

Attachment 3b.

Wave 2 Survivor Survey (paper, English)

Public reporting burden of this collection of information is estimated to average of 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-####).

CDC APHIR Barriers Along Cancer Continuum – W2 Survivor Survey

Preload variables:

- RTI_ID
- PATIENT_ID_LINK (To link to original patient)
- CANC_TYPE (breast/cervical/colorectal)
- STATE
- STATE_MEDICAID (Medicaid/Medi-Cal [for California]; Medicaid/North Carolina Medicaid [for NC]; Medicaid [for Texas])

Intro.

Thank you for agreeing to participate in this study.

This survey will take you about **20** minutes to complete. After you submit the survey, you will receive a \$40 check or electronic gift card as a token of appreciation for your time.

A goal of this study is to collect information about your experience as someone who was diagnosed with cancer. This survey includes questions on several topics. For example, you will be asked about your general background and experiences related to cancer treatment. What we learn from this study will help the CDC make recommendations to assist future cancer patients and their caregivers.

Although the answers may be hard to remember, please do the best you can. There are no right or wrong answers to any of these questions. You should just report what you have been through as an individual diagnosed with or living with cancer.

Participation in this study is voluntary. Questions answered in this study will not affect your health care. You can skip any question you do not want to answer. Just go on to the next question. You may exit the survey at any time. You may also complete the survey in multiple sittings; your answers will be saved. Joining this study has minimal risks. Some of the questions on the survey may be upsetting, but you don't have to answer them. Protections are in place to keep your data as safe as possible.

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MODULE A: DEMOGRAPHICS

A2. In 2021, you were diagnosed with [CANC TYPE] cancer.

Since then, have you been diagnosed with any type of cancer?

1. Yes
2. No

A2a. [IF A2=1 CONTINUE, ELSE GOTO A3] What type of cancer were you diagnosed with?

1. Breast
2. Colorectal
3. Cervical
4. Other cancer – Please specify: [OPEN FIELD]

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A3. What is your current employment status?

1. Employed for pay (including self-employed) – 40 hours or more per week
2. Employed for pay (including self-employed) – Less than 40 hours per week
3. Retired
4. Homemaker
5. Student
6. Out of work
7. Unable to work (e.g., due to disability, work authorization)

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A4. What is your current health insurance status? Please select all that apply.

1. No insurance
2. Lapse in coverage
3. Private health insurance (purchased on your own or from your job or from your spouse's / partner's / parent's job)
4. Medicaid
5. Medicare/Medicare Advantage
6. Military (Tricare, Champ-VA, or some other insurance)
7. Other [please specify]: (OPEN FIELD IF SELECTED)

A4a. [IF A4=1 OR 2 CONTINUE, ELSE GOTO A5] Please select the main reason why you are not currently enrolled in a health care plan.

1. You or the policyholder retired, lost a job, or changed employers
2. You missed a deadline for signing up or paying for coverage
3. You became ineligible (e.g., your age, health status)
4. The cost of coverage increased
5. You had Medicaid or other public coverage, but were no longer eligible

6. You do not need or want insurance
99. Prefer not to answer

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A5. Which best describes your current home?

1. A one-family house detached from any other house (including mobile homes)
2. A one-family house attached to one or more houses (e.g., townhome, duplex)
3. An apartment building, apartment complex, or condo
4. I do not have stable housing (staying in a hotel, in a shelter, living outside on the street or in a park, etc.).
5. Other (please specify): [OPEN FIELD]

A5a. [IF A5=1, 2, OR 3 CONTINUE, ELSE GOTO A6] Does anyone in the family own this home?

1. Yes
2. No

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A6. How many people are currently living or staying at this address?

This includes everyone who is living or staying at your home for more than 2 months, including you.

[DROP DOWN - ALLOW 1-15]

77. More than 15 people (e.g., group home or assisted living)

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A7. At your home, do you or any other member of your household have access to the internet?

1. Yes
2. No

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A8. Are you scared to walk around your neighborhood...	1. Yes	2. No	99. Prefer not to answer
A8_1. ... during the day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A8_2. ... at night?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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A9. In general, what is your primary form of transportation?

