**Attachment 2b.**

Wave 1 Survivor Survey (paper, English)

**CDC APHIR Barriers Along Cancer Continuum – W1 Survivor Survey**

Preload variables:

* CANC\_TYPE (breast/cervical/colorectal)
* 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 barriers you may have faced along the cancer continuum – from screening to diagnosis and treatment.

This survey includes questions on several topics. For example, you’ll be asked about the type of cancer you had, how old you were at diagnosis, and whether you had insurance. Some of these questions ask you to think back to events that may have occurred a few years ago.

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

A1. When you were diagnosed, what was the stage of your [CANC\_TYPE] cancer?

1. Stage 0
2. Stage 1
3. Stage 2
4. Stage 3
5. Stage 4
6. Don’t know / can’t remember

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A2. What is your biological sex? This is a category that is based upon your original birth certificate.

1. Male
2. Female
3. Prefer not to answer

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A3. How old are you?

1. 21-24 years old
2. 25–29 years old
3. 30–34 years old
4. 35–39 years old
5. 40–44 years old
6. 45–49 years old
7. 50–54 years old
8. 55–59 years old
9. 60–64 years old
10. 65–69 years old
11. 70–74 years old
12. 75 years old or older

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A5. What is your race and/or ethnicity? Select all that apply.

1. American Indian or Alaska Native
2. Asian
3. Black or African American
4. Hispanic or Latino
5. Middle Eastern or North African
6. Native Hawaiian or Other Pacific Islander
7. White
8. Other [please specify]: [OPEN FIELD IF SELECTED]
9. Don’t know
10. Prefer not to answer

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A6. What was your marital status when you were first diagnosed with [CANC-TYPE] cancer?

|  |
| --- |
| 1. Never married |
| 1. Married |
| 1. Living together with a partner as an unmarried couple / cohabitating |
| 1. Widowed |
| 1. Separated or divorced |

A6a. What is your current marital status?

|  |
| --- |
| 1. Never married |
| 1. Married |
| 1. Living together with a partner as an unmarried couple / cohabitating |
| 1. Widowed |
| 1. Separated or divorced |

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A7. What was your employment status when you were first diagnosed with [CANC-TYPE] cancer?

|  |
| --- |
| 1. Employed for pay (including self-employed) – 40 or more hours per week |
| 1. Employed for pay (including self-employed) – Less than 40 hours per week |
| 1. Retired |
| 1. Homemaker |
| 1. Student |
| 1. Out of work for 1 year or more |
| 1. Out of work for less than 1 year |
| 1. Unable to work (e.g., due to disability, work authorization) |

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A7a. What is your current employment status?

|  |
| --- |
| 1. Employed for pay (including self-employed) – 40 or more hours per week |
| 1. Employed for pay (including self-employed) – Less than 40 hours per week |
| 1. Retired |
| 1. Homemaker |
| 1. Student |
| 1. Out of work for 1 year or more |
| 1. Out of work for less than 1 year |
| 1. Unable to work (e.g., due to disability, work authorization) |

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A8. What was your total household income in 2021?

1. Less than $20,000
2. $20,001–$40,000
3. $40,001–$60,000
4. $60,001–$80,000
5. $80,001–$100,000
6. $100,001–$120,000
7. More than $120,000
8. Don’t know

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A9. What was your health insurance status when you were first diagnosed with [CANC-TYPE] cancer? Please select all that apply.

|  |
| --- |
| 1. No insurance |
| 1. Lapse in coverage |
| 1. Private health insurance (purchased on your own or from your job or from your spouse’s / partner’s / parent’s job) |
| 1. [STATE\_MEDICAID] |
| 1. Medicare/Medicare Advantage |
| 1. Military (Tricare, Champ-VA, or some other military insurance) |
| 1. Other [please specify]: [OPEN FIELD IF SELECTED] |

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A9a. What is your current health insurance status? Please select all that apply.

|  |
| --- |
| 1. No insurance |
| 1. Lapse in coverage |
| 1. Private health insurance (purchased on your own or from your job or from your spouse’s / partner’s / parent’s job) |
| 1. [STATE\_MEDICAID] |
| 1. Medicare/Medicare Advantage |
| 1. Military (Tricare, Champ-VA, or some other military insurance) |
| 1. Other [please specify]: [OPEN FIELD IF SELECTED] |

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A10. What is the highest level of school that you completed?

1. Elementary or middle school
2. 9th –12th grade but not a high school graduate
3. High school graduate or GED
4. Some college or technical school
5. College graduate
6. Post-graduate or professional degree

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A11. [NUMERIC] What was your zip code at the time of your [CANC\_TYPE] cancer diagnosis?

[OPEN – ALLOW 5-DIGIT ZIP CODE]

777777. I lived in multiple zip codes around the time of my cancer diagnosis.

888888. Don’t know

A11\_SPEC: [SHOW IF A11=777777] Please enter the zip codes where you lived.

1. [OPEN – ALLOW 5-DIGIT ZIP CODE]

2. [OPEN – ALLOW 5-DIGIT ZIP CODE]

3. [OPEN – ALLOW 5-DIGIT ZIP CODE]

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A12. Which best describes your home at the time of your diagnosis?

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 did 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):

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

A13. 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

A14. “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: HEALTH BACKGROUND

B1. Before your [CANC\_TYPE] cancer diagnosis, what condition(s) had you been diagnosed with? Select all that apply.

