

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 Women 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)

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OK

One moment please...

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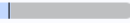
Breast Cancer In Young Women Survey

Please select your language:

- English
- Spanish

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1% 

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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3% 

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-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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4%

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.

OK

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7% | 

Sample 2 then proceeds with 4 eligibility questions.

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Breast Cancer In Young Women Survey

S1. Are you a female?

Yes

No

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7% | 

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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)?

Yes

No

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8% | 

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S3. Were you diagnosed between the ages 18-49?

Yes

No

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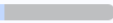
9% | 

Breast Cancer In Young Women Survey

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

- Yes
- No

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11% | 

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. Sorry, 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

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12% 

Sample 1 participants and eligible Sample 2 participants can proceed with the survey questionnaire.

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
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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14% 

Breast Cancer In Young Women Survey

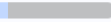
A2. What type of medical insurance did you have at the time of your initial breast cancer diagnosis? Please mark ALL that apply

- None and I did not receive charity care
- 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
- 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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14%

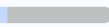


Breast Cancer In Young Women Survey

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?

- Yes
- No

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16% 

Breast Cancer In Young Women Survey

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

- Insured continuously by same insurance plan
- Insured continuously but switched insurance plan
- Uninsured for some months
- Uninsured for all of the 12 months

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17% | 

Breast Cancer In Young Women Survey

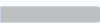
A5. Did you experience any of the following during the past 12 months?

Please mark ALL that apply.

- Lost your health insurance coverage
- Paid a higher price than expected to obtain health insurance coverage
- Could not buy health insurance coverage because it was too expensive
- Was turned down when you tried to buy health insurance coverage
- Had a specific health condition excluded from the health insurance coverage
- Did not experience any of the above

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18% | 

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.

- ...completely covered by health insurance (except for copayments or deductibles)?
- ...partially covered by health insurance (except for copayments or deductibles)?
- ...not covered at all by health insurance (except for copayments or deductibles)?

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20% | 

Breast Cancer In Young Women Survey

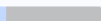
B. Financial Burden and Out of Pocket Costs

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.

- Went without health insurance
- Stopped working or lost job
- 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

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21% 

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?

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

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22% 

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.

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

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24% 

Breast Cancer In Young Women Survey

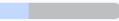
B4. How did you pay for these out-of-pocket expenses including copayments, hospital bills, deductibles, and medication costs for medical services – including medications to help prevent cancer recurrence?

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

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25% | 

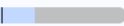
Breast Cancer In Young Women Survey

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?

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

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26% 

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
- 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

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28%



Breast Cancer In Young Women Survey

B7. Because of your medical cost, did you have to...
Please select YES or No for each item

	YES	NO
a. ...delay or stop breast cancer treatment?	<input type="radio"/>	<input type="radio"/>
b. ...go without any medication prescribed?	<input type="radio"/>	<input type="radio"/>
c. ...take less than the fully prescribed amount of a prescription?	<input type="radio"/>	<input type="radio"/>
d. ...miss a doctor's appointment?	<input type="radio"/>	<input type="radio"/>
e. ...miss a follow-up mammogram, MRI, or ultrasound?	<input type="radio"/>	<input type="radio"/>
f. ...delay or did not receive breast reconstruction?	<input type="radio"/>	<input type="radio"/>
g. ...forgo fertility preservation?	<input type="radio"/>	<input type="radio"/>

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29% 

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...

- ...more money than I expected
- ...about what I expected
- ...less money than I expected
- ...Not applicable as I did not have health coverage or insurance

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30% 

Breast Cancer In Young Women Survey

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

- ...more money than I expected
- ...about what I expected
- ...less than I expected

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32% 

Breast Cancer In Young Women Survey

B10. Did you ever discuss the cost of treatment for your cancer with your care team?

Yes

No

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33% 

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
- Yes, somewhat
- Yes, a great deal

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34% 

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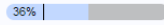
C. Employment Status

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?

- Yes
- No

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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 at the time you were diagnosed with breast cancer?

- 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

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37% 

Breast Cancer In Young Women Survey

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

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

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38% 

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

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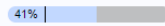
39% 

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?

- I was not working
- 0 days
- 1 – 7 days
- 8 – 14 days
- 15 – 21 days
- 22 – 29 days
- More than 30 days
- I stopped working all together

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41% | 

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 each item

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

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43% 

Breast Cancer In Young Women Survey

C7. Overall, how supportive was your employer of you when you were being treated for breast cancer?

- My employer did not know about my breast cancer diagnosis
- Very supportive
- Somewhat supportive
- Neutral
- Somewhat not supportive
- Not supportive at all

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44% 

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
a. ...gave me permission to take the necessary time off for treatments	<input type="radio"/>	<input type="radio"/>
b. ...allowed me to have a flexible schedule so I could get treatments	<input type="radio"/>	<input type="radio"/>
c. ...paid me for sick days	<input type="radio"/>	<input type="radio"/>
d. ...Other (please explain):	<input type="radio"/>	<input type="radio"/>
<input type="text" value="Enter another option"/>	<input type="radio"/>	<input type="radio"/>

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Breast Cancer In Young Women Survey

C9. Are you currently working for pay?

