

ATTACHMENT 5A

Survivor Interview Guide

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Survivor in-depth interview guide

SDOH Survivor Interview Guide

Introduction

Thank you for taking the time to speak with me today. We would like to learn more about your experiences as a cancer survivor – from screening to diagnosis, treatment, and follow-up visits to the doctor. We would like to talk about challenges that you have had along the way.

We have planned for a 45-60-minute call. With your permission, we would like to record the Zoom session to back up our notes. The recording will include both audio and video unless you turn your camera off. If you prefer not to be recorded on video, please feel free to turn off your camera at any time during the session. Turning off your camera does not preclude you from participating in the study, and you will still be audibly recorded if you have provided permission. Your name and the recording will not be shared with anyone outside of the core survey team who will analyze the findings. Your responses will be grouped together with responses we get from other survivors to identify common challenges that survivors have faced in addition to solutions that can be implemented to reduce cancer disparities. These findings will be shared with CDC and other organizations that support cancer patients and survivors.

Please keep in mind that there are no right or wrong answers. Your participation in this interview is voluntary, and you can skip a question or stop me at any point. Joining this study has no more risks than everyday use of the phone or video calls. Some of the interview questions may be upsetting, but you don't have to answer them. Protections are in place to keep your data as safe as possible. Do you have any questions before we begin?

Do I have your permission to start recording the interview?

[If yes, start recording]

For this interview, we will be asking follow-up questions to your initial survey to learn more about your specific experiences in obtaining care. As a note, depending on your age and sex, you may have not answered all of the survey questions we will be asking about today.

1. In your survey, you indicated that the following were the top issues you faced in receiving screening for colorectal cancer OR breast cancer OR cervical cancer. *[Interviewer, please determine top 3 issues for specific cancer addressed based on survey responses.]*

[insert cancer type]	Issues
	Could not afford care (e.g., cost too much; other competing expenses)
	No insurance coverage, or insurance company would not approve, cover or pay for care
	Problems getting transportation to doctor's office for cancer screening
	Unable to understand the doctor's language or language of screening instructions/materials (e.g., different language without access to interpretation)
	Medical information was too hard to understand
	Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave)
	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)
	Was refused services (e.g., out of network provider, not accepting new patients)
	Couldn't get dependent care (e.g., for child, elderly relative, or relative with a disability)
	Could not get a friend or family member to go with me to appointment
	Took too long to get an appointment that worked for my schedule
	Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status)
	Afraid of the potential diagnosis, of discomfort, embarrassment, or pain associated with the screening procedure
	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)
	Did not know I needed it / doctor did not say screening was needed
	Other
	Did not face any issues with scheduling my screening*

[Probes]

Can you tell me more about why [ISSUE 1] was the most difficult for you?

How did you deal with this barrier to screening?

Repeat for each screening barrier

*confirm that interviewee did not have any barriers

[If barriers during screening not reported] In your survey, you indicated that you did not face any barriers related to [colorectal cancer OR breast cancer OR cervical cancer] screening(s). Can you please share what helped facilitate a smooth process (e.g., got appointment in timely manner, access to transportation, had health insurance/ability to pay for doctor's visit/screening test, had paid sick leave)?

2. [If barriers during diagnosis reported] In your survey, you indicated that the following were the top issues you faced when being diagnosed with [colorectal cancer OR breast cancer OR cervical cancer].
[Interviewer, please determine top 3 issues from the survey responses]

[insert cancer type]	Issues
	Could not afford care (e.g., cost too much; other competing expenses)
	No insurance coverage, or insurance company would not approve, cover, or pay for care
	Problems getting transportation to doctor's office to undergo a procedure
	Unable to understand the doctor's language (e.g., different language without access to interpretation)
	Medical information was too hard to understand
	Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule)
	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)
	Was refused services (e.g., out of network provider, not accepting new patients)
	Couldn't get dependent care (e.g., for child, elderly relative, or relative with a disability)
	Could not get a friend or family member to go with me to appointment
	Took too long to get an appointment that worked for my schedule
	Experienced discrimination (e.g., racial or ethnic, gender, weight, sexual orientation, disability status discrimination)
	Afraid of the potential diagnosis, or of hearing diagnosis without a loved one present
	Other
	Received a timely diagnosis / did not encounter any issues *
	Prefer not to answer

[Probes]

Could you tell me more about why [ISSUE 1] was the most difficult for you? How did you deal with this barrier?

