

## **SEPSIS EDUCATIONAL EFFORT - MODERATOR'S GUIDE CONSUMERS - SEPSIS SURVIVORS AND THEIR CAREGIVERS**

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### **I. WELCOME, OVERVIEW, AND RULES [5 MINUTES]**

Welcome and thank you for agreeing to participate in this focus group. My name is [NAME] and my role is to guide the discussion. I'm not an expert in the topic we'll discuss, so I have no particular agenda or point of view. I work for ICF, a private research organization. The Centers for Disease Control and Prevention (CDC) is sponsoring this health communication initiative. I did not develop any of the messages you will be seeing, so I want to get your honest and frank opinions about them.

The purpose of this focus group is to hear your views and opinions on important health topics concerning sepsis. We will also ask for your feedback on a few materials. Your insights are very important to us, and CDC will use your feedback to improve the materials you will see. Your time today is appreciated. We will have about an hour for our discussion.

Before we begin, I want to point a few things out:

- Most importantly, there are no “right” or “wrong” answers to the questions I’m going to ask. Please relax and enjoy the discussion.
- We are recording this discussion to ensure that we capture all the information that is provided. I want to give you my full attention and not have to take a lot of notes. At the end of our discussion, I have to write a report and will refer to the recording when writing the report.
- Also, some of the people working on this project are observing or listening to this discussion
- Everything you have to say will be kept private and any identifying information will be removed from reports and other data. While those of us here today know your name, only the recruitment team/facility knows your address and phone number, and this information will not be given to anyone and no one will contact you after this focus group is over.
- Information learned from these discussions may be presented in documents or materials like reports, conference presentations or posters, or publications. The information may also be shared with other health departments and organizations working to improve sepsis to areas assist with their efforts. Please know that the information you share will not be linked to your name or any other identifying information.
- If at any time you are uncomfortable with my questions, you can choose not to answer. Simply let me know that you prefer not to answer. Your participation in this project is completely voluntary.
- Be sure to only use first names during the discussion or use a made-up name, if you prefer. Please do not use your last name. Also, if you bring up a friend or other person you know as an example in our discussions, please do not use their last name either. So, whenever you mention a name, it should only be a first name and never a last name.

Finally, a few requests before we begin:

Public reporting burden of this collection of information is estimated to average 60 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 0920-0572

- Please respect the other participants' opinions.
- Please maintain privacy - what is said here remains here.
- Please speak one at a time.
- Please turn off your cell phone or put it in vibrate or silent mode.

And as mentioned when you were recruited to participate, you will receive a token of appreciation for participating. At the end, there will be a few minutes to address questions you may have about sepsis with a CDC team member.

Do you have any questions before we get started?

*Begin recording and ask:*

We are now recording this session. I want to ask you again:

- Do you agree to participate in this interview?
- Do you agree to being recorded?

Alright, let's get started. I'd like to go around and have everyone introduce themselves. Please tell me your first name. I'll go first.

## **II. SEPSIS EXPERIENCE AND SOURCES OF INFORMATION ABOUT SEPSIS [10 MINUTES]**

Nice to meet you all. Let's get started. First, I'm going to ask you a few questions about your sepsis experience and where you go to get health information.

- 1. You've all been invited here because you are either sepsis survivors or are the caregiver of a sepsis survivor. Can you tell us more about your experience with sepsis?**
  - PROBE: What did you know about sepsis before your/the sepsis survivor's diagnosis?
  - PROBE: What have you learned about sepsis since your/the sepsis survivor's diagnosis?
  - PROBE: How would you define sepsis?
  - PROBE: What are the signs and symptoms?
  - PROBE: Where did you get your information about sepsis?
  - PROBE: How has life changed for you (if at all) since your/the sepsis survivor's sepsis diagnosis?
  - PROBE: What information was helpful to you before, during, and after your sepsis experience?
  - PROBE: What do you wish you would have known/what information/resources would have been helpful to you before, during, and after your sepsis experience?
- 2. Do you think you/the sepsis survivor are at high-risk for sepsis again? What concerns, if any, do you have about your/the sepsis survivor's risk of developing an infection and/or sepsis again?**
- 3. What would you do if you suspected you/the sepsis survivor had another infection?**
  - PROBE: What steps would you take if you/the sepsis survivor had an infection that was not getting better or was getting worse?
- 4. What do you want to tell people about sepsis?**

- PROBE: How would you tell high-risk individuals to prevent infections that can lead to sepsis?
  - PROBE: What would you tell sepsis survivors to expect after they've recovered from sepsis?
5. **Have you actively looked for information about infections and sepsis within the last 3 months? Where did you go to look for this information and why did you go there?**
  6. **Have you ever seen, heard, or read any TV, radio, or online advertising about *Get Ahead of Sepsis*?**
  7. **Have you ever seen this logo before?**
    - PROBE: **[If yes]** Where have you seen or heard about *Get Ahead of Sepsis*?
      - On TV?
      - On Social media?
      - Through e-mail?
      - On a website?



**KNOW THE RISKS. SPOT THE SIGNS. ACT FAST.**



- PROBE: If so, where have you seen this logo?

### **III. MATERIAL TESTING [35 MINUTES]**

Thank you all so much for the information you've shared so far. Now, I'd like to share some materials with you and get your feedback.

