

AHRQ PFE Guide Focus Groups

Post-Implementation Protocol—Patients and family members, Component 2

July 1, 2010

Research design

- AIR will conduct a total of 9 focus groups with patients and family members during the post-implementation period (3 groups at each of 3 hospitals). At each hospital we will conduct:
 - 1 group of 6-8 patients – Focus on Component 1
 - 1 group of 6-8 family members – Focus on Component 1
 - **1 group of 6-8 patients and family members – Focus on Component 2** (this protocol)

Recruitment criteria

- Patients and family members who have been recruited during the intervention period to serve in advisory capacity at the intervention hospitals—for example, as hospital advisors, members of Patient and Family Advisory Councils (PFACs), or members of hospital committees such as quality and safety committees
- As possible, mix of age, sex, race/ethnicity

Testing materials

- Copies of intervention materials
- Informed consent forms (1 copy for participant to sign, plus 1 copy for participant to keep)
- Incentive receipt forms
- Incentives
- Moderator time clock
- Name placards

Obtain informed consent

As participants arrive, have them read and sign the informed consent form. Give each person an unsigned copy of the form to keep.

Public reporting burden for this collection of information is estimated to average 90 minutes per response, the estimated time required to complete the group. 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: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

PFE Focus Group with Family Members & Patients– Component 2

Topic
Introduction (welcome; background, ground rules)
Warm-up --brief introductions
Background
Recruitment
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Introduction

INSTRUCTIONS:

AS PARTICIPANTS ARRIVE, GREET PARTICIPANTS AND GIVE THEM INFORMED CONSENT FORMS (1 TO SIGN, 1 TO KEEP).

1. Welcome

Thank people for coming.

2. Background—explain purpose of the group

- Hello. My name is {NAME} and I'm the moderator for today's discussion. I'm here with {NOTE-TAKER}, who will be taking notes. We both work for a company called the American Institutes for Research, which is an independent non-profit research organization.
- Our group discussion today is part of a project being funded by a governmental organization known as the Agency for Healthcare Research and Quality to develop a guide to patient and family engagement around the issues of hospital safety and quality.
- The purpose of this discussion today is to talk about your experiences serving as a patient and family advisor to [HOSPITAL NAME].
- Nothing that you say or share today will affect your treatment or care at the hospital, or your continued participation as an advisor. We will not share your name or anything that you say individually.
- We are taping the discussion so that we can share what you say with other people who are working on this project.
- Questions?

3. Go over ground rules.

- During our discussion today, you may hear personal information about fellow participants. Please keep this information to yourself and within this room in order to be respectful of others' privacy.
- We want to hear from everyone and want your honest opinions and reactions. There are no wrong answers—feel free to disagree.

- Don't need to wait for me to call on you—though I may need to interrupt from time to time to keep the discussion moving. We have a lot to cover, so we can't spend too long on just one topic.
- Since we're recording, it's very important for us to have only one person speaking at a time. So please take turns—let's give everyone a chance to share their opinions.
- Also, because we're recording, please try to speak in a voice at least as loud as the one I'm using now so that we can hear everyone on the tape.
- Location of bathroom.
- Turn off cell phones or set to vibrate.
- Questions?

Warm-up

Brief introductions

Let's start with brief introductions. We'll go around the table.

Starting with *{name, seat #1}*,

- Please give your *first name* only and then briefly tell us:
 - a. Your current role at the hospital (e.g., occasional advisor, advisory council member, or member of quality and safety committee)
 - b. How long you have served in this role
 - c. Whether you have had other experience serving as a patient / family advisor

Background

I'd like to start our discussion today by asking some general questions about your thoughts on patients and family members serving as advisors to hospitals along with some general information about your role and involvement.

1. In general, what do you think is the purpose of having patient and family advisors?

- a. How important do you think it is for hospitals to have patient and family advisors? Why?
2. What are the benefits of having patients and family members serve as advisors?
 - a. What are the benefits for patients and family members? Health care professionals? The hospital as a whole?
3. How, if at all, does involving patients and family members as advisors to the organization contribute to quality and safety of care?
4. How, if at all, does involving patients and family members as advisors to the organization hinder or deter the quality and safety of care?