1. Walking
2. Bicycle
3. Personal vehicle (e.g., car, truck, SUV, minivan)
4. Carpool or borrow personal vehicle of a friend, family member, or neighbor
5. Taxi or rideshare (e.g., Uber, Lyft)
6. Rental car or car sharing service (e.g., Zipcar, Car2go)
7. Bus or trolley
8. Subway or train
9. Motorcycle
10. Paratransit (specialized door-to-door transport service for people with disabilities)
11. Other – Please specify: [OPEN FIELD]

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A10. Think about your household, which includes everyone who lives with you.

Please indicate whether the following statements are often true, sometimes true, or never true.

“Within the past 12 months, we worried whether our food would run out before we had money to buy more.”

1. Often true
2. Sometimes true
3. Never true

A11. “Within the past 12 months, the food we bought just didn’t last and we didn’t have money to get more.”

1. Often true
2. Sometimes true
3. Never true

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MODULE B: TREATMENT

B1. Is there a doctor’s office, clinic, health center, or other place where you usually go if you are sick or need advice about your health (regular, non-cancer-related care)? This does not include care received in Emergency Rooms (ER), urgent care centers, or drug/grocery store clinics.

1. Yes

2. No

B1a. [IF B1=2 CONTINUE, ELSE GOTO B2] What is the main reason you do not have a usual source of health care?

1. I seldom or never get sick.
2. I recently moved to the area.
3. I don't know where to go for care.
4. The usual source of my medical care in this area is no longer available.
5. I can't find a provider who speaks my language.
6. I like to go to different places for different health needs.
7. I just changed insurance plans.
8. I don't use doctors/I just treat myself.
9. I can't afford the cost of medical care.
10. I have no health insurance.
11. I can't find a provider who is available when I am (e.g., due to work schedule).
12. Other reason – Please specify: [OPEN FIELD]
99. Prefer not to answer

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B2. What types of cancer treatment have you received? If you have been diagnosed with cancer more than once, please think about treatment for your most recent diagnosis for [CANC_TYPE] cancer. Select all that apply.

1. IV Chemotherapy
2. Oral Chemotherapy
3. Radiation
4. Surgery
5. Immunotherapy (e.g., interferon or cancer vaccines) or another biological therapy (e.g., Car-T, Gleevec, Iressa, Tarceva, Herceptin, or Erbitux)
6. Hormonal therapy (e.g., Tamoxifen, Adjuvant, Zoladex, Lupron)
7. Precision medicine / targeted therapy (using medication to target specific genes and proteins of the cancer)
8. Bone marrow or stem cell transplant
9. Complementary and alternative therapy (e.g., acupuncture, reiki)
10. Other
11. I have not received any treatment for cancer [EXCLUSIVE].

B2_SPEC. [IF B2=10 CONTINUE, ELSE GOTO B3]: Please specify the other type of treatment(s): [OPEN FIELD]

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B3. Please select whether you have completed each of the treatment(s) you selected in the previous question:

[GRID showing answers from B2, then Yes, No, DK]

1. IV Chemotherapy
2. Oral Chemotherapy
3. Radiation
4. Surgery
5. Immunotherapy (e.g., interferon or cancer vaccines) or another biological therapy (e.g., Car-T, Gleevec, Iressa, Tarceva, Herceptin, or Erbitux)
6. Hormonal therapy (e.g., Tamoxifen, Adjuvant, Zoladex, Lupron)
7. Precision medicine / targeted therapy (using medication to target specific genes and proteins of the cancer)
8. Bone marrow or stem cell transplant
9. Complementary and alternative therapy (e.g., acupuncture, reiki)
10. [RESPONSE FROM B2_SPEC]

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B5. Did you participate in a clinical trial as part of your cancer treatment?

1. Yes
2. No
88. Don't Know

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B5a. How informed did you feel about the potential side effects from treatment?

