mark ONE.	
○ less than \$10,000	
O \$10,000 - \$19,999	
O \$20,000 - \$29,999	
O \$30,000 - \$39,999	
O \$40,000 - \$49,999	
○ \$50,000 - \$59,999	
O \$60,000 - \$69,999	
O \$70,000 - \$79,999	
O \$80,000 - \$89,999	
O \$90,000 or more	
○ I don't know	
Back Next	
95%	

Breast Cancer In Young Women Survey	
H11. When you were diagnosed with breast cancer, how many people were supported by the total income for your household <u>including yourself?</u> Please mark ONE. O 1 (just you) O 2 O 3 O 4 or more	
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Breast Cancer In Young Women Survey
H12. Did someone help you complete this survey? O Yes O No
Back Next

If answer to H12 is "No", then survey is complete. If answer to H12 is "Yes", then survey will proceed with H13 before completion.

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	Breast Cancer In Young Women Survey		
	H13. How did that person help you? Please mark ALL that apply.		
	O Read the questions to me		
	O Wrote down the answers I gave		
	O Answered the questions for me		
	O Translated the questions into my language		
	O Helped in some other way		
	Back Submit		

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Breast Cancer In Young Women Survey

Submitted

Thank you for completing this survey. We appreciate your significant contribution to breast cancer research.