#### **"Protect Yourself and Your Family from Sepsis" Fact Sheet [17.5 MINUTES]**

I'd like to share a fact sheet with you. Please take a few minutes to read through it before we discuss it. It's ok if you don't finish reading it all. (Provide 3-4 minutes to read)

8. **What is your general reaction to this fact sheet?**
  - PROBE: Would you have liked a material like this when you/the sepsis survivor were diagnosed?
  - PROBE: Who would you expect to receive it from?
9. **Is the information in the fact sheet new or something you've heard before? (HMTS 12d) What was the new information to you?**
10. **What information, if any, is confusing, unclear, or hard to understand? (HMTS 6d)**
  - PROBE: Were there any words that were unusual or unfamiliar? (HMTS 4d)
  - PROBE: Do you have any suggestions for making it easier to understand?
11. **Would you take time to read it if a healthcare professional gave it to you? If you saw it online? Why or why not?**
12. **Is there anything you want to know that the fact sheet doesn't tell you? (HMTS 29d)**
  - PROBE: What additional questions (if any) does the fact sheet bring up for you but does not answer?

Now, I have a few questions about the motivational aspects of the fact sheet.

- 13. Do you think you can do/help the sepsis survivor do what the fact sheet recommends? Why or why not?**
- 14. Does the fact sheet motivate you to learn more about sepsis and how to prevent infections? Why or Why not?**

Next, I have a few questions about the visual aspects of the fact sheet.

- 15. What do you think about the overall design?**
  - PROBE: “Signs and symptoms” graphic? Image? Colors/font? Format of the information within the material? What do you like/don’t like?
- 16. Would it catch your attention if you saw it somewhere? Would you stop to read it?**
  - PROBE: What about this fact sheet, if anything, grabs your attention?
- 17. Where would you expect to receive or find this fact sheet?**
  - PROBE: At a healthcare professional’s office? On social media?
- 18. Would another type of material with this information be more helpful? If so, what type and why would that format be more helpful?**
  - PROBE: What about a poster at your/the sepsis survivor’s healthcare professional’s office?
  - PROBE: What about a message on the TV at your/the sepsis survivor’s healthcare professional’s office?
- 19. Any other comments you would like to make about this fact sheet before we move on to the next material? (HMTS 43e)**
  - PROBE: Likes? Dislikes? Additional suggestions for improvement?

### **“Life After Sepsis” Fact Sheet [17.5 MINUTES]**

I’d like to share another fact sheet with you. Please take a few minutes to read through it before we discuss it. It’s ok if you don’t finish reading it all. (Provide 3-4 minutes to read)

- 20. What is your general reaction to this fact sheet?**
  - PROBE: Would you have liked a material like this when you were diagnosed?
  - PROBE: Who would you expect to receive it from?
- 21. Is the information in the fact sheet new or something you’ve heard before? (HMTS 12d) What was the new information to you?**
- 22. What information, if any, is confusing, unclear, or hard to understand? (HMTS 6d)**
  - PROBE: Were there any words that were unusual or unfamiliar? (HMTS 4d)
  - PROBE: Do you have any suggestions for making it easier to understand?
- 23. Would you take time to read it if a healthcare professional gave it to you? If you saw it online? Why or why not?**
- 24. Is there anything you would have wanted to know before your sepsis experience that the fact sheet doesn’t tell you? (HMTS 29d)**
  - PROBE: What additional questions (if any) does the fact sheet bring up for you but does not answer?

Now, I have a few questions about the motivational aspects of the fact sheet.

25. **Do you think you can do/help the sepsis survivor do what the fact sheet recommends? Why or why not?**
26. **Does the fact sheet motivate you to learn more about sepsis and how to prevent infections? Why or Why not?**

Next, I have a few questions about the visual aspects of the fact sheet.

27. **What do you think about the overall design?**
  - PROBE: Images? Colors/font? Format of the information within the material? What do you like/don't like?
28. **Would it catch your attention if you saw it somewhere? Would you stop to read it?**
  - PROBE: What about this fact sheet, if anything, grabs your attention?
29. **Where would you expect to receive or find this fact sheet?**
  - PROBE: At a healthcare professional's office? On social media?
30. **Would another type of material with this information be more helpful? If so, what type and why would that format be more helpful?**
  - PROBE: What about a poster for your/the sepsis survivor's healthcare professional's office?
  - PROBE: What about a message on the TV at your/the sepsis survivor's healthcare professional's office?
31. **Any other comments you would like to make about this fact sheet? (HMTS 43e)**
  - PROBE: Likes? Dislikes? Additional suggestions for improvement?

#### **IV. CLOSING [10 MINUTES]**

This has been really great – thank you so much for sharing your thoughts and opinions. Do you have any comments or questions about the materials that you'd like to bring up before we end our discussion?

**[After comments/questions are addressed]** Let me step out for a moment and check in with my team to see if there are any additional questions before I invite a CDC expert in to answer any questions you may have.

**[Ask questions if project team had any. After or if there are no questions, invite CDC expert in and introduce them for QA.]**

Thanks for those questions. I hope you found the information helpful. I will go ahead and conclude our discussion now. Please visit [www.cdc.gov/sepsis](http://www.cdc.gov/sepsis) for more information about sepsis. Thanks so much again for your participation.