

Moderator Guide for Focus Groups with Heart Failure Patients

Objectives

Note: This section will not be read to consumer participants.

The purpose of the focus groups with patients who have heart failure is to:

- capture heart failure patient perspectives on the types of goals they would set for themselves as a part of their care delivery
- to explore experiences of patients when setting goals, including sharing with their healthcare team and outcomes or not sharing and reasons why they do not share.

Focus Group Instructions and Questions (Allow approximately 2 hours)

(Bold type = Instructions for moderator or observer, not to be read aloud)

A. WELCOME [10 minutes]

As participants arrive, invite them to pick up their name tent, help themselves to refreshments and have a seat. Ask them to complete participant information sheet (i.e., demographics).

Make sure everyone has two pieces of paper and pencil or pen for focus group questions being asked first.

B. INTRODUCTION [5 minutes]

MODERATOR: “I’d like to welcome you to this focus group session. Thank you all for taking the time to join us today. My name is _____. I’ll be leading our discussion today.” **(Moderator says a little more about who she is and introduces anyone assisting her.)**

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0990-xxxx. The time required to complete this information collection is estimated to average 2 hours per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: U.S. Department of Health & Human Services, OS/OCIO/PRA, 200 Independence Ave., S.W., Suite 336-E, Washington D.C. 20201, Attention: PRA Reports Clearance Officer

C. STUDY INFORMATION SHEET (Printed Generic Informed Consent Document)

MODERATOR: “Ok, before we get started, I want to make sure everyone received a focus group information sheet. This describes what this focus group is about, and what your participation involves. Are there any questions about this information right now?”

Answer any questions.

E. GROUND RULES FOR DISCUSSION [5 minutes]

MODERATOR: “Before we get started, I would like to go over a few ground rules for our discussion:

1. You are the experts and we would like to know what YOU think. There are no right or wrong answers, so please feel free to say whatever you like.
2. In our discussion, we want to know what everyone in the group thinks. It will help me if only one person talks at a time. And we want everyone to get a chance to talk. Even if you have an opinion that is different from other people, it is important to tell the group about your opinion. In fact, different opinions are very important to help us understand everything people think and believe. You don’t need to answer any questions that you don’t want to.
3. Your voices will be digitally recorded. The digital recording will help us to remember exactly what was said during our discussion. So I need you to speak clearly so that the recording device can pick up your voice. **IT WILL HELP US A GREAT DEAL IF YOU COULD SAY YOUR NAME EACH TIME YOU SPEAK; THAT WAY WHEN WE LISTEN TO THE RECORDING WE CAN TELL WHO IS SPEAKING.** The recording will be transcribed onto a document and be reviewed by the researchers of this project. But your names will be removed from the transcription. Later the digital recording will be erased.
4. Occasionally we will put a topic or idea in the “parking lot.” What this means is that we will jot down an idea on the pad of paper when we feel it is an important topic that we want to come back to later in the discussion.
5. Please let me know if the temperature in the room becomes too warm/cold. (Add additional misc. comments here, e.g., whether we’ll take a break.)

F. ICE BREAKER [10 minutes]

(Consider included an ice-breaker question, such as having everyone share their name and when they were diagnosed with the condition. Or, have everyone introduce the person next to them and one thing he/she likes to do for fun.)

G. QUESTIONS: IMPACT ON DAILY LIVING [20 minutes]

1. Every person experiences their chronic conditions or illnesses in different ways. I would like to start by having each of you think about how symptoms related to heart failure impact your daily life . This could include how having your condition has

affected you physically, emotionally, socially, or with regard to how you function day-to-day – at home and/or at work.

- Please take 5 minutes to think about this and write down how your daily life has changed.
- **(Allow time)**
- We will ask everyone to provide their feedback, if you wish. Who would like to share first?
- **Moderator will use White Board to write down general topics being discussed roughly by domain: physical, emotional, social, cognitive, work life.**

- *Probing questions:* Can you give me an example? Can you explain this more? Have others experienced the same situation? Are there other things that come to mind?

- *Additional questions:* What would you like to do that you may no longer be able to do, or that you still do but perhaps with more difficulty?

G. QUESTIONS: GOAL SETTING [30 minutes]

1. Thank you for all of your thoughts. Now given all the areas we have discussed, I would like you to think about what goals you might have related to your condition. In other words, what are things you want to be able to focus on or change related to having your condition?
 - I'll give you a few minutes to think of goals and write these down. **(Allow 5 minutes)**

 - Who would like to share first?
2. Did you ever discuss any of these goals with your doctor or other people who work in your doctor's office?
 - For those of you who did share your goal, what did you discuss? How did that conversation go? What happened after you shared this goal?

 - For those of you who did not, what prevented you from discussing your goals with your doctor or someone else in the practice? What could your doctor or other members of the healthcare team do to help you meet your goals?

G. REVIEW OF FUNCTIONAL STATUS AREAS AND FURTHER PROBING ON GOALS (20 minutes)

Thank you for the discussion on goals. I would like us to talk about this more.

1. I have a list of things that other patients with heart failure have talked about in relation to their condition that are difficult for them or bother them. We've already discussed a number of these but wanted to have you look at them for a minute. As you look at them, please think first about if you have had concerns in these areas. Then think about if you might set goals around these areas or if you already have and if you would share these with your doctor or healthcare team.

Allow a minute

- Who would like to share first?
2. Did you or would you ever discuss any of these goals with your doctor or other people who work in your doctor's office?
 - For those of you who did share your goal, what did you discuss? How did that conversation go? What happened after you shared this goal?
 - For those of you who did not, what prevented you or would prevent you from discussing these types of goals with your doctor or someone else in the practice? What could your doctor or other members of the healthcare team do to help you meet your goals?
 3. Imagine that you end up setting goals with your doctor or healthcare team and that you could see how you are doing over time. What do you think of having this type of information? What would you do with it?
 - What information would you like to see about your goal over time? (*Probe on information related to how to improve if you're not meeting your goals, what contributed to improvement and how to keep it up, etc.*)

H. WRAP-UP [10 minutes]

4. Would anyone like to offer any last thoughts?

I. CLOSING

- Thank you so much for your thoughts and time. We really appreciate your help.
- On behalf of our entire project team, I want to thank you for taking your time and also contributing to this discussion on possible future developments in health care delivery.