

Breast Cancer in Young Women Survey

Sponsored by

The Centers for Disease Control and Prevention

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Tips for Filling out the Survey

- Please share your honest opinions. All of your answers are kept private.
- Please use a **BLACK** or **DARK BLUE** ink pen to mark your answers.
- Be sure to read all of the answer choices before marking your answer.
- Sometimes the instruction will say to skip one or more questions. Look for notes telling you whether you should skip a question. If there is no note, go to the next question.
- Answer all questions by putting an "X" in the box next to your answer, like this:

Exam	ple					
		the p	east month, did you have any hear Yes No [] Go to Question 3 Don't know [] Go to Question 3			
2	2. In the past month, how many times did you have a headach 1-2 times 3-5 times 6 times or more Don't know				he?	
3.						
	Ple	ase s	elect YES or NO for each item	1YES	₂ NO	
	Did y	ou res	pond to this question?	\boxtimes		
	Exam	nple qu	uestion 2		×	

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. $^1\Box$ None and I do not receive charity care $^2\Box$ 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
	⁷ □ Medicaid or other state insurance (including coverage by Medicaid authorized by Breast and Cervical Cancer Prevention and Treatment Act)
	⁸ □ Medicare ⁹ □ CHAMPVA and TRICARE
	¹º□ Indian Health Service
	$^{11}\Box$ Other (please specify):
A2.	What type of medical insurance did you have at the time of your initial breast cancer diagnosis? Please mark ALL that apply.
	¹□ None and I did not receive charity care
	² □ None and I received charity care
	$^3\square$ Insurance available through my employer or union (including HMO) $^4\square$ Insurance available through my spouse's employer or union (including HMO)
	5 □ Insurance that I purchased with financial assistance (subsidy) from the state or federal
	government (Obamacare, Affordable Care Act)
	⁶ □ Insurance that I purchased myself, not through an employer
	⁷ □ Medicaid or other state insurance (including coverage by Medicaid authorized by Breast and Cervical Cancer Prevention and Treatment Act) ⁸ □ Medicare
	⁸ □ Medicare ⁹ □ CHAMPVA and TRICARE
	□ Champ va and Tricard 10□ Indian Health Service
	¹¹□ Other (please specify):
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? $^1\Box$ Yes $^2\Box$ No
A4.	Which best describes your insurance status over the past 12 months?
	$^1\square$ Insured continuously by same insurance plan
	² □ Insured continuously but switched insurance plan
	³ ☐ Uninsured for some months
	$^4\square$ Uninsured for all of the 12 months

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
A6.	In the past 12 months, have the costs of your prescription medicine(s) been Please mark ONE response.
B. Fi	nancial Burden and Out of Pocket Costs
	ext few questions are about the financial challenges you may have encountered following you to 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. ¹□ Went without health insurance ²□ Stopped working or lost job ³□ Had utilities turned off because the bill was not paid ⁴□ Cut down on spending for medication for my self ⁵□ Had to move out of house or apartment because we could not afford to stay there 6□ Had to declare bankruptcy or are in the process of declaring bankruptcy 7□ Cut down on expenses in general such as food, recreational activities, educational activities 8□ I took out a loan or borrowed against my car or home 9□ My illness has had no impact on my household finances. → GO TO QUESTION B3 ¹o□ Other (please specify/explain):
B2.	How much is the decline in financial situation due to your breast cancer and treatment? ¹□ Not much at all ²□ A little ³□ Somewhat ⁴□ Quite a bit ⁵□ Very much

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. 1 Less than \$500 2 \$500-\$2,000 3 \$2,001-\$5,000 4 \$5,001-\$10,000 5 More than \$10,000
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. 1
B5.	How much money would you estimate you have paid in the past 12 months for <u>other</u> expenses related to your breast cancer such as travel costs, parking, child/elderly care, etc? ¹ Less than \$500 ² \$500–\$2,000 ³ \$2,001–\$5,000 ⁴ \$5,001–\$10,000 ⁵ More than \$10,000
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. 1

