



Agency for Healthcare Research and Quality

Advancing Excellence in Health Care

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ATTACHMENT D1 Focus Group Discussion Guide

Group 1: Health care practitioners **only** involved in educating patients and caregivers about treatment/ intervention options and/or helping patients to understand available information (e.g., Nurses, Pharmacists, Certified Health Education Specialists, Care Coordinators, etc.)

Interview Group: _____

Date: _____

Site: _____ Time Discussion Started: _____

Time Ended: _____

Participant Summary: No. of Women: _____ No. of Men: _____

Total No.: _____

Introduction by Facilitator (5 minutes)

Hello, my name is [facilitator name] and I'll be moderating this discussion. Thank you for agreeing to help us with this project. We appreciate your willingness to share your time and expertise. This focus group is part of a larger needs assessment process that we are conducting to better understand [—health discipline's—] needs with regards to the practice of using comparative effectiveness evidence in shared decisionmaking. Your feedback will help us understand how we might customize AHRQ's patient-centered outcomes research educational products, tools, and materials to better fit your needs when educating your patients about their health care options. We will have about 1 hour and 45 minutes [possibly 2 hours] for our discussion.

Please note that we will be recording this session and [name of note-taker] will be taking notes. This helps ensure we adequately capture your feedback and ideas during the conversation. We're interested in hearing about your experiences, views, and opinions.

Know that any comments you make today will remain confidential to the extent permitted by law and your name will not be attached to anything you say. Also, please note that there are not any "right" or "wrong" answers. I want to know your opinions.

Public reporting burden for this collection of information is estimated to average 1 hour and 45 minutes per response, the estimated time required to complete the focus 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) AHRO, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

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. Do you have any questions before we begin?

Go over ground rules and agree on group norms

[For in-person focus groups-present them on a flip chart]

- Only one person talks at a time; be courteous of other participants.
- What is shared in the group remains confidential.
- All points of view are welcome (both positive and negative).
- Please turn your cell phone to vibrate or silent mode. If you need to go to the restroom during the discussion, please feel free to leave, but please return as soon as possible.

[For Webinar-based focus groups-to be listed in a slide deck]

- Only one person talks at a time; be courteous of other participants.
- What is shared in the group remains confidential.
- All points of view are welcome (both positive and negative).
- Mute your phone only if there is noise in the background; Make sure to UNMUTE to speak].
- Please state your first name before speaking.

Warm up (10 minutes)

(Screening questions and pre-focus group questions would have already been answered by participants. The moderator will have this information on the group before beginning the focus group).

Before we begin our discussion, let's spend a little time getting to know one another.

[Refer to flip chart with three items listed and ask individuals to briefly answer each item in a round-robin]

1. Your first name
2. The type of organization where you work (hospital, clinic, non-profit agency etc.)
3. Other people at your organization who also aid patients and caregivers with decisions about treatment, procedures, or tests

Please tell me your first name and the type of health care setting you work in. No need to list your organization- just the type. Please also share who else in your organization helps patients make decisions regarding options related to their care (such as treatments, diagnostic procedures, or screening tests)

Probe with the latter item- the types of clinicians involved with educating patients about treatment decisions.

Discussion Questions

Patient Education and/or Shared Decisionmaking Knowledge and Practice [20 minutes]

(Note: all participants indicated familiarity with the approach of shared decisionmaking or patient education to help patients understand their health care options in prescreen questionnaire).

You mentioned that patient education is one of your job responsibilities. You also noted that you are **familiar with the approach of shared decisionmaking** and that you **help patients understand their options** for treatments or interventions.

I'd like to spend the first part of this discussion talking about shared decisionmaking and how you incorporate this kind of patient education in your work setting. For the purposes of this discussion, we are defining shared decisionmaking as:

A process where both the patient and clinician share information, participate in the decisionmaking process, and agree on the best strategy for treatment. The clinician provides personalized information, tools, and/or decision aids to help the patient understand available treatment options, and encourages the patient to consider his or her personal values in making treatment-related decisions.

Question 1: Briefly describe what your typical conversations with patients look like. When you are engaged in discussions with patients, what are you most often trying to achieve or accomplish with patients?

Probe: These discussions with patients may include one or more of the following components:

- Helping patients/caregivers to understand technical information about their options – That is, making sure patients understand the information
- Helping patients clarify their values
- Eliciting patients' preferences

Question 2: How have you been trained on ways to engage patients in making decisions about their health care—including discussing risks and benefits of available health care options? Did you ever attend a training specifically geared to shared decisionmaking?

Probe for more information about training programs that they have undergone; when, and through what institution?

Question 3: Based on your experience, what content do you think is important in a continuing education program about teaching patients about making informed health decisions on treatments, medicines, or procedures?

Probe for information about what they would find most valuable to them in a training program (where to find sources of information that is relevant for their situation, how to communicate potential risks and benefits, etc.)

Awareness of and Use of Tools/Products in Decisionmaking with Patients [20 minutes]

Thank you. That was very helpful information. Next, I'd like to discuss more specifics about HOW you engage patients in these types of discussions, including the types of resources/tools that you use when having these discussions.