- Yes
- Not now, but I plan to seek future employment
- Not now, nor in the foreseeable future

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47% | 

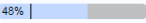
If answer to C9 is “Not now, but I plan to seek future employment” or “Not now, nor in the foreseeable future”, then survey will skip C10, and proceed with C11. If answer to C9 is “Yes”, survey will proceed with C10.

Breast Cancer In Young Women Survey

C10. If you work for pay, are you self-employed or do you have an employer?

- Self-employed
- I have an employer

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48% 

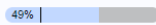
After answering to C10, survey will proceed with C12.

Breast Cancer In Young Women Survey

C11. How long has it been since you have worked for pay?

- 1 to 6 months
- 7 to 12 months
- 1 to 2 years
- More than 2 years but less than 5 years
- 5 years or more
- I've never worked for pay or profit

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Breast Cancer In Young Women Survey

C12. How important is it for you to work for financial reasons?

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

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50% | 

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)?

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

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51% 

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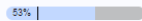
D. Access to Cancer Treatment

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 (Trelstar®); 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

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53% 

Breast Cancer In Young Women Survey

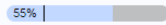
D2. At any time since you were first diagnosed with breast cancer, did you receive all of the medical care, tests, or treatments that your doctor believed was necessary?

Yes

No

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55% | 

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

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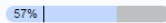
Breast Cancer In Young Women Survey

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	<input type="radio"/>	<input type="radio"/>
b. Insurance company wouldn't approve or pay for it	<input type="radio"/>	<input type="radio"/>
c. Doctor did not accept your insurance	<input type="radio"/>	<input type="radio"/>
d. Had transportation problems getting to the doctor's office	<input type="radio"/>	<input type="radio"/>
e. Had problems other than transportation challenges getting to the doctor's office	<input type="radio"/>	<input type="radio"/>
f. Couldn't get time off from work	<input type="radio"/>	<input type="radio"/>
g. Didn't know where to go to get care/treatment	<input type="radio"/>	<input type="radio"/>
h. Couldn't get child care/adult care	<input type="radio"/>	<input type="radio"/>
i. Didn't have time as care/test/treatment took too long	<input type="radio"/>	<input type="radio"/>
j. I was afraid of the treatment's side effects	<input type="radio"/>	<input type="radio"/>
k. I wanted to preserve my fertility	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>
<input type="text" value="Enter another option"/>	<input type="radio"/>	<input type="radio"/>

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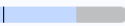
57% 

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)?

- Not a problem
- A small problem
- A large problem

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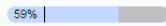
58% 

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?

- Never
- Sometimes
- Usually
- Always

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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?

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

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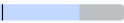
61% 

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®).

- Yes
- No

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62% 

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

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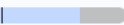
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Breast Cancer In Young Women Survey

D8. Did you begin hormonal therapy or did you receive LHRH agonists during the past 12 months?

- Yes, hormonal therapy alone
- Yes, hormonal therapy with LHRH agonist
- Yes, LHRH agonist alone
- No

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63% 

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

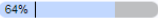
<https://www.surveygizmo.com/s3/2476789/Breast-Cancer-English-Version>
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Breast Cancer In Young Women Survey

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 each item

	YES	NO
a. Copayment for the therapy was high	<input type="radio"/>	<input type="radio"/>
b. Insurance wouldn't cover the therapy	<input type="radio"/>	<input type="radio"/>
c. Potential side effects or experienced side effects	<input type="radio"/>	<input type="radio"/>
d. Wanted to get pregnant	<input type="radio"/>	<input type="radio"/>
e. Other (please explain):	<input type="radio"/>	<input type="radio"/>
<input type="text" value="Enter another option"/>	<input type="radio"/>	<input type="radio"/>

64% 

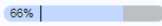
Breast Cancer In Young Women Survey

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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. You took fewer doses of your hormonal therapy for treating your breast cancer to save money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. You delayed receiving hormonal therapy to treat your breast cancer to save money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. You asked your doctor for a lower cost hormonal therapy to treat your breast cancer to save money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. You bought breast cancer hormonal therapy from another country to save money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. You used other therapies to avoid purchasing breast cancer hormonal therapy to save money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Breast Cancer In Young Women Survey

E. Quality and Coordination of Care and Treatment

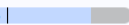
For the next series of questions, we will be asking about the care you received from doctors, nurses, and other health care professionals involved in your breast cancer care and treatment.

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.

- Primary care doctor or family doctor or nurse practitioner
- Gynecologist
- Medical oncologist or nurse oncologist
- Breast surgeon
- Other - Write In

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67% 

Breast Cancer In Young Women Survey

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
- Always

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68% 

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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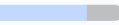
70% | 

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 your breast cancer?