1. Arthritis, rheumatism, or gout
2. Benign tumors or cysts
3. Cancers other than [CANC\_TYPE] cancer
4. Chronic pain
5. Circulation problems (including blood clots)
6. Dementia or Alzheimer’s
7. Depression, anxiety, or emotional problem
8. Diabetes
9. Epilepsy or seizures
10. Fibromyalgia or lupus
11. Gastrointestinal conditions or disorders
12. Hearing problem
13. Heart problem
14. Hernia
15. Hypertension or high blood pressure
16. Kidney, bladder, or renal problems
17. Lung or breathing problem (e.g., asthma and emphysema)
18. Migraine headaches (not just headaches)
19. Multiple Sclerosis (MS) or Muscular Dystrophy (MD)
20. Osteoporosis or tendinitis
21. Parkinson’s disease or other tremors
22. Stroke
23. Thyroid problems or Graves’ disease
24. Ulcer
25. Vision problem or problem seeing
26. Weight problem
27. Other impairment or problem - Please specify one: [SHOW IF SELECTED – OPEN]
28. None of the above [EXCLUSIVE SELECT]

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B2. [IF A2=2] Have you had a hysterectomy?

1. Yes, full hysterectomy
2. Yes, partial hysterectomy
3. Yes, don’t know if full or partial hysterectomy
4. No

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B3. Have you ever tested positive for COVID-19? Select all that apply.

1. No
2. Yes, before my cancer diagnosis.
3. Yes, during my cancer treatment.
4. Yes, after my cancer treatment.

B3a. [SHOW IF B3=2, 3, OR 4] Have you ever been hospitalized due to COVID-19?

1. No
2. Yes

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B4. 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

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MODULE C: COLORECTAL

[IF A3 = 6, 7, 8, 9, 10, 11, 12 CONTINUE, ELSE GOTO D1]

C1. The next questions are about colorectal cancer screening tests.

|  |  |  |
| --- | --- | --- |
| C2. Have you ever had a test to check for colorectal cancer before your diagnosis? | **Yes** | **No** |
| **C2\_1. Stool test, except Cologuard**  [Includes several types of blood stool or occult blood test, fecal immunochemical or FIT test. You use a kit at home to collect a small amount of stool and send it back to the doctor or lab.] |  |  |
| **C2\_2. Cologuard**  [Cologuard is also a kit that you use at home to collect stool samples. The test  looks for changes in DNA in addition to checking for blood in your stool] |  |  |
| **C2\_3. Sigmoidoscopy**  [The doctor inserts a tube into the rectum to check only part of the colon and you are fully awake] |  |  |
| **C2\_4. Colonoscopy**  [The doctor inserts a tube into the rectum to check the entire colon, and you are given  medication to make you sleepy, and told to have someone take you home] |  |  |
| **C2\_5. CT Colonography or Virtual Colonoscopy**  [Unlike regular colonoscopies, you do not need medication to make you sleepy. Your colon is filled with air and you are moved through a donut-shaped X-ray machine as you lie on your back and then your stomach] |  |  |

[IF C2\_1 !=1 AND C2\_2!=1 AND C2\_3!=1 AND C2\_4!=1 AND C2\_5!=1 GOTO C7, ELSE CONTINUE]

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C3. You indicated that you had the following test(s).

[IF C2\_1 = 1] [**Stool test, except Cologuard]**

[IF C2\_2 = 1] [**Cologuard]**

[IF C2\_3 = 1] [**Sigmoidoscopy]**

[IF C2\_4 = 1] [**Colonoscopy]**

[IF C2\_5 = 1] [**CT Colonography or Virtual Colonoscopy]**

For each test, about how long has it been since your MOST RECENT test using the selected method?

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Test** | **Within past year (< 12 months ago)** | **Within past 2 years (over 1 year but < 2 years ago)** | **Within past 3 years (over 2 years but < 3 years ago)** | **Within past 5 years (over 3 years but < 5 years ago)** | **Within past 10 years (over 5 years but < 10 years ago)** | **10+ years ago** |
| C3\_1. [IF C2\_1 = 1 SHOW, ELSE SUPPRESS]  Stool test, except Cologuard |  |  |  |  |  |  |
| C3\_2. [IF C2\_2 = 1 SHOW, ELSE SUPPRESS] Cologuard |  |  |  |  |  |  |
| C3\_3. [IF C2\_3 = 1 SHOW, ELSE SUPPRESS]  Sigmoidoscopy |  |  |  |  |  |  |
| C3\_4. [IF C2\_4 = 1 SHOW, ELSE SUPPRESS]  Colonoscopy |  |  |  |  |  |  |
| C3\_5. [IF C2\_5 = 1 SHOW, ELSE SUPPRESS]  CT Colonoscopy or Virtual Colonoscopy |  |  |  |  |  |  |

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C4. What was the reason for the following test(s)?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Part of a routine exam / check-up | Because of a problem or symptom | Follow-up to a (positive) screening test | Other reason (e.g., family history, genetic predisposition) |
| C4\_1. [IF C3\_3 = 1,2,3,4,5 OR 6 SHOW, ELSE SUPPRESS] Sigmoidoscopy |  |  |  |  |
| C4\_2. [IF C3\_4 = 1,2,3,4,5 OR 6 SHOW, ELSE SUPPRESS] Colonoscopy |  |  |  |  |
| C4\_3. [IF C3\_5 = 1,2,3,4,5 OR 6 SHOW, ELSE SUPPRESS] CT Colonography or Virtual Colonoscopy |  |  |  |  |

C4\_1\_OTH. [SHOW IF C4\_1=4] Please specify the reason for your sigmoidoscopy test? [Optional] [OPEN FIELD]

C4\_2\_OTH. [SHOW IF C4\_2=4] Please specify the reason for your colonoscopy test? [Optional] [OPEN FIELD]

C4\_3\_OTH. [SHOW IF C4\_3=4] Please specify the reason for your colonography or virtual colonoscopy test? [Optional] [OPEN FIELD]

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C6. Before your diagnosis, were you able to schedule your colorectal cancer screening within a reasonable timeframe?