В7.	Because of your medical cost, did you have to		
	Please select YES or No for <u>each</u> item	1YES	₂ NO
a.	delay or stop breast cancer treatment?		
b.	go without any medication prescribed?		
C.	take less than the fully prescribed amount of a prescription?		
d.	miss a doctor's appointment?		
e.	miss a follow-up mammogram, MRI, or ultrasound?		
f.	delay or did not receive breast reconstruction?		
g.	forgo fertility preservation?		
B8. B9.	How would you describe your reaction to how your medical benefits (health in including Medicaid and Medicare) covered the cost of your cancer treatment? The medical benefits contributed 1more money than I expected 2about what I expected 3less money than I expected 4Not applicable as I did not have health coverage or insurance How would you describe your reaction to the money you spent for cancer treat spent 1more money than I expected 2about what I expected 3less than I expected Did you ever discuss the cost of treatment for your cancer with your care tear	atment?	I
B10.	Did you ever discuss the cost of treatment for your cancer with your care tean $^1\Box$ Yes $^2\Box$ No	n'?	
B11.	When choosing a treatment course for your cancer, did you consider the cost treatments? $^1\Box$ No, not at all $^2\Box$ Yes, somewhat $^3\Box$ Yes, a great deal	s of spec	ific

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? ¹□ Yes ²□ No → GO TO QUESTION C9
C2	Which of these best describes the job you held at the time you were diagnosed with breast cancer? ¹□ Employee of a PRIVATE or NONPROFIT company (working for pay) ²□ A FEDERAL government employee ³□ A STATE government employee ⁴□ A LOCAL government employee ⁵□ Worked for self (e.g. operated a business, professional practice or farm) 6□ Don't know
C3	On average, about how many hours per week did you work 1 month before your diagnosis? ¹□ 1 – 8 hours per week ²□ 9 – 16 hours per week ³□ 17 – 32 hours per week ⁴□ 33 – 40 hours per week ⁵□ More than 40 hours per week
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
C5	In total, about how many days of work did you miss because of your breast cancer or its treatment? 1

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	1YES	₂ NO
a.	I changed jobs within the company to accommodate my breast cancer diagnosis		
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		
e.	I took time off without pay		
f.	I quit my job		

g.	I decided to retire early		
h.	l 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		
	I increased my work hours in order to cover my breast cancer related medical expenses		
I.	Other (please explain):		
C7.	Overall, how supportive was your employer of you when you were being treated cancer? 1 My employer did not know about my breast cancer diagnosis 2 Very supportive 3 Somewhat supportive 4 Neutral 5 Somewhat not supportive 6 Not supportive at all	d for brea	ast
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	1YES	2 NO
	when you were being treated for breast cancer. My employer	¹YES	2NO
a	when you were being treated for breast cancer. My employer Please select YES or No for each item		2NO
a	when you were being treated for breast cancer. My employer Please select YES or No for each item gave me permission to take the necessary time off for treatments		
a	when you were being treated for breast cancer. My employer Please select YES or No for each item gave me permission to take the necessary time off for treatments allowed me to have a flexible schedule so I could get treatments		
a b	when you were being treated for breast cancer. My employer Please select YES or No for each item gave me permission to take the necessary time off for treatments allowed me to have a flexible schedule so I could get treatments paid me for sick days		

C11.	How long has it been since you have worked for pay?			
	$^1\square$ 1 to 6 months			
	$^2\square$ 7 to 12 months			
	³ □ 1 to 2 years			
	$^4\Box$ More than 2 years but less than 5 years			
	⁵ □ 5 years or more			
	$^{6}\square$ I've never worked for pay or profit			
C12.	How important is it for you to work for financial reasons?			
	$^1\square$ Not at all important			
	$^2\square$ A little important			
	³☐ Somewhat important			
	⁴ □ Quite important			
	⁵□ Very important			
C13.	How important is it for you to work for other non-financial reasons (for example, persona satisfaction, emotional wellbeing)?			
	$^1\square$ Not at all important			
	$^2\square$ A little important			
	³☐ Somewhat important			
	⁴ □ Quite important			
	⁵ □ Very important			