- Poor
- Fair
- Good
- Very good
- Excellent

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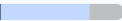
71% 

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?

- Never
- Sometimes
- Usually
- Always

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72% | 


Breast Cancer In Young Women Survey

E6. How often did the provider **most involved** in directing your care for your breast cancer spend enough time with you?

- Never
- Sometimes
- Usually
- Always

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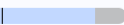
74% | 

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?

- Poor
- Fair
- Good
- Very good
- Excellent

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75% 

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 past 7 days.

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

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76% | 

Breast Cancer In Young Women Survey

G. Cancer History

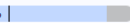
The next few questions are about the history of your cancer

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
- Triple positive, positive for estrogen receptors, progesterone receptors and HER2
- Inflammatory breast cancer
- Don't know

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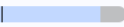
78% 

Breast Cancer In Young Women Survey

G2. Select the one response that best describes your breast cancer stage **at diagnosis**.

- Stage 0
- Stage I
- Stage II
- Stage III
- Stage IV
- Don't Know

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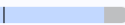
79% | 

Breast Cancer In Young Women Survey

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

- Recurrence of breast cancer – non-metastatic
- Recurrence of breast cancer – metastatic
- Diagnosed with another type of cancer
- Neither

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80% 

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
- Less than 1 year ago
- 1 year ago to less than 3 years ago
- 3 years ago to less than 5 years ago
- 5 years ago to less than 10 years ago
- 10 years ago to 20 years ago
- More than 20 years ago
- I have not been treated for cancer

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82% 

Breast Cancer In Young Women Survey

G5. In addition to breast cancer, what other conditions have caused you problems?
Select ALL 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)
- l. Cancers other than breast cancer
- m. Birth defect
- n. Intellectual disability, also known as mental retardation
- o. Other developmental problem (for example, cerebral palsy)
- p. Depression/anxiety/emotional problem
- q. Senility
- r. Weight problem
- s. Missing limbs (fingers, toes or digits), amputee
- t. Kidney, bladder or renal problems
- u. Circulation problems (including blood clots)
- v. Benign Tumors, Cysts
- w. Fibromyalgia, lupus
- x. Osteoporosis, tendinitis

Scroll down

- y. Epilepsy, seizures
- z. Multiple Sclerosis (MS), Muscular Dystrophy (MD)
- aa. Polio (myelitis), paralysis, para/quadruplegia
- bb. Parkinson's disease, other tremors
- cc. 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
- ll. Other impairment/problem
- mm. None of the above
- nn. Don't know/Not sure

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83% 

Breast Cancer In Young Women Survey

H. Demographics

The last few questions are about you.

H1. What is your age?

- 18–24 years old
- 25–29 years old
- 30–34 years old
- 35–39 years old
- 40–44 years old
- 45–49 years old
- 50–54 years old
- 55–59 years old
- 60–64 years old
- 65 years old or older

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84% 

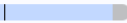
Breast Cancer In Young Women Survey

H2. What was your age when you were initially diagnosed with breast cancer?

- 18–24 years old
- 25–29 years old
- 30–34 years old
- 35–39 years old
- 40–44 years old
- 45–49 years old

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86% 

Breast Cancer In Young Women Survey

H3. What is the highest level of education you have completed?

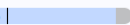
- Less than High School
- High School Graduate or G.E.D.
- Some College or Technical School
- College Graduate (Bachelor's Degree)
- Graduate Degree

H4. Are you of Hispanic or Latino origin or descent?

- Yes, Hispanic or Latino
- No, not Hispanic or Latino

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87% 

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

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Breast Cancer In Young Women Survey

H6. When you were diagnosed with breast cancer, what was your marital status?

Please mark ONE.

- Married
- Widowed
- Divorced
- Separated
- Never married
- Living with your partner
- Do not want to report

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89% | 

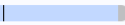
Breast Cancer In Young Women Survey

H7. What is your current marital status? Please mark ONE.

- Married
- Widowed
- Divorced
- Separated
- Never married
- Living with your partner
- Do not want to report

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91% 


Breast Cancer In Young Women Survey

H8. 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
- 4 – 6 children
- 7 – 9 children
- 10 or more children

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92% 


Breast Cancer In Young Women Survey

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

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

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93% 

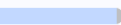
Breast Cancer In Young Women Survey

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
- \$10,000 - \$19,999
- \$20,000 - \$29,999
- \$30,000 - \$39,999
- \$40,000 - \$49,999
- \$50,000 - \$59,999
- \$60,000 - \$69,999
- \$70,000 - \$79,999
- \$80,000 - \$89,999
- \$90,000 or more
- I don't know

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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 including yourself? Please mark ONE.

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

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95% 

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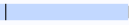
H12. Did someone help you complete this survey?

Yes

No

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97% | 

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.

- Read the questions to me
- Wrote down the answers I gave
- Answered the questions for me
- Translated the questions into my language
- Helped in some other way

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Submit

98% |

Breast Cancer In Young Women Survey

Submitted

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

100% | 