Question 4: When you do engage in such conversations, do you use DVDs, Web sites, pamphlets, or other types of decision aids to guide the discussion? If so, which do you use?

- a. Where do you find these products or tools? (Listen for mention of AHRQ)

Probe to find out more about the dissemination vehicles that are successful in disseminating resources

Probe to find out how easy/not easy participants say it is to find tools and resources

Probe to find out more about the dissemination vehicles that are successful in disseminating resources.

- b. How useful are the products or tools that you use?

Probe for strengths and weaknesses of products

Question 5: What do you look for in evaluating patient educational tools? That is, what do you look for in a tool when deciding whether or not to use it?

Probe for things like based on evidence, available in print or electronic form, written at a low literacy level, use visuals or graphics, reasonable length, depth of information that is provided is appropriate for patients and the time available to discuss, etc.

Question 6: What type of information should decision aids or other tools provide to make them useful in your discussions with patients?

Probe for the type of information they would like to have included in available tools to facilitate their discussions with patients (e.g., background information about the health condition, types of adverse effects and their likelihood for different treatment or intervention options; the types of outcomes patients can expect.)

Awareness of PCOR/CER to Support Patient Decisionmaking [40 minutes]

Now we are going to turn our focus slightly. We are going to spend the remainder of our discussion talking about a related topic called patient-centered outcomes research or PCOR for short and how you discuss this type of information with patients. This is also sometimes called comparative effectiveness research. For the purpose of our discussion today, this is how PCOR or CER is defined.

[Refer to flip chart/slide] PCOR/CER is a type of research that is designed to inform health care decisions by providing evidence on the effectiveness, benefits, and harms of different treatment options. PCOR compares drugs, medical devices, tests, surgeries, or ways to deliver health care, and focuses on highlighting comparisons and outcomes that matter to people.

I'd like to give you some information about a particular resource for this kind of information who is also the sponsor of this focus group study – the Effective Health Care Program at the Agency for Healthcare Research and Quality (also called AHRQ for short). AHRQ is one of the Agencies within the U.S. Department of Health and Human Services. Some of you may already be familiar with this Agency or with the Effective Health Care Program but I would like to review for the whole group.

[Share samples of AHRQ/EHC program products and the list of products on the 1-page flyer].

I'm passing around some information about AHRQ's EHC program and some samples of the EHC materials (and a list of the topics) developed for clinicians like yourself about PCOR on particular health care topics. I am also passing around a list of topics that AHRQ provides products for (refer to 1-page listing of topics). Please take a few minutes to look through these materials and the list of products.

[Referring to the handouts] The Agency's EHC Program conducts research and produces effectiveness and comparative effectiveness research products for health care professionals, patients, and policymakers across various health conditions and diseases. [Refer them to the list of AHRQ/EHC priority conditions on the one page flyer.]

The EHC program reviews and synthesizes published and unpublished scientific evidence on a given topic and then generates comprehensive reports about the benefits and harms of different treatments for different health conditions. The summaries are based on comparative effectiveness reviews that cover health topics suggested by the public.

The EHC program then translates the findings from these reports into tools and resources to help consumers, clinicians, policymakers, and others make more informed health care decisions. These tools and resources are available for free and they typically provide summaries of the harms and benefits of different treatments that are available on a particular topic.

[Refer participants to the list of priority conditions and the list of consumer and clinician summaries]

Question 7: In looking at the conditions that are covered, does the EHC program cover the kinds of topics that you address in your discussions with patients or their caregivers? What health conditions or diseases do you see the greatest need for more shared decisionmaking products, tools, or programs? Why?

Probe for topics on the list that would be useful to them. Are there other topics that aren't covered that they would find useful?

Question 8: We have provided you with some samples of the types of tools that are currently available for clinicians and for patients. Note also that the most of the patient materials are also available in Spanish. Would these types of tools be useful to you?

What other PCOR products would you be interested in having access to that are not currently on this list of AHRQ/EHC products? If you could add any product to the PCOR website, what would it be?

Probe for other languages that are often encountered in their work with patients?

Question 9: What could AHRQ do to help make these tools more useful for you? Or to help you to use these products?

Probe for the types of resources or tools that would be useful to them when they are providing education to patients. For instance, would they value having:

- Tools that are aimed at a lower literacy level?
- Some form of Web-based tool that gives them quick access to the topics of particular interest?
- Quick and easy access to the risks and benefits associated with particular treatments?

Question 10: How do you think the PCOR/ EHC tools would best be disseminated to you or your colleagues? How can AHRQ raise awareness of the tools within the professional educator community?

What types of products, tools or programs do you believe are most likely to be adopted and integrated into regular practice? Why?

Conclusion [5-10 mins]

Is there anything else we haven't discussed yet that you think is important for AHRQ to know about your needs with regards to how to increase use of PCOR in shared medical decisionmaking with patients?

Anything else we should know about as we create accredited tools and materials to educate (- **health educator discipline** -) about integrating and applying PCOR into your practice?

Do you have any questions for us?

This concludes our focus group. Thank you for your time and input. AHRQ greatly appreciates your participation.