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? Pleather apply	se mark	ALL
	that apply. $^1\square$ Chemotherapy		
	□ Chemotherapy ² □ Radiation		
	³□ Surgery—Lumpectomy		
	⁴ □ Surgery—Mastectomy		
	⁵ □ Surgery—Oophorectomy		
	$^{6}\square$ Breast reconstruction		
	$^7\square$ Lymph node removal		
	 Hormonal Therapy [For example, Tamoxifen; Toremifene (Fareston®); Fulve (Faslodex®); Leuprolide (Lupron ®); Goserelin (Zolade®); Triptorelin (Trelst Aromatase inhibitors - Letrozole (Femara ®), Anastrozole (Arimidex ®)] Immunotherapy [For example, Trastuzumab (Herceptin), Pertuzumab (Perje Bevacizumab (Avastin®)] Bone-directed Therapy [For example, Denosumab (Xgeva®, Prolia®), Pam 	tar®); eta®),	
	(Aredia®) and Zoledronic acid (Zometa)] 11 Physical Therapy	iuionate	
	 12 Complementary alternative medicine (CAM) treatments such as acupuncture nutrition counseling, etc. 	re, mass	age,
	$^{13}\square$ Fertility preservation procedures		
	¹⁴ ☐ Genetic testing		
	¹⁵□ Other (Specify):		
D3	medical care, tests, or treatments that your doctor believed was necessary? ¹□ Yes → GO TO QUESTION D4 ²□ No 4. 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 <u>each</u> item	1YES	2NO
a.	Couldn't afford it		
b.	Insurance company wouldn't approve or pay for it		
c.	Doctor did not accept your insurance		
d.	Had transportation problems getting to the doctor's office		
e.	Had problems other than transportation challenges getting to the doctor's office		
f.	Couldn't get time off from work		
g.	Didn't know where to go to get care/treatment		
h.	Couldn't get child care/adult care		
i.	Didn't have time as care/test/treatment took too long		
j.	I was afraid of the treatment's side effects		
k.	I wanted to preserve my fertility		
I.	Other reason (please describe):	П	П

D4	How much of a problem if any, was it to get the breast cancer care that you or a believed was necessary (for example, reaction to the treatments or had transport or financial problems)? 1 Not a problem 2 A small problem 3 A large problem		sues
D5	How often did you have to wait longer than you wanted to get an appointment v doctor? 1 Never 2 Sometimes 3 Usually 4 Always	vith your	
D6	When you went to see your doctor for breast cancer care, how long did you typ the office to see the doctor? 1	ically wai	t in
D7	During the past 12 months, was hormonal therapy recommended to you to trea cancer? Hormonal therapy includes the use of Tamoxifen; Toremifene (Faresto Fulvestrant (Faslodex®); Luteinizing hormone-releasing hormone (LHRH) a Leuprolide (Lupron ®), Goserelin (Zolade®), Triptorelin (Trelstar®); Aromatase Letrozole (Femara ®); Anastrozole (Arimidex ®). ¹□ Yes ²□ No → GO TO SECTION E	n®); gonists -	_
D8	 Did you begin hormonal therapy or did you receive LHRH agonists during the p months? ¹□ Yes, hormonal therapy alone → GO TO QUESTION D10 ²□ Yes, hormonal therapy with LHRH agonist → GO TO QUESTION D10 ³□ Yes, LHRH agonist alone → GO TO QUESTION D10 ⁴□ No 	ast 12	
С	19. 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	1YES	2NO
а	. Copayment for the therapy was high		
b			
С	. Potential side effects or experienced side effects		

