

National Cancer Institute Environmental Scan

Caregiver Discussion Guide

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INTRODUCTION FOR RESPONDENTS

Thank you very much for agreeing to participate in this discussion. My name is ____ and I work for a third-party marketing company called Heartbeat. We are conducting an interview on behalf of the National Cancer Institute (NCI) to better understand the available types of cancer-related information as well as the most helpful ways of sharing this information.

The focus of today's call is to understand the type of cancer information you have sought over the course of your journey since your loved one was diagnosed with cancer, where you turned to find this information, and how you accessed it.

Before we start, can you please confirm that you received the image that was sent to you prior to this call? Secondly, how do you like to be referred to?

I want to review a few quick things with you before we get started so you know what to expect:

- This interview will last about 30-45 minutes.
- Participation is voluntary and there are no penalties for not participating or withdrawing at any time. Refusal to participate will not affect your benefits in any way.
- The information collected will be kept private to the extent provided by law. Names and other identifiers will not appear in any report. Information provided will be combined for all participants and reported as summaries.
- We will be recording audio from the interview. Only Heartbeat and NCI staff who are associated with this project will hear the recording, and we will not include your name or personal information in the recording. The recordings are a memory aid for me so I can go back later to recall what happened during each interview. Are you okay if we record this conversation? *(If yes, start recording. If no, do not record.)*
- Some people from my team and from the NCI may be listening in remotely to take notes and record your comments. Your honest and candid feedback will be very valuable, so even though people may be listening in, please speak openly about your opinions and experiences. There are no wrong responses to the questions I'll be asking.
- If you do not want to answer any of my questions, you do not have to. Please just say so, and we will move on. And of course, you can stop at any time.

Do you have any questions before we begin?

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Warm Up Question

Can you share with me a little bit about your role in helping your loved one who has cancer?

- Probe around educational level and past experience with the health care system.
- Probe around the nature of the relationship, cancer type, who made the first diagnosis, symptom presentation, timing, treatment (if applicable), where the patient receives care, the care team, their role in care decisions and their role in the search for information.

Seeking Content/Information Questions

1. Let's talk a little about information you looked for along the way. What type of information did you seek at each point, for example, starting at diagnosis and moving forward. What questions did you have at each stage that you sought to answer?
 - Probe around supportive care information needs, treatment related questions, treatment outcomes, unanswered questions and if the caregiver felt supported.
2. What information was your [caregiver's reference for the patient]'s doctor or their office able to provide to answer those questions for themselves? What specific support did they provide to you as the caregiver?
 - Probe around specific materials and recommended websites.
3. Beyond asking the doctor, where else did you look for information to answer the questions you had at each stage in the journey?
 - Probe around search engine and terms used.
4. How do you look for health information online?
 - Probe around device, the situation, and formats (i.e. web, video, print, podcast, live classes/talks, blogs, social media).
5. What websites did you find most useful, and why? Which did you feel were least useful?
 - Probe around trustworthiness and breadth.

Cancer.gov and PDQ Familiarity

Cancer.gov

- Are you familiar with Cancer.gov, which is the National Cancer Institute's website? [If not, skip to Question 8.]
 - Probe: Can you please open the file that was sent to you prior to this call? Is this the website you were referring to in your previous response?
 - Roughly, how often would you say you visit it? (Probe: daily, weekly, monthly, infrequently, etc.)
 - Would you consider Cancer.gov to be a trusted source of information? Why or why not?
6. How did you learn about Cancer.gov – for example, was it through seeking information on the Internet or did your doctor recommend going there as a resource?
 7. What type of information or questions were you trying to address using the information you found on Cancer.gov?
Probe:
 - How useful was the information you found on Cancer.gov?
 - To what extent did you find Cancer.gov to be credible? Do you feel this source is trustworthy? Did you find it comprehensive? Please explain your response.
 - At what point in the journey did you find Cancer.gov most helpful?

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Future Engagement Methods and Technologies

8. Describe your use of technology in everyday life.
 - Probe around mobile devices, wearables, internet enabled devices in the home.
9. To what extent are you active on social networks? Which ones? What do you use each for?
 - Probe around use for health education, patient support groups.
10. Describe how frequently you use podcasts and videos to educate yourself on any topic.
 - Probe around the speaker, sponsor, method of access and motivation.
11. Is there technology or social media that would be helpful to you as a caregiver that you use or that you would like to be using? Describe it.

Closing Question

12. What else would you like to share about finding information about cancer and cancer treatment?
13. What is the highest level of school you have completed? (i.e. high school, college or post grad)
(Note to facilitator: If the answer is unclear, probe for clarity)

This concludes our interview. Do you have any more questions for me?

Your input is extremely helpful and will be used to help us make our programs stronger. Thank you again for your time.