1. Yes
2. No

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C7. What were the top non-medical issues you faced when staying up-to-date with your colorectal cancer screening? **You may select up to 5 issues. [Programmer:** Only ask for colorectal cancer patients. Suppress C7, C7\_RANK, and C7\_FACILITATE for breast and cervical cancer patients.**]**

|  |  |
| --- | --- |
| [SELECT ALL THAT APPLY – UP TO 5] |  |
| C7\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| C7\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover or pay for care |
| C7\_3. \_\_\_ | Problems getting transportation to/from doctor's office for cancer screening |
| C7\_4. \_\_\_ | Unable to understand the doctor’s language or language of screening instructions/materials (e.g., different language without access to interpretation) |
| C7\_5. \_\_\_ | Medical information was too hard to understand |
| C7\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave) |
| C7\_7. \_\_\_ | 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) |
| C7\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| C7\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| C7\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| C7\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| C7\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status) |
| C7\_13. \_\_\_ | Afraid of the potential diagnosis, of discomfort, embarrassment, or pain associated with the screening procedure |
| C7\_14. \_\_\_ | Did not feel screening was urgent (e.g., never thought about scheduling a screening; put it off / didn’t get around to it; haven’t had any problems or symptoms) |
| C7\_15. \_\_\_ | Did not know I needed it / doctor did not say screening was needed |
| C7\_16. \_\_\_ | Other |
| C7\_17. \_\_\_ | **Did not face any issues with scheduling my colorectal cancer screening.** [EXCLUSIVE SELECT] **[Programmer:** If selected, go to C7\_FACILITATE.**]** |

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C7\_OTH. [SHOW IF C7\_16 NE BLANK] Please describe the other issue(s) that you faced when getting your colorectal cancer screening. [OPEN FIELD]

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C7\_RANK. Of the top issues you selected, please rank them, with “1” being the most important.

[NOTE: DISPLAY ONLY THE ISSUES ENDORSED IN QUESTION C7]

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| C7\_ RANK\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| C7\_ RANK\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover or pay for care |
| C7\_ RANK\_3. \_\_\_ | Problems getting transportation to/from doctor's office for cancer screening |
| C7\_ RANK\_4. \_\_\_ | Unable to understand the doctor’s language or language of screening instructions/materials (e.g., different language without access to interpretation) |
| C7\_ RANK\_5. \_\_\_ | Medical information was too hard to understand |
| C7\_ RANK\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave) |
| C7\_ RANK\_7. \_\_\_ | 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) |
| C7\_ RANK\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| C7\_ RANK\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| C7\_ RANK\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| C7\_ RANK\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| C7\_ RANK\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status) |
| C7\_ RANK\_13. \_\_\_ | Afraid of the potential diagnosis, of discomfort, embarrassment, or pain associated with the screening procedure |
| C7\_ RANK\_14. \_\_\_ | Did not feel screening was urgent (e.g., never thought about scheduling a screening; put it off / didn’t get around to it; haven’t had any problems or symptoms) |
| C7\_ RANK\_15. \_\_\_ | Did not know I needed it / doctor did not say screening was needed |
| C7\_ RANK\_16. \_\_\_ | [C7\_OTH] |

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C7\_FACILITATE. Please select the top 5 factors that made it easier to get your colorectal cancer screening on-time.

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| C7\_FACILITATE\_1 | Worked with a nurse/patient navigator who provided additional support |
| C7\_FACILITATE\_2 | Was able to afford care |
| C7\_FACILITATE\_3 | Was able to cover all my expenses like food |
| C7\_FACILITATE\_4 | Had permanent, stable housing |
| C7\_FACILITATE\_5 | Insurance covered most of my medical costs |
| C7\_FACILITATE\_6 | Easy access to transportation |
| C7\_FACILITATE\_7 | Convenient location of health care provider |
| C7\_FACILITATE\_8 | Was able to take time off work for appointment (e.g., paid sick leave, flexible work schedule, medical leave available) |
| C7\_FACILITATE\_9 | Connected to a provider by someone I know (e.g., doctor, nurse, family member, friend, others on social media) |
| C7\_FACILITATE\_10 | Was able to get an appointment with a doctor or specialist within a reasonable timeframe |
| C7\_FACILITATE\_11 | Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed |
| C7\_FACILITATE\_12 | Was treated with respect by my doctor or specialist |
| C7\_FACILITATE\_13 | Was able to understand medical information that was shared with me |
| C7\_FACILITATE\_14 | Other [please specify]: \_\_\_OPEN TEXT FIELD |

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MODULE D: CERVICAL

[IF A2=2 CONTINUE, ELSE GO TO E1]

D1. The next questions are about cervical cancer screening tests.

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|  |  |  |  |
| --- | --- | --- | --- |
| D2. There are two different kinds of tests to check for cervical cancer. One is a Pap smear or Pap test and the other is the HPV or Human Papillomavirus test. Have you ever had a test to check for cervical cancer? These are tests for women in which a doctor or other health professional takes a sample from the cervix with a swab or brush and sends it to the lab. | Yes | No | Don’t know |
| D2\_1. Pap smear or Pap test |  |  |  |
| D2\_2. HPV or Human Papillomavirus test |  |  |  |

[IF D2\_1 !=1 AND D2\_2!=1 GOTO D7, ELSE CONTINUE]

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D3. You indicated that you had the following test(s).

[IF D2\_1 = 1] [Pap smear or Pap test**]**

[IF D2\_2 = 1] [HPV or Human Papillomavirus test**]**

For each test, about how long has it been since your MOST RECENT test using the selected method?