d.	d. Wanted to get pregnant						
e. Other (please explain):							
D1	O. 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 <u>each</u> item	1YES	₂ NO	₃Refused	₄Don't Know		
a.	You skipped doses of hormonal therapy or LHRH agonist for treating your breast cancer to save money						
b.	You took fewer doses of your hormonal therapy for treating your breast cancer to save money						
C.	You delayed receiving hormonal therapy to treat your breast cancer to save money						
d.	You asked your doctor for a lower cost hormonal therapy to treat your breast cancer to save money						
e.	You bought breast cancer hormonal therapy from another country to save money						
f.	You used other therapies to avoid purchasing breast cancer hormonal therapy to save money						
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 <i>most involved</i> in directing your care and treatment for your breast cancer in the past 12 months? Please select one only. 1 Primary care doctor or family doctor or nurse practitioner 2 Gynecologist 3 Medical oncologist or nurse oncologist 4 Breast surgeon 5 Other (please specify):							
E2.	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? 1 Never 2 Sometimes 3 Usually 4 Always						
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 <i>most involved</i> in directing your care for your breast cancer? Would you say ⁰ □ 0 = (Worst doctor possible) ¹ □ 1						

	²□ 2
	3□ 3
	4□ 4
	5□ 5
	6□ 6
	⁷ □ 7
	8□ 8
	9□ 9
	¹º□ 10 = (Best doctor possible)
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 <i>most involved</i> in directing your care for your breast cancer?
	¹□ Poor
	$^2\square$ Fair
	³□ Good
	⁴ □ Very good
	⁵ ☐ Excellent

E5.	How often did the provider most involved in directing your care for your breast cancer explain things in a way you could understand?
	¹□ Never
	² □ Sometimes
	³ □ Usually
	⁴ □ Always
E6.	How often did the provider <i>most involved</i> in directing your care for your breast cancer spend enough time with you?
	¹□ Never
	² □ Sometimes
	³□ Usually
	⁴ □ Always
E7.	How would you describe the knowledge of your relevant medical history by the provider <i>most involved</i> in directing your breast cancer treatment?
	¹□ Poor
	² □ Fair
	³□ Good
	⁴ □ Very good
	⁵ ☐ Excellent

F. Disease-specific symptom index

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

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	Some- what	Quite a bit	Very much
a.	I have a lack of energy	0	1	2	3	4
b.	I have pain	0	1	2	3	4
C.	I have nausea	0	1	2	3	4
d.	I have certain parts of my body where I experience pain	0	1	2	3	4
e.	I have been short of breath	0	1	2	3	4
f.	I worry that my condition will get worse	0	1	2	3	4
g.	I am content with the quality of my life right now	0	1	2	3	4
h.	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4

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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. ¹□ Endocrine receptor (estrogen or progesterone receptor) positive ²□ HER2 positive ³□ Triple negative, not positive to receptors for estrogen, progesterone, or HER2 ⁴□ Triple positive, positive for estrogen receptors, progesterone receptors and HER2 ⁵□ Inflammatory breast cancer ⑥□ Don't know
G2.	Select the one response that best describes your breast cancer stage at diagnosis. 1 Stage 0 2 Stage I 3 Stage II 4 Stage III 5 Stage IV 6 Don't Know
G3.	Have you experienced a recurrence or been diagnosed with another cancer since your initial breast cancer diagnosis? ¹ Recurrence of breast cancer non-metastatic ² Recurrence of breast cancer metastatic ³ Diagnosed with another type of cancer ⁴ Neither
G4.	About how long ago did you receive your last cancer treatment (chemotherapy, radiation, surgery, hormonal therapy)? 1