Can you provide examples about how you dealt with these other barriers?

Repeat for each diagnosis barrier

*confirm that interviewee did not have any barriers

[If barriers during diagnosis not reported] In your survey, you indicated that you did not face any barriers during your [colorectal cancer OR breast cancer OR cervical cancer] diagnosis. Can you please share what helped facilitate a smooth process (e.g., got appointment in timely manner, caregiver available for appointment, access to transportation, had health insurance/ability to pay for doctor's visit/procedure, had paid sick leave)?

3. In your survey, you indicated that the following were the top issues you faced in being treated for [colorectal cancer, breast cancer and cervical cancer]. *[Interviewer, please determine top 3 issues from the survey responses.]*

[insert cancer type]	Issues
	Could not afford care (e.g., cost too much; other competing expenses)
	No insurance coverage, or insurance company would not approve, cover, or pay for care
	Problems getting transportation to doctor's office for treatment
	Unable to understand the doctor's language (e.g., different language without access to interpretation)
	Medical information was too hard to understand
	Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave)
	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)
	Was refused services (e.g., out of network provider, not accepting new patients)
	Couldn't get dependent care (e.g., for child, elderly relative, or relative with a disability)
	Could not get a friend or family member to go with me to appointment
	Took too long to get an appointment that worked for my schedule
	Experienced discrimination (e.g., racial or ethnic, gender, weight, sexual orientation, disability status discrimination)
	Afraid the treatment will be too painful or unpleasant
	Other
	Did not encounter any issues*

	Prefer not to answer
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[Probes]

Could you tell me more about why [ISSUE 1/] was the most difficult for you? How did you deal with this barrier?

Repeat for each treatment barrier

*confirm that interviewee did not have any barriers

[If barriers during treatment not reported] In your survey, you indicated that you did not face any barriers during your [colorectal cancer OR breast cancer OR cervical cancer] treatment. Can you please share what helped facilitate a smooth process (e.g., patient navigator, health care facility located nearby, caregiver available for appointments, access to transportation, had health insurance/ability to pay for treatment, had paid sick leave)?

4. [If faced any barriers] Of all the barriers you have faced, from screening through after care, which barrier was the most challenging for you?

Probes: Were you able to overcome it? How?

[If no barriers faced] What do you think was the single greatest contributor to you having consistent access to care from screening through diagnosis, treatment, and follow-up visits?

Now, thinking specifically about your cancer treatment, I would like to ask a few more questions.

**build on responses to previous questions as you address the next three questions on cancer treatment*

5. Has your [employment status/insurance/housing/transportation/food insecurity/lack of paid sick leave] affected your ability to be treated for cancer?

[Probes]

What could have made accessing your cancer treatment easier?

Has anyone shared potential solutions to these barriers with you?

6. How did cost affect your decisions about your cancer treatment? (e.g., timing of treatment, type of treatment(s))

[Probes]

Did you choose an alternative treatment due to cost? Or decline a treatment due to cost?

Did you prolong or delay treatment due to cost?

7. Thinking about the doctor – and their staff - you spent most time with during cancer treatment, did you feel that they treated you respectfully? If no, could you talk about why you felt they did not?

[Probes]

Did they spend enough time with you?

Did they answer all of your questions?

Did they allow you to speak and ask questions?

Did they talk to you in a way you could understand?

Did they treat you with empathy?

How could they have made your experience better?

Now, I would like to ask you a couple of questions about follow-up care you received after your initial cancer treatment. "Follow-up care" could include plastic surgery, long-term hormonal therapy, physical therapy or other medical care that typically follows surgery, radiation, or chemotherapy.

8. Did [employment status/ insurance/ housing/ transportation/ food insecurity/lack of paid sick leave] affect your ability to receive follow-up care after your initial cancer treatment?

[Probes]

What could have helped you have a better experience?

Has anyone shared potential solutions to these barriers with you?

Closing: Is there anything else you would like to discuss before we end the interview?

Wrap-up: Thank you for your time!