1. Very
2. Somewhat
3. Not at all

B5a_OPEN: Please describe your experience (optional): [OPEN FIELD]

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B5b. How difficult were the side effects that you experienced?

1. Not at all difficult
2. Somewhat difficult
3. Difficult
4. Very difficult

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B6. When you called your cancer doctor's office or clinic during regular office hours with questions about your cancer treatment, how often did you get the help or advice you needed?

1. Never

2. Sometimes
3. Usually
4. Always
5. Not applicable: I never called my doctor's office or clinic with questions.

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B7. In general, how often did you leave your doctor's office or clinic with unanswered questions related to your cancer?

1. Never
2. Sometimes
3. Usually
4. Always

B7_OPEN: Please describe your experience (optional): [OPEN FIELD]

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B8. During your cancer treatment, how supportive were your friends and relatives?

1. Not at all supportive
2. Not very supportive
3. Somewhat supportive
4. Very supportive

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B9. Do you currently need any assistance to do your day-to-day activities?

1. A lot of assistance
2. Some assistance
3. A little assistance
4. Not at all

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B10. Did you ever discuss the cost of treatment for your cancer with your doctor(s) or other health care providers?

1. Yes
2. No
88. Don't know

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B11. When choosing a treatment course for your cancer, how much did you consider the costs of specific treatments?

1. No, not at all

2. Yes, somewhat
3. Yes, a great deal

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B12a. At any time since your first cancer diagnosis, did you take extended paid time off work, unpaid time off, or make a change in your hours, duties, or employment status?

1. Yes
2. No

B12b. [IF B12a=1 CONTINUE, ELSE GOTO B13_INTRO] Did you make these work changes...

1. Because of your cancer, its treatment, or its lasting effects?
2. Some other reason
88. Don't know
99. Prefer not to answer

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B13_INTRO. The next few questions ask about your experiences in the past 12 months.

B13. How much money would you estimate you have paid out-of-pocket in the past 12 months for medical expenses related to your [CANC_TYPE] 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 have spent and not money provided by the insurance company.

1. Less than \$500
2. Between \$500 to \$2,000
3. Between \$2,001 to \$5,000
4. Between \$5,001 to \$10,000
5. More than \$10,000
88. Don't know

B14. How much money would you estimate you have paid out-of-pocket in the past 12 months for other expenses related to your [CANC_TYPE] cancer, such as travel costs, parking, child/elderly care, special diet/food/drinks, etc.?

For this question, please think of out-of-pocket money that you spent and not money provided by the insurance company.

1. Less than \$500
2. Between \$500 to \$2,000

3. Between \$2,001 to \$5,000
4. Between \$5,001 to \$10,000
5. More than \$10,000
88. Don't know

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B15. How would you describe your reaction to the money you spent for cancer treatment?

I spent...

1. ...more money than I expected
2. ...about as much money as I expected
3. ...less money than I expected

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B15a. Did you receive financial assistance from any of the following people or places? Please select all that apply.

1. Family or friends
2. Local support organizations
3. National cancer organizations
4. Your church or faith-based community
5. I did not receive any financial assistance. [Programmer: If this is selected none of the other options should be checkable.]

B15b. [IF B15a=1, 2, 3, OR 4 CONTINUE, ELSE GOTO B16]

What type of financial assistance did you receive? Please select all that apply.

1. Cash assistance or money transfer
2. Gift card or pre-loaded credit card
3. Gas cards or rideshare vouchers
4. Coupons or discounted services
5. Other (please specify):

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B16. How would you describe your reaction to the time you spent related to your cancer treatment?

I spent...

1. ...more time than I expected
2. ...about as much time as I expected
3. ...less time than I expected

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B17. How often did your doctor(s) or other healthcare providers show respect for what you had to say?

1. Never
2. Sometimes
3. Usually
4. Always

B17_SPEC. Please describe your experience (optional): [OPEN FIELD]

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B18. How often did your doctor(s) or other healthcare providers give you as much cancer-related information as you wanted?

1. Never
2. Sometimes
3. Usually
4. Always

B18_SPEC. Please describe your experience (optional): [OPEN FIELD]

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B20. What were the top non-medical issues you faced in the past 12 months related to your cancer treatment or follow-up cancer care?