G5. In addition to breast cancer, what other conditions have caused you problems? Select ALL that apply					
a.	Vision/problem seeing		u.	Circulation problems (including blood clots)	
b.	Hearing problem		V.	Benign Tumors, Cysts	
c.	Arthritis/rheumatism		w.	Fibromyalgia, lupus	
d.	Back or neck problem		X.	Osteoporosis, tendinitis	
e.	Fracture, bone/joint injury		у.	Epilepsy, seizures	
f.	Other injury		Z.	Multiple Sclerosis (MS), Muscular Dystrophy (MD)	
g.	Heart problem		aa.	Polio (myelitis), paralysis, para/quadriplegia	
h.	Stroke problem		bb.	Parkinson's disease, other tremors	
i.	Hypertension/high blood pressure		cc.	Other nerve damage, including carpal tunnel syndrome	
j.	Diabetes		dd.	Hernia	
k.	Lung/breathing problem (for example, asthma and emphysema)		ee.	Ulcer	
I.	Cancers other than breast cancer		ff.	Varicose veins, hemorrhoids	
m.	Birth defect		gg.	Thyroid problems, Grave's disease, gout	
n.	Intellectual disability, also known as mental retardation		hh.	Knee problems (not arthritis (c.), not joint injury (e.))	
0.	Other developmental problem (for example, cerebral palsy)		ii.	Migraine headaches (not just headaches)	
p.	Depression/anxiety/emotional problem		jj.	Other impairment/problem (Specify one)	
q.	Senility		kk.	Other impairment/problem (Specify one)	
r.	Weight problem		II.	Other impairment/problem (Specify one)	
S.	Missing limbs (fingers, toes or digits), amputee		mm	n. None of the above	
t.	Kidney, bladder or renal problems		nn.	Don't know/Not sure	

H. Demographics

The last few questions are about you. H1. What is your age? ¹ □ 18–24 years old $^2\square$ 25–29 years old ³ ☐ 30–34 years old $^4\square$ 35–39 years old $^5\square$ 40–44 years old $^{6}\square$ 45–49 years old $^7\square$ 50–54 years old $^{8}\square$ 55–59 years old ⁹ □ 60–64 years old ¹⁰ □ 65 years old or older H2. What was your age when you were initially diagnosed with breast cancer? $^{1}\square$ 18–24 years old ² □ 25–29 years old ³ □ 30–34 years old $^4\square$ 35–39 years old ⁵ 40–44 years old 6 □ 45–49 years old H3. What is the highest level of education you have completed? ¹☐ Less than High School ²☐ High School Graduate or G.E.D. ³□ Some College or Technical School ⁴□ College Graduate (Bachelor's Degree) ⁵☐ Graduate Degree H4. Are you of Hispanic or Latino origin or descent? ¹☐ Yes, Hispanic or Latino ² □ No, not Hispanic or Latino H5. What is your race? Please mark ALL that apply. ¹□ White ² □ Black or African American ³□ Asian ⁴□ Native Hawaiian or Other Pacific Islander

⁵☐ American Indian or Alaska Native

H6.	When you were diagnosed with breast cancer, what was your marital status? Please mark ONE. Married Divorced Separated Never married Living with your partner Do not want to report
H7.	What is your current marital status? Please mark ONE. ¹☐ Married ²☐ Widowed ³☐ Divorced ⁴☐ Separated ⁵☐ Never married ⁶☐ Living with your partner 7☐ Do not want to report
H8.	When you were initially diagnosed with breast cancer, how many children under 18 years old did you have living at your home? $^1\Box$ None $^2\Box$ 1 – 3 children $^3\Box$ 4 – 6 children $^4\Box$ 7 – 9 children $^5\Box$ 10 or more children
H9.	How would you describe yourself? Please mark ALL that apply. ¹□ I work full time or part time ²□ I am unemployed ³□ I am a homemaker ⁴□ I am a student ⁵□ I am retired
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. ¹□ less than \$10,000 ²□ \$10,000 - \$19,999 ³□ \$20,000 - \$29,999 ⁴□ \$30,000 - \$39,999 ⁵□ \$40,000 - \$49,999 ⁵□ \$50,000 - \$59,999 ³□ \$60,000 - \$69,999 ³□ \$70,000 - \$79,999 °□ \$80,000 - \$89,999 ¹□□ \$90,000 or more ¹¹□ I don't know

HII.	income for your household including yourself? Please mark ONE. 1 (just you) 2 2 3 3 4 4 or more
H12.	Did someone help you complete this survey? ¹□ Yes ²□ No → END SURVEY
H13.	How did that person help you? Please mark ALL that apply. ¹□ Read the questions to me ²□ Wrote down the answers I gave ³□ Answered the questions for me ⁴□ Translated the questions into my language ⁵□ Helped in some other way

Thank you for completing the survey