Recruitment

5. How did you become involved in your current role? Who told you about the opportunity? How, if at all, were you involved in the hospital previously?
6. Why did you decide to become involved?
 - a. How were you motivated or encouraged to become involved?
 - b. Who or what influenced your decision?
7. When you were deciding whether to become involved as an advisor, did you receive any materials from the hospital about being an advisor?

[SHOW RECRUITMENT MATERIALS TO PARTICIPANTS]

8. Do you remember receiving these materials?
 - c. IF YES: What did you think of them? Were they helpful? Did they answer the questions you had about being an advisor? Did they make you want to get involved?

9. Did you have any worries or concerns when you were thinking about becoming an advisor?
 - d. Did you raise these concerns with anyone?
 - e. How, if at all, were your concerns addressed?

Patient and Family Advisor Training and Materials

Now I'd like to talk to you about the training you had before becoming an advisor.

10. How many people remember attending training before they began their role? [COUNT SHOW OF HANDS]
 - a. What was the training like? Who conducted it?
 - b. What topics were covered?
 - c. Was it useful? Effective? Why or why not?
 - d. What was the most helpful part of the training?
 - e. What, if anything, would you have changed about the training?
 - f. Overall, how helpful was the training in preparing you to serve as an advisor?
 - g. What information do you wish you had gotten during the training but did not receive?

Now I'm going to hand out some materials. [DESCRIBE THE MATERIALS.] These are materials that you received during the training.

11. How many people remember getting these materials? [COUNT SHOW OF HANDS]

12. What were your reactions to these materials? [FOR THOSE WHO DON'T REMEMBER OR DIDN'T GET THEM: Take a minute to review these materials now. What do you think of them?]
- a. Did you find the information helpful, or not?
 - b. Did you find the information easy to understand?
 - c. What did you like best? Was there anything you would have changed?
 - d. How was the format of these materials? Would you have preferred a different format? If so, describe.
 - e. What materials did you find most helpful?
13. How, if at all, did you use the information you received in the training or the training materials during your role?
- a. How well did the training and materials prepare you to be an effective advisor?
 - b. How confident did you feel about your ability to participate in your role? Were you given enough information and the right information to participate?
 - c. Did the training and materials give you a clear understanding of your role and responsibilities as an advisor?
 - d. Did the materials help you communicate better with others?
 - e. Did the materials improve your experience as an advisor? Why or why not?
14. What has helped most in preparing you to become an advisor? Experiences? Training?

General Experience

15. In general, in your role as an advisor, what kinds of things do you do?

- a. How are you given assignments or tasks? How do you find out about what kinds of help the hospital needs?
 - b. How much of your time is devoted to being a patient / family advisor to the hospital?
16. Who do you interact with in your role?
- c. Do you work with other advisors?
 - i. IF YES: How often do you meet? What is a typical meeting like?
 - d. Do you interact with patients and family members who are not advisors?
 - e. Do you interact with health care professionals?
 - i. IF YES: How often? What are the interactions like?
 - f. Hospital administrators?
 - i. IF YES: How often? What are the interactions like?
17. In your opinion, do you think you were prepared for your role? Why or why not? Did you feel supported?
18. What have been the impacts of your role as an advisor?
- g. On hospital staff?
 - h. On hospital policies and procedures?
 - i. On other patients or family members?
 - j. On a personal level?
19. Describe any challenges you have had during your role as an advisor.
20. How did you overcome these challenges?
21. What were your expectations of being an advisor? How well has your experience as an advisor matched your expectations about what the experience would be like?

22. Have you been able to participate in your current role as much as you wanted? In the way you wanted? Why or why not? Probe for specifics about what it means to them to participate in this role.
23. How satisfied are you with your current role?
24. Did you feel like health care providers and hospital leaders want you to participate?
25. How receptive have health care professionals been to your involvement? How receptive have hospital leaders been to your involvement?
26. Did you feel like your input has been valued? Did you feel like your voice has been heard? Are others respectful of your opinions?
27. From your perspective, what could have or can be done to make this experience even better for you? What might allow you to be the most effective?
28. What advice do you have for someone new taking on your role?

Closing

Before we end, I'd like to give everyone a chance to share any additional thoughts or comments about the things we talked about today. Is there anything that you didn't have a chance to say during our discussion today, or something that we didn't talk about that you wish we had, or any other thoughts you'd like to share with us?

Thank you very much for participating in this discussion today. We appreciate your time.