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Test** | **Within past year (< 12 months ago)** | **Within past 2 years (over 1 year but < 2 years ago)** | **Within past 3 years (over 2 years but < 3 years ago)** | **Within past 5 years (over 3 years but < 5 years ago)** | **Within past 10 years (over 5 years but < 10 years ago)** | **10+ years ago** |
| D3\_1. [IF D2\_1 = 1 SHOW, ELSE SUPPRESS]  Pap smear or Pap test |  |  |  |  |  |  |
| D3\_2. [IF D2\_2 = 1 SHOW, ELSE SUPPRESS] HPV or Human Papillomavirus test |  |  |  |  |  |  |

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D4. What was the reason for each test?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Part of a routine exam / check-up | Because of a problem or symptom | Follow-up to a (positive) screening test | Other reason (e.g., family history, genetic predisposition) |
| D4\_1. [IF D3\_1 = 1,2,3,4,5 OR 6 SHOW, ELSE SUPPRESS] **Pap smear or Pap test** |  |  |  |  |
| D4\_2. [IF D3\_2 = 1,2,3,4,5 OR 6 SHOW, ELSE SUPPRESS] **HPV or Human Papillomavirus test** |  |  |  |  |

D4\_1\_OTH. [SHOW IF D4\_1=4] Please specify the reason for your Pap smear or Pap test? [Optional] [OPEN FIELD]

D4\_2\_OTH. [SHOW IF D4\_2=4] Please specify the reason for your HPV or Human Papillomavirus test? [Optional] [OPEN FIELD]

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D6. Before your diagnosis, were you able to schedule your cervical cancer screening within a reasonable timeframe?

1. Yes
2. No

88. Don’t know

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D7. What were the top non-medical issues you faced when staying up-to-date with your cervical cancer screening? **You may select up to 5 issues. [Programmer:** Only ask for cervical cancer patients. Suppress D7, D7\_RANK, and D7\_FACILITATE for colorectal and breast cancer patients.**]**

|  |  |
| --- | --- |
| [SELECT ALL THAT APPLY – UP TO 5] |  |
| D7\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| D7\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover or pay for care |
| D7\_3. \_\_\_ | Problems getting transportation to/from doctor's office for cancer screening |
| D7\_4. \_\_\_ | Unable to understand the doctor’s language or language of screening instructions/materials (e.g., different language without access to interpretation) |
| D7\_5. \_\_\_ | Medical information was too hard to understand |
| D7\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave) |
| D7\_7. \_\_\_ | 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) |
| D7\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| D7\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| D7\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| D7\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| D7\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status) |
| D7\_13. \_\_\_ | Afraid of the potential diagnosis, of discomfort, embarrassment, or pain associated with the screening procedure |
| D7\_14. \_\_\_ | Did not feel screening was urgent (e.g., never thought about scheduling a screening; put it off / didn’t get around to it; haven’t had any problems or symptoms) |
| D7\_15. \_\_\_ | Did not know I needed it / doctor did not say screening was needed |
| D7\_16. \_\_\_ | Had HPV vaccines and did not think screening was needed |
| D7\_17. \_\_\_ | Other |
| D7\_18. \_\_\_ | **Did not face any issues with scheduling my cervical cancer screening.** [EXCLUSIVE SELECT] **[Programmer:** If selected, go to D7\_FACILITATE.**]** |

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D7\_OTH. [SHOW IF D7\_17 NE BLANK] Please describe the other issue(s) that you faced when scheduling your cervical cancer screening. [OPEN FIELD]

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D7\_RANK. Of the top issues you selected, please rank them , with “1” being the most important.

[NOTE: DISPLAY ONLY THE ISSUES ENDORSED IN QUESTION D7]

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| D7\_ RANK\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| D7\_ RANK\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover or pay for care |
| D7\_ RANK\_3. \_\_\_ | Problems getting transportation to/from doctor's office for cancer screening |
| D7\_ RANK\_4. \_\_\_ | Unable to understand the doctor’s language or language of screening instructions/materials (e.g., different language without access to interpretation) |
| D7\_ RANK\_5. \_\_\_ | Medical information was too hard to understand |
| D7\_ RANK\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave) |
| D7\_ RANK\_7. \_\_\_ | 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) |
| D7\_ RANK\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| D7\_ RANK\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| D7\_ RANK\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| D7\_ RANK\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| D7\_ RANK\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status) |
| D7\_ RANK\_13. \_\_\_ | Afraid of the potential diagnosis, of discomfort, embarrassment, or pain associated with the screening procedure |
| D7\_ RANK\_14. \_\_\_ | Did not feel screening was urgent (e.g., never thought about scheduling a screening; put it off / didn’t get around to it; haven’t had any problems or symptoms) |
| D7\_ RANK\_15. \_\_\_ | Did not know I needed it / doctor did not say screening was needed |
| D7\_ RANK\_16. \_\_\_ | Had HPV vaccines and did not think screening was needed |
| D7\_ RANK\_17. \_\_\_ | [D7\_OTH] |

{PAGE BREAK}

D7\_FACILITATE. Please select the top 5 factors that made it easier to get your cervical cancer screening on-time.

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| D7\_FACILITATE\_1 | Worked with a nurse/patient navigator who provided additional support |
| D7\_FACILITATE\_2 | Was able to afford care |
| D7\_FACILITATE\_3 | Was able to cover all my expenses like food |
| D7\_FACILITATE\_4 | Had permanent, stable housing |
| D7\_FACILITATE\_5 | Insurance covered most of my medical costs |
| D7\_FACILITATE\_6 | Easy access to transportation |
| D7\_FACILITATE\_7 | Convenient location of health care provider |
| D7\_FACILITATE\_8 | Was able to take time off work for appointment (e.g., paid sick leave, flexible work schedule, medical leave available) |
| D7\_FACILITATE\_9 | Connected to a provider by someone I know (e.g., doctor, nurse, family member, friend, others on social media) |
| D7\_FACILITATE\_10 | Was able to get an appointment with a doctor or specialist within a reasonable timeframe |
| D7\_FACILITATE\_11 | Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed |
| D7\_FACILITATE\_12 | Was treated with respect by my doctor or specialist |
| D7\_FACILITATE\_13 | Was able to understand medical information that was shared with me |
| D7\_FACILITATE\_14 | Other [please specify]: \_\_\_OPEN TEXT FIELD |

{PAGE BREAK}

MODULE E: BREAST

[IF A2=2 OR A3=5,6,7,8,9,10,11, OR 12 CONTINUE, ELSE GOTO F1]

E1. The next questions are about breast cancer screening tests, or mammograms.

A mammogram is an x-ray taken only of the breast by a machine that presses against the breast.