You may select up to 5 issues.

[CHECK ALL THAT APPLY – UP TO 5]	
B20_1. ____	Afraid the treatment will be too painful or unpleasant
B20_2. ____	Could not afford care (e.g., cost too much; other competing expenses)
B20_3. ____	Could not afford food
B20_4. ____	Lack of permanent, stable housing
B20_5. ____	No insurance coverage, or insurance company would not approve, cover or pay for care
B20_6. ____	Problems getting transportation to doctor's office or office was too far away
B20_7. ____	Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave)
B20_8. ____	Didn't know where to go to get care (e.g., no primary doctor or usual source of care to make referral; unfamiliar with local providers; local specialty practice closed)
B20_9. ____	Was refused services (e.g., out of network provider, not accepting new patients)

B20_10. ____	Took too long to get an appointment that worked for my schedule
B20_11. ____	Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status)
B20_12. ____	Unable to understand the doctor's language (e.g., different language without access to interpretation)
B20_13. ____	Medical information was too hard to understand
B20_14. ____	Couldn't get dependent care (e.g., for child, elderly relative, or relative with a disability)
B20_15. ____	Could not get a friend or family member to go with you to appointment(s)
B20_16. ____	Other
B20_17. ____	I did not encounter any issues. [EXCLUSIVE SELECT]

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B20_OTH. [SHOW IF B20_16 NE BLANK] Please describe the other issue(s) that you faced in the past 12 months related to your cancer treatment or follow-up cancer care. [OPEN FIELD]

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B20_RANK. Of the top issues you selected, please rank them, with "1" being the most important.

[NOTE: DISPLAY ONLY THE ISSUES ENDORSED IN QUESTION B20]

[NUMERIC RESPONSE - UP TO 5]	[NUMERIC RESPONSE - UP TO 5]
B20_RANK_1. ____	Afraid the treatment will be too painful or unpleasant
B20_RANK_2. ____	Could not afford care (e.g., cost too much; other competing expenses)
B20_RANK_3. ____	Could not afford food
B20_RANK_4. ____	Lack of permanent, stable housing
B20_RANK_5. ____	No insurance coverage, or insurance company would not approve, cover or pay for care
B20_RANK_6. ____	Problems getting transportation to doctor's office or office was too far away
B20_RANK_7. ____	Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave)
B20_RANK_8. ____	Didn't know where to go to get care (e.g., no primary doctor or usual source of care to make referral; unfamiliar with local providers; local specialty practice closed)
B20_RANK_9. ____	Was refused services (e.g., out of network provider, not accepting new patients)
B20_RANK_10 ____	Took too long to get an appointment that worked for my schedule
B20_RANK_11 ____	Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual

	orientation, disability status)
B20_RANK_12 ____	Unable to understand the doctor's language (e.g., different language without access to interpretation)
B20_RANK_13 ____	Medical information was too hard to understand
B20_RANK_14 ____	Couldn't get dependent care (e.g., for child, elderly relative, or relative with a disability)
B20_RANK_15 ____	Could not get a friend or family member to go with you to appointment(s)
B20_RANK_16 ____	[B20_OTH]

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B20_FACILITATE. Please select the top 5 factors that made it easier to get medical care for your cancer treatment.

You may select up to 5 factors.

[NUMERIC RESPONSE - UP TO 5]	[NUMERIC RESPONSE - UP TO 5]
B20_FAC_1. ____	Worked with a nurse/patient navigator who provided additional support
B20_FAC_2. ____	Was able to manage side effects
B20_FAC_3. ____	Was able to afford care
B20_FAC_4. ____	Was able to cover all my expenses like food
B20_FAC_5. ____	Had permanent, stable housing
B20_FAC_6. ____	Insurance covered most of my medical costs
B20_FAC_7. ____	Easy access to transportation
B20_FAC_7_a. ____	Convenient location of healthcare provider
B20_FAC_8. ____	Was able to take time off work for appointments and care (e.g., paid sick leave, flexible work schedule, medical leave available)
B20_FAC_9. ____	Connected to a provider by someone I know (e.g., doctor, nurse, family member, friend, others on social media)
B20_FAC_10. ____	Was able to get an appointment with a doctor or specialist within a reasonable timeframe
B20_FAC_11. ____	Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed
B20_FAC_12. ____	Was treated with respect by my doctor or specialist
B20_FAC_13. ____	Was able to understand medical information that was shared with me
B20_FAC_14. ____	Other [please specify]: ____ [OPEN TEXT FIELD]

