

ATTACHMENT 7A

Patient and Survivor Advocacy Organizations – Focus Group Guide

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Advocacy group focus group guide

Introduction

Thank you for taking the time to participate in this focus group. We are interested in learning about your experiences as a representative of various advocacy groups and community groups for persons with cancer. The purpose of the focus group is to learn about any barriers to care, particularly social determinants of health, from screening and diagnosis to treatment and aftercare your members may have encountered. We'd like to hear any ways your members may have dealt with these difficulties. We are also interested in learning about approaches to overcome barriers identified.

We have planned for a 45-60-minute call. With your permission, we would like to record the Zoom session. 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 responses will be summarized and shared with CDC and other stakeholders to better understand any challenges your members have had in receiving cancer care, including screening, treatment, follow-up appointments and visits to the doctor. No identifying information will be shared.

Do I have your permission to start recording the interview?

[If yes, start recording]

Please keep in mind that there are no right or wrong answers. This focus group is voluntary, and you can stop me at any point. Joining this study has no more risks than everyday use of the phone or video calls. Some of the focus group 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?

1. We are interested in starting our discussion by talking about factors that made it difficult for your members to get their cancer diagnosis. In your experience, could you talk about the main issues that your members face in getting a timely cancer diagnosis?
 - a. [Probe – if silence or uncertainty] For example, if they were misdiagnosed. Or if they had trouble getting to their appointments, do not have stable housing, or have limited funds to pay for medical care.
2. Now let's talk about factors that made it difficult for your members to find a cancer doctor after diagnosis. What are some of the main barriers your members have experienced when identifying providers for their cancer care?

- a. [Probe-if silence or uncertainty] For example, finding a provider who speaks their language? Finding a provider who is accepting new patients? Finding a provider whose office they can easily get to?
- b. [Probe – for the factors that are not mentioned] What about their employment status (e.g., work schedule, flexibility to get time off for doctor's visit), insurance status, or _____? How do these barriers impact your members' ability to find a doctor to be treated for cancer?

Factors for interviewer to probe on:

- *Employment status*
- *Insurance status/coverage and cost of treatment*
- *Housing, housing stability*
- *Transportation*
- *Food insecurity*
- *Inability to get time off work*
- *Difficulty finding child or elderly parent care*
- *Fear*

- c. [Probe]: Have your members been able to overcome these barriers to establish care with an oncologist? If so, how? What resources were helpful? Are these resources that your organization provides?

3. We've talked about a few great examples [insert responses from question 1 here] of barriers your members have faced when being diagnosed with cancer and identifying a cancer provider. Are those the same or different as factors that might have affected their ability to be treated for cancer?

- a. [Probe- if silence or uncertainty] For example, you mentioned that _____ impacted patients' ability to get a timely diagnosis or find a doctor for treatment. Does this also affect your members' ability to be treated for cancer?

Factors for interviewer to probe on:

- *Employment status*
- *Insurance status/coverage and cost of treatment*
- *Housing, housing stability*
- *Transportation*
- *Food insecurity*
- *Inability to get time off work*
- *Difficulty finding child or elderly parent care*
- *Fear*
- *Any other factors mentioned in question 1*

- b. [Probe]: Have your members been able to overcome these barriers? If so, how? What resources were helpful? Are these resources that your organization provides?

4. Have your members talked with you about their experiences with their cancer doctors? If so, what concerns have they talked about?

- a. [Probe – if silence or uncertainty] For example, have members talked about their doctors not spending enough time with them? Or not treating them with respect?
- b. [Probe] Have members talked about their doctors not answering all of their questions? Or providing them with insufficient answers? Or not giving them room to talk or ask questions?
- c. [Probe] Have members had difficulty with their doctors not talking to them in a way that they could understand? Using jargon or terms that were difficult to understand? Or not being spoken to in their native language (and without access to an interpreter)?

[Probe]: Have your members been able to overcome these barriers? If so, how? How have you helped your members overcome these challenges?

5. How have the barriers we have discussed - for example, [insert examples from question 2] - impacted your members' ability to get health care after their active cancer treatment [during survivorship]?
 - a. [Probe- if silence or uncertainty] For example, you mentioned that _____ impacted patients' ability to be treated for cancer. Does this also affect your members' ability to be receive health care after their cancer treatment?

Factors for interviewer to probe on:

- *Employment status*
- *Insurance status/coverage and cost of care*
- *Housing, housing stability*
- *Transportation*
- *Food insecurity*
- *Inability to get time off work*
- *Difficulty finding child or elderly parent care*
- *Fear*
- *Any other factors mentioned in question 1 or 3*

- b. [Probe]: Have your members been able to overcome these barriers? If so, how? What resources have been helpful? Are these resources that your organization provides?

[Probe]: What is your role in removing barriers and facilitating access to care after your members received active cancer treatment (e.g., chemo, radiation, surgery)?

6. Are there any other factors or issues not discussed today that can impact receipt of quality cancer care and the health care of individuals who have completed active cancer care?

Closing: Is there anything else anyone would like to discuss before we end the focus group?

Thank you for your time.