Have you ever had a mammogram to check for breast cancer?

1. Yes
2. No

[IF E1 !=1 GOTO E6, ELSE CONTINUE]

{PAGE BREAK}

E2. You indicated that you had a mammogram. About how long has it been since your MOST RECENT mammogram?

1. Within past year (Less than 12 months ago)
2. Within past 2 years (over 1 year but less than 2 years ago)
3. Within past 3 years (over 2 years but less than 3 years ago)
4. Within past 5 years (over 3 years but less than 5 years ago)
5. Within past 10 years (over 5 years but less than 10 years ago)
6. 10 or more years ago

88. Don’t know

[IF E2 =88 OR 99 GOTO E6, ELSE CONTINUE]

{PAGE BREAK}

E3. What was the reason for your mammogram?

1. Part of a routine exam / check-up
2. Because of a problem or symptom
3. Follow-up to a (positive) screening test
4. Other reason (e.g., family history, genetic predisposition)

E3\_OTH. [SHOW IF E3=4] Please specify the reason for your mammogram? [Optional] [OPEN FIELD]

{PAGE BREAK}

E5. Before your diagnosis, were you able to schedule your mammogram within a reasonable timeframe?

1. Yes
2. No

{PAGE BREAK}

E6. What were the top non-medical issues you faced when staying up-to-date with your mammogram? **You may select up to 5 issues. [Programmer:** Only ask for breast cancer patients. Suppress E6, E6\_RANK, and E6\_FACILITATE for colorectal and cervical cancer patients.**]**

|  |  |
| --- | --- |
| [SELECT ALL THAT APPLY – UP TO 5] |  |
| E6\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| E6\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover or pay for care |
| E6\_3. \_\_\_ | Problems getting transportation to/from doctor's office for cancer screening |
| E6\_4. \_\_\_ | Unable to understand the doctor’s language (e.g., different language without access to interpretation) |
| E6\_5. \_\_\_ | Medical information was too hard to understand |
| E6\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave) |
| E6\_7. \_\_\_ | 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) |
| E6\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| E6\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| E6\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| E6\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| E6\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status) |
| E6\_13. \_\_\_ | Afraid of the potential diagnosis, of discomfort, embarrassment, or pain associated with the screening procedure |
| E6\_14. \_\_\_ | Did not feel screening was urgent (e.g., never thought about scheduling a screening; put it off / didn’t get around to it; haven’t had any problems or symptoms) |
| E6\_15. \_\_\_ | Did not know I needed it / doctor did not say screening was needed |
| E6\_16. \_\_\_ | Other |
| E6\_17. \_\_\_ | **Did not face any issues with scheduling my mammogram.** [EXCLUSIVE SELECT] **[Programmer:** If selected, go to E6\_FACILITATE.**]** |

{PAGE BREAK}

E6\_OTH. [SHOW IF E6\_16 NE BLANK] Please describe the other issue(s) that you faced when staying up to date with your mammogram. [OPEN FIELD]

{PAGE BREAK}

E6\_RANK. Of the top issues you selected, please rank them , with “1” being the most important.

[NOTE: DISPLAY ONLY THE ISSUES ENDORSED IN QUESTION E6]

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| E6\_RANK\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| E6\_ RANK\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover or pay for care |
| E6\_ RANK\_3. \_\_\_ | Problems getting transportation to/from doctor's office for cancer screening |
| E6\_ RANK\_4. \_\_\_ | Unable to understand the doctor’s language (e.g., different language without access to interpretation) |
| E6\_ RANK\_5. \_\_\_ | Medical information was too hard to understand |
| E6\_ RANK\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave) |
| E6\_ RANK\_7. \_\_\_ | 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) |
| E6\_ RANK\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| E6\_ RANK\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| E6\_ RANK\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| E6\_ RANK\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| E6\_ RANK\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status) |
| E6\_ RANK\_13. \_\_\_ | Afraid of the potential diagnosis, of discomfort, embarrassment, or pain associated with the screening procedure |
| E6\_ RANK\_14. \_\_\_ | Did not feel screening was urgent (e.g., never thought about scheduling a screening; put it off / didn’t get around to it; haven’t had any problems or symptoms) |
| E6\_ RANK\_15. \_\_\_ | Did not know I needed it / doctor did not say screening was needed |
| E6\_ RANK\_16. \_\_\_ | [E6\_OTH] |

{PAGE BREAK}

E6\_FACILITATE. Please select the top 5 factors that made it easier to get your mammogram on-time.

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| E6\_FACILITATE\_1 | Worked with a nurse/patient navigator who provided additional support |
| E6\_FACILITATE\_2 | Was able to afford care |
| E6\_FACILITATE\_3 | Was able to cover all my expenses like food |
| E6\_FACILITATE\_4 | Had permanent, stable housing |
| E6\_FACILITATE\_5 | Insurance covered most of my medical costs |
| E6\_FACILITATE\_6 | Easy access to transportation |
| E6\_FACILITATE\_7 | Convenient location of health care provider |
| E6\_FACILITATE\_8 | Was able to take time off work for appointment (e.g., paid sick leave, flexible work schedule, medical leave available) |
| E6\_FACILITATE\_9 | Connected to a provider by someone I know (e.g., doctor, nurse, family member, friend, others on social media) |
| E6\_FACILITATE\_10 | Was able to get an appointment with a doctor or specialist within a reasonable timeframe |
| E6\_FACILITATE\_11 | Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed |
| E6\_FACILITATE\_12 | Was treated with respect by my doctor or specialist |
| E6\_FACILITATE\_13 | Was able to understand medical information that was shared with me |
| E6\_FACILITATE\_14 | Other [please specify]: \_\_\_OPEN TEXT FIELD |

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MODULE F: DIAGNOSIS

The next few questions are about the process of getting your cancer diagnosis.

F1. Did you receive an initial misdiagnosis prior to your cancer diagnosis?