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MODULE C: SURVIVORSHIP

C1. Have you ever received instructions from a doctor, nurse, or other health professional about when you should return or who you should see for routine cancer check-ups after completing your treatment for cancer?

1. Yes
2. No
88. Don't know

C1a. [IF C1=1 CONTINUE, ELSE GOTO C2] Were the instructions written down (e.g., in your patient portal, Survivorship Care Plan) or printed on paper for you?

1. Yes
2. No
88. Don't know

C1b. [IF C1=1 CONTINUE, ELSE GOTO C2] Did someone from your doctor's office talk through the instructions with you, either in-person or over the phone?

1. Yes
2. No
88. Don't know

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C2. Which of the following topics have you discussed with your doctor(s) in post-treatment care? Select all that apply.

1. Follow-up testing
2. Risk of recurrence
3. Quality of life
4. Exercise and nutrition
5. Physical function
6. Mental and emotional impact/health
7. Fatigue
8. Pain
9. Other - Please specify: [OPEN FIELD]
99. Prefer not to answer [EXCLUSIVE SELECT]

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C3. How would you rate your doctors' knowledge of how cancer and its treatment have affected the quality of your life?

1. Poor
2. Fair
3. Good
4. Very good
5. Excellent

C3_SPEC: Please describe your experience (optional): [OPEN FIELD]

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C4. If you've spoken with your cancer care doctor(s) in the past year, how often did your cancer care doctor(s) explain things in a way you could understand?

1. Never
2. Sometimes
3. Usually
4. Always
5. Not applicable: I haven't spoken with my doctor(s) in the past year.

C4_SPEC: Please describe your experience (optional): [OPEN FIELD]

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C5. How often did your follow-up cancer care doctor(s) spend enough time with you?

1. Never
2. Sometimes
3. Usually
4. Always

C5_SPEC. [SHOW IF C5= 1 OR 2] Please describe your experience (optional): [OPEN FIELD]

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C6. After completing your initial course of cancer treatment, how difficult was it to see a specialist for follow-up cancer care?

1. Not at all difficult
2. Somewhat difficult
3. Difficult
4. Very difficult

C6_SPEC. [SHOW IF C6= 3 OR 4] Please describe your experience (optional): [OPEN FIELD]

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MODULE D: CONTACT

D1_INCENT. As a thank you for completing this survey, we will provide you with \$40. Do you prefer to receive an electronic VISA gift card emailed to you or a check mailed to your home? Processing time for an e-card is about a week. Processing time for a check is about 3-4 weeks.

1. Electronic gift card emailed to me
2. Check mailed to my home

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D1. [IF D1_INCENT=2] Please enter your contact information so that we may send you a \$40 check.

D1_1. Full name: [OPEN]

D1_2. Street address line 1: [OPEN]

D1_3. Street address line 2: [OPEN]

D1_4. City [OPEN]

D1_5. State: [OPEN]

D1_6. Zip code: [OPEN]

[POST LOGIC: GO TO END]

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D2: [IF D1_INCENT=1] Please enter your e-mail address for the electronic gift card: [OPEN]

D3: Please retype the email address for confirmation: [OPEN]

EMAIL_CHK. [IF D2 != D3: The email address that you provided does not match. Please re-enter the email address.]

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END. Thank you!

If you have any questions about the survey, please do not hesitate to call us toll free at (833) 997-2714 or email us at CDC_CancerSurvey@rti.org.

Please click [SUBMIT] to submit your responses.