1. Yes
2. No

{PAGE BREAK}

F2. How much time passed between your first test (e.g., positive screening test or test that you had because of symptoms) and receiving your cancer diagnosis?

1. Less than 1 month
2. 1 month to under 2 months
3. 2 months to under 3 months
4. 3 months to under 6 months
5. 6 months or more

88. Don’t Know

{PAGE BREAK}

F3. What were the top non-medical issues you faced when getting your cancer diagnosis?

**You may select up to 5 issues.**

|  |  |
| --- | --- |
| [SELECT ALL THAT APPLY – UP TO 5] |  |
| F3\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| F3\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover, or pay for care |
| F3\_3. \_\_\_ | Problems getting transportation to/from doctor's office to undergo a procedure |
| F3\_4. \_\_\_ | Unable to understand the doctor’s language (e.g., different language without access to interpretation) |
| F3\_5. \_\_\_ | Medical information was too hard to understand |
| F3\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule) |
| F3\_7. \_\_\_ | 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) |
| F3\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| F3\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| F3\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| F3\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| F3\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic, gender, weight, sexual orientation, disability status discrimination) |
| F3\_13. \_\_\_ | Afraid of the potential diagnosis, or of hearing diagnosis without a loved one present |
| F3\_14. \_\_\_ | Other |
| F3\_15. \_\_\_ | **Did not encounter any issues.** [EXCLUSIVE SELECT] **[Programmer:** If selected, go to F3\_FACILITATE.**]** |

{PAGE BREAK}

F3\_OTH. [SHOW IF F3\_14 NE BLANK] Please describe the other issue(s) that you faced when getting your cancer diagnosis. [OPEN FIELD]

{PAGE BREAK}

F3\_RANK. Of the issues you selected, please rank them , with “1” being the most important.

[NOTE: DISPLAY ONLY THE ISSUES ENDORSED IN QUESTION F3]

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| F3\_RANK\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| F3\_ RANK\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover, or pay for care |
| F3\_ RANK\_3. \_\_\_ | Problems getting transportation to/from doctor’s office to undergo a procedure |
| F3\_ RANK\_4. \_\_\_ | Unable to understand the doctor’s language (e.g., different language without access to interpretation) |
| F3\_ RANK\_5. \_\_\_ | Medical information was too hard to understand |
| F3\_ RANK\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule) |
| F3\_ RANK\_7. \_\_\_ | 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) |
| F3\_ RANK\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| F3\_ RANK\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| F3\_ RANK\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| F3\_ RANK\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| F3\_ RANK\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic, gender, weight, sexual orientation, disability status discrimination) |
| F3\_ RANK\_13. \_\_\_ | Afraid of the potential diagnosis, or of hearing diagnosis without a loved one present |
| F3\_ RANK\_14. \_\_\_ | [F3\_OTH] |

{PAGE BREAK}

F3\_FACILITATE. Please select the top 5 factors that made it easier for you to get a timely cancer diagnosis.

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| F3\_FACILITATE\_1 | Worked with a nurse/patient navigator who provided additional support |
| F3\_FACILITATE\_2 | Was able to afford care |
| F3\_FACILITATE\_3 | Was able to cover all my expenses like food |
| F3\_FACILITATE\_4 | Had permanent, stable housing |
| F3\_FACILITATE\_5 | Insurance covered most of my medical costs |
| F3\_FACILITATE\_6 | Easy access to transportation |
| F3\_FACILITATE\_7 | Convenient location of health care provider |
| F3\_FACILITATE\_8 | Was able to take time off work for appointment (e.g., paid sick leave, flexible work schedule, medical leave available) |
| F3\_FACILITATE\_9 | Connected to a provider by someone I know (e.g., doctor, nurse, family member, friend, others on social media) |
| F3\_FACILITATE\_10 | Was able to get an appointment with a doctor or specialist within a reasonable timeframe |
| F3\_FACILITATE\_11 | Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed |
| F3\_FACILITATE\_12 | Was treated with respect by my doctor or specialist |
| F3\_FACILITATE\_13 | Was able to understand medical information that was shared with me |
| F3\_FACILITATE\_14 | Other [please specify]: \_\_\_OPEN TEXT FIELD |

{PAGE BREAK}

F4. Did you seek a second opinion about your cancer diagnosis?

1. Yes à Go to F4a
2. No

F4a. Were you able to receive the second opinion in a reasonable timeframe (e.g., within 3 weeks)?

1. Yes
2. No

88. Don’t know

{PAGE BREAK}

F5. How difficult was it to see a doctor about your cancer diagnosis?

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

{PAGE BREAK}

MODULE G: TREATMENT

G1. The next questions are about your cancer treatment.

Were you able to begin treatment on-schedule with your doctor’s recommendation?

1. Yes
2. No, the start of my treatment was delayed (e.g., I chose to delay, or my provider was unavailable)
3. No, I chose not to engage in medical treatment.

G1\_SPEC1. [SHOW IF G1=2] Please specify why the start of treatment was delayed (Optional): [OPEN FIELD]

G1\_SPEC2. [SHOW IF G1=3] Please specify what, if anything, you are or were doing as an alternative to medical treatment (Optional): [OPEN FIELD]

{PAGE BREAK}

G2. What were the top non-medical issues you faced during your cancer treatment?

**You may select up to 5 issues.**

|  |  |
| --- | --- |
| [SELECT ALL THAT APPLY – UP TO 5] |  |
| G2\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| G2\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover, or pay for care |
| G2\_3. \_\_\_ | Problems getting transportation to/from doctor's office for treatment |
| G2\_4. \_\_\_ | Unable to understand the doctor’s language (e.g., different language without access to interpretation) |
| G2\_5. \_\_\_ | Medical information was too hard to understand |
| G2\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave) |
| G2\_7. \_\_\_ | 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) |
| G2\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| G2\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| G2\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| G2\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| G2\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic, gender, weight, sexual orientation, disability status discrimination) |
| G2\_13. \_\_\_ | Afraid the treatment will be too painful or unpleasant |
| G2\_14. \_\_\_ | Other |
| G2\_15. \_\_\_ | **Did not encounter any issues.** [EXCLUSIVE SELECT] **[Programmer:** If selected, go to G2\_FACILITATE.**]** |

{PAGE BREAK}

G2\_OTH. [SHOW IF G2\_14 NE BLANK] Please describe the other issue(s) that you faced during your cancer treatment. [OPEN FIELD]

{PAGE BREAK}

G2\_RANK. Of the top issues you selected, please rank them , with “1” being the most important.

[NOTE: DISPLAY ONLY THE ISSUES ENDORSED IN QUESTION G2]

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| G2\_ RANK\_1. \_\_\_ | Could not afford care (e.g., cost too much; other competing expenses) |
| G2\_ RANK\_2. \_\_\_ | No insurance coverage, or insurance company would not approve, cover, or pay for care |
| G2\_ RANK\_3. \_\_\_ | Problems getting transportation to/from doctor's office for treatment |
| G2\_ RANK\_4. \_\_\_ | Unable to understand the doctor’s language (e.g., different language without access to interpretation) |
| G2\_ RANK\_5. \_\_\_ | Medical information was too hard to understand |
| G2\_ RANK\_6. \_\_\_ | Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave) |
| G2\_ RANK\_7. \_\_\_ | 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) |
| G2\_ RANK\_8. \_\_\_ | Was refused services (e.g., out of network provider, not accepting new patients) |
| G2\_ RANK\_9. \_\_\_ | Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability) |
| G2\_ RANK\_10. \_\_\_ | Could not get a friend or family member to go with me to appointment |
| G2\_ RANK\_11. \_\_\_ | Took too long to get an appointment that worked for my schedule |
| G2\_ RANK\_12. \_\_\_ | Experienced discrimination (e.g., racial or ethnic, gender, weight, sexual orientation, disability status discrimination) |
| G2\_ RANK\_13. \_\_\_ | Afraid the treatment will be too painful or unpleasant |
| G2\_ RANK\_14. \_\_\_ | [G2\_OTH] |

{PAGE BREAK}

G2\_FACILITATE. Please select the top 5 factors that made it easier to get medical care for your cancer treatment.

|  |  |
| --- | --- |
| [NUMERIC RESPONSE – UP TO 5] | [NUMERIC RESPONSE – UP TO 5] |
| G2\_FACILITATE\_1 | Worked with a nurse/patient navigator who provided additional support |
| G2\_FACILITATE\_2 | Was able to manage side effects |
| G2\_FACILITATE\_3 | Was able to afford care |
| G2\_FACILITATE\_4 | Was able to cover all my expenses like food |
| G2\_FACILITATE\_5 | Had permanent, stable housing |
| G2\_FACILITATE\_6 | Insurance covered most of my medical costs |
| G2\_FACILITATE\_7 | Easy access to transportation |
| G2\_FACILITATE\_8 | Convenient location of health care provider |
| G2\_FACILITATE\_9 | Was able to take time off work for appointments and care (e.g., paid sick leave, flexible work schedule, medical leave available) |
| G2\_FACILITATE\_10 | Connected to a provider by someone I know (e.g., doctor, nurse, family member, friend, others on social media) |
| G2\_FACILITATE\_11 | Was able to get an appointment with a doctor or specialist within a reasonable timeframe |
| G2\_FACILITATE\_12 | Was able to make arrangements for dependent care (e.g., for child, elderly relative, or relative with a disability), if needed |
| G2\_FACILITATE\_13 | Was treated with respect by my doctor or specialist |
| G2\_FACILITATE\_14 | Was able to understand medical information that was shared with me |
| G2\_FACILITATE\_15 | Other [please specify]: \_\_\_OPEN TEXT FIELD |

{PAGE BREAK}

G3. Have you experienced any of the following challenges in accessing cancer care or treatment due to the COVID-19 pandemic? Please select all that apply.

1. I had a hard time getting an appointment because of limited appointments or clinic availability.
2. I didn’t go to an appointment because it was only available by telephone or video call.
3. I didn’t go to an appointment because I was worried about exposure to COVID-19.
4. I didn’t go to an appointment because I tested positive for COVID-19.
5. I couldn’t get to an appointment because my caregiver was not able to come with me (e.g., due to contact restrictions, not wanting to be exposed to COVID-19, or caregiver was an essential worker and unable to take time off work).
6. My appointment was postponed.
7. My appointment was cancelled.
8. I had challenges getting my cancer prescriptions filled.
9. Other challenges – Please specify: [SHOW OPEN FIELD IF SELECTED]
10. I have not experienced any challenges in getting timely cancer care and treatment. [EXCLUSIVE]

{PAGE BREAK}

G4. What precautions did your provider take while you received treatment during the pandemic? Select all that apply.

1. Required masks
2. Added hand sanitizer to waiting room and/or exam rooms
3. Put social distancing measures in place in waiting room
4. Limited number of family members who could accompany me to appointments
5. Closed the waiting room (patients check in by phone)
6. Limited number of patients in the office at the same time/reduced number of daily appointments
7. Required COVID screening (e.g., temperature check, symptom screener) prior to entering building for treatment
8. Added air purifiers to treatment room(s)
9. Extended access to clinical staff (e.g., 24/7 nurses’ line, weekend office hours) to prevent emergency department visits due to side effects
10. Required all clinic staff to be up-to-date with COVID vaccination
11. Offered telehealth visits
12. Other – Please specify: [SHOW IF SELECTED – OPEN]

88. Don’t know [EXCLUSIVE]

{PAGE BREAK}

G5. Were there any precautionary measures for COVID-19 that were a barrier to you receiving treatment? [**PROGRAMMER**: SKIP if G4\_88=1]

1. Yes
2. No

G5.\_SPEC [SHOW if G5=1 ] Please describe your experience (optional): [OPEN FIELD]

{PAGE BREAK}

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| G6. Below is a list of statements that other people with your illness have said are important. Please select your response to the following statement as it applies to the **past 7 days**. | **1 – Not at all** | **2 – A little bit** | **3 – Some-what** | **4 – Quite a bit** | **5 – Very much** |
| G6\_1. I have a lack of energy. |  |  |  |  |  |
| G6\_2. I have pain. |  |  |  |  |  |
| G6\_3. I have nausea. |  |  |  |  |  |
| G6\_4. I worry that my condition will get worse. |  |  |  |  |  |
| G6\_5. I am sleeping well. |  |  |  |  |  |
| G6\_6. I am able to enjoy life. |  |  |  |  |  |
| G6\_7. I am content with the quality of my life right now. |  |  |  |  |  |

{PAGE BREAK}

G7. 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 – Please specify: [SHOW OPEN FIELD IF SELECTED]
11. I have not received any medical treatment for cancer [EXCLUSIVE]

{PAGE BREAK}

G8. Please select whether you have completed the following treatment(s) for your [CANC\_TYPE] cancer. [**Programmer:** For all treatment modalities selected in G7, add a column of yes/no responses, indicating they have completed or not completed treatment.

Do not show this question to any who answered G7\_11]

|  |  |  |  |
| --- | --- | --- | --- |
|  | Completed treatment? | | |
|  | Yes | No | Don’t know |
| IV Chemotherapy | o | o | o |
| Oral Chemotherapy | o | o | o |
| Radiation | o | o | o |
| Surgery | o | o | o |
| Immunotherapy (e.g., interferon or cancer vaccines) or another biological therapy (e.g., Car-T, Gleevec, Iressa, Tarceva, Herceptin, or Erbitux) | o | o | o |
| Hormonal therapy (e.g., Tamoxifen, Adjuvant, Zoladex, Lupron) | o | o | o |
| Precision medicine / targeted therapy (using medication to target specific genes and proteins of the cancer) | o | o | o |
| Bone marrow or stem cell transplant | o | o | o |
| Complementary and alternative therapy (e.g., acupuncture, reiki) | o | o | o |
| Other – Please specify: [SHOW OPEN FIELD IF SELECTED] | o | o | o |

{PAGE BREAK}

G9. When choosing a treatment course for your cancer, did you consider the costs of specific treatments?

1. Yes, a great deal
2. Yes, somewhat
3. No, not at all

{PAGE BREAK}

G10. How would you describe your reaction to the money you spent or you are spending for cancer treatment?

I spent/am spending…

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

{PAGE BREAK}

G11. Overall, how informed did you feel about the potential side effects from treatment?

1. Very
2. Somewhat
3. Not at all

G11.\_OPEN [SHOW if G11=1 OR 2 OR 3] Please describe your experience (optional): [OPEN FIELD]

{PAGE BREAK}

G12. In general, 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

G12.\_OPEN [SHOW if G12=1 OR 2 OR 3 OR 4] Please describe your experience (optional): [OPEN FIELD]

{PAGE BREAK}

G13. In general, 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

G13.\_OPEN [SHOW if G13=1 OR 2 OR 3 OR 4] Please describe your experience (optional): [OPEN FIELD]

{PAGE BREAK}

MODULE H: CONTACT

{PAGE BREAK}

H1a. We will be conducting 1-hour phone /online interviews with a subset of individuals diagnosed with or living with cancer who complete this survey and are willing to volunteer their time.  The purpose of the interview is to learn more about your experiences from cancer screening through treatment and beyond. Would you like to be considered to participate in a 1-hour phone/online interview?

1. Yes

2. No

{PAGE BREAK}

H1b.  [SHOW IF H1a=1] Please provide your phone number: [OPEN]

H1c. [SHOW IF H1a=1] Please provide your e-mail address: [OPEN]

H1d. Please retype the email address for confirmation: [OPEN]

EMAIL\_CHK2.  [IF H1c != H1d: The email address that you provided does not match. Please click [Next] to make any corrections.]

{PAGE BREAK}

H1e. The support of a caregiver during your cancer journey can be important. A person in this role typically provides ongoing support at multiple times during your cancer treatment.

If you had someone who fits this description, may we contact them about participating in a brief survey? The survey will ask about their experience providing care. Caregivers must be 18 years of age or older to participate in the survey. They will receive $40 for completing the survey.

1. Yes
2. No

{PAGE BREAK}

H2. Please provide the name, address, and email-address for this caregiver.

H2\_1. Name: [OPEN]

H2\_2. Street address line 1: [OPEN]

H2\_3. Street address line 2: [OPEN]

H2\_4. City [OPEN]

H2\_5: State: [OPEN]

H2\_6: Zip code [OPEN – ALLOW 5-DIGIT ZIP CODE]

H3: E-mail address: [OPEN]

H4: Please retype the email address for confirmation: [OPEN]

[IF H3 != H4: The email address that you provided does not match. Please click [Next] to make any corrections.]

{PAGE BREAK}

H5\_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

{PAGE BREAK}

H6. [IF H5\_INCENT = 2] Please enter your contact information so that we may send you a $40 check.

H6\_1. Name: [OPEN]

H6\_2. Street address line 1: [OPEN]

H6\_3. Street address line 2: [OPEN]

H6\_4. City [OPEN]

H6\_5: State: [OPEN]

H6\_6: Zip code [OPEN – ALLOW 5-DIGIT ZIP CODE]

[POST LOGIC: GO TO END]

{PAGE BREAK}

H6: [IF H5\_INCENT=1] Please enter your e-mail address for the $40 electronic gift card: [OPEN]

H7: Please retype the email address for confirmation: [OPEN]

[IF H6 != H7: The email address that you provided does not match. Please click [Next] to make any corrections.]

{PAGE BREAK}

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. We may contact you again to complete another brief follow-up survey. Please click [SUBMIT] to submit your responses.

[END SURVEY– REDIRECT TO COMPLETE]

{PAGE BREAK}