

Moderator’s Topic Guide -Those who are aware of CER and have self-reported use in their survey responses.

ROAD MAP of Discussion

Introduction and Warm-Up	10
General Perceptions	10
Awareness of Research	20
Awareness of Understanding	20
Behavior Change/Use	15
Research Benefits	10
False Close	5
Close	5
Total	90-95

I. Introduction (10 minutes)

(a) Introduction

- (i) Thanks for attending the teleconference/webinar.
- (ii) Your participation is important.
- (iii) Describe what a focus group is – like an opinion survey, but very general, broad questions.

(b) Purpose

- (i) We will be discussing your experiences in making health care decisions for your family and yourself.
- (ii) You already participated in a telephone survey x months ago, and in that survey you indicated you were aware of Patient Centered Outcomes Research.
- (iii) Ground Rules (go over verbally)

1. I am interested in all your ideas, comments, and suggestions.
2. Please be in a quiet place where you will not be interrupted.
3. There is no right or wrong answers.
4. All comments, both positive and negative, are welcome.
5. Please feel free to disagree with one another. We would like to have many points of view.
6. Please turn off cell phones.
7. Please use your first name only.

(c) Procedure

Public reporting burden for this collection of information is estimated to average 90 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) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

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(i) Explain the use of audiotape. All comments are confidential, to be used for research purposes only, as explained in the consent form you signed.

(ii) I want this to be a group discussion, so you need not wait for me to call on you. Please speak one at a time so that the recorder can pick up everything. Please state your name before you speak so I know who is talking.

(iii) We have a lot of ground to cover, so I may change the subject or move ahead. Please stop me if you want to add something.

(iv) When it comes to our health and our experiences surrounding our health, there is a lot we can discuss; however, in the interest of our discussion and so I get you out of here on time, please stay focused on the questions I will be asking.

Warm-up

Let's do introductions. Please introduce yourself, one at a time, first name only.

- Tell us your first name and
- Your favorite vacation spot

General perceptions on how you make medical decisions (10 minutes)

I'd like you to think about a time when you had to make a choice about the right medicine or the best health care treatment for yourself or a family member. This can be a variety of situations such as learning of a life-threatening or serious diagnosis, learning that a loved one has a chronic condition like asthma or diabetes, or perhaps an elective procedure such as cataract surgery or a hysterectomy.

1. As you were deciding, what types of information did you want/need to make the decision? What concerned you the most when making the decision? Did anyone help you make the decision? (Probe for physicians or medical staff.)
 - a. Did you use any resources to help you make the decision? (Probe for Internet, specific Web sites, brochures etc...)
2. Did you feel you were able to get the information you needed to make the best decisions? Do you feel you had sufficient information?
 - a. Was there other information that would have been useful to you? (Probe for sources – doctor, family members, online, comparisons of information.) What additional resources would you have liked to have?
 - b. What prevented you from getting the information? (Probe for: I didn't know where to look, I didn't know it existed, I felt intimidated, etc.)

Awareness of the Research (20 minutes)

I want to talk now about PCOR, which stands for Patient Centered Outcomes Research, also known as comparative effectiveness research. PCOR provides health care decision-makers—including patients and doctors—with current, scientific, evidence-based information that compares the benefits and risks of different treatment options, including possible side effects of treatment options. PCOR is designed to help people make informed health care decisions and allows the patient's voice to be heard in choosing the best options. PCOR compares drugs, medical devices, tests, surgeries, and other ways to deliver health care. (Note to Moderator: Have the definition displayed somewhere, so participants can see it.)

3. When you participated in the survey, you indicated that you are aware of Patient Centered Outcomes Research, or PCOR. How and when did you first hear about PCOR?
 - a. How long have you been aware of PCOR? (Probe for a year, 6-9 months, longer than a year)
 - b. How did you become aware of it (Probe for health care provider-if this ask what type of provider-RN, NP, PA; TV; radio; print; advertisement; social media avenue; conference; membership organization; Web sites (which ones))?
4. In your opinion, why do you feel there is a need for research that compares medical treatment options?
5. Have you heard about the Effective Health Care Program (EHCP)? (Note to Moderator: if no one is familiar, describe here and post it so people can see it)

THE EFFECTIVE HEALTH CARE PROGRAM (EHCP) funds individual researchers, research centers, and academic organizations to work together with the Federal Agency for Healthcare Research and Quality (AHRQ) to produce PCOR, also known as comparative effectiveness research, for clinicians, consumers, and policymakers. The EHCP funds the research that produces PCOR.

- a. Of those of you that are familiar with the EHCP, tell me about what you know or have heard about it? Where did you learn about the program?
- b. Some of you mentioned that you have been exposed to PCOR through certain Web sites (responses from Q3 above).
 - i. (If they are familiar with EHCP) Have you been to the EHCP Web site? If not, do you think you would you visit it? Tell me about more about that?

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- ii. (If they have been exposed to PCOR through Web sites mentioned in Q3) Have you visited the AHRQ Web sites that mention PCOR? If not, do you think you would visit the Web site? Tell me more about that?
 - c. PCOR and the EHCP are federally sponsored programs. Does that make a difference to you in any way? (Probe for use, non-use, trust, credibility.)
6. How do you currently receive PCOR or information on treatment options? Are you actively searching for materials? Has someone relayed or is someone relaying the information to you? (Probe for Web sites, friends, family, doctors, etc.)

Understanding of the Research (20 minutes)

Let's talk about understanding PCOR and the methods to best convey what PCOR is.

7. Of those of you who learned about PCOR from a health care provider, was it explained to you clearly? What could the provider do or say to make it clearer? Did you follow up with another source, such as a Web site or another provider, to understand it better? If no, would you in retrospect?
8. Of those of you who learned about PCOR through another source such as TV, radio, print, advertisement, social media, conference, membership organization, Web site, etc. was it clear to you what PCOR is after seeing or hearing it through these sources? What would make it clearer to understand what PCOR is? (Probe for better visuals, word choice, time of day, Web site.) Were you interested in learning more about PCOR?

If yes, tell me about that?

- a. The information was unclear and you needed to find out more to understand
- b. You were interested in learning more
- c. Other.

If no, tell me about that?

- a. You were not interested in learning more.
- b. The information provided was clear enough that you did not need to find out more.
- c. You thought PCOR would not address your family member's or your condition.

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- d. Your physician had already provided information.
 - e. You had prior use and comfort level with PCOR.
 - f. Other.
9. Do you feel comfortable explaining PCOR to a family member or friend? If not, tell me about that?
10. What do you think is the best way to help consumers understand PCOR? Probe for health care provider, TV, radio, brochure in provider's office, etc...

Behavior Change/Use (15 minutes)

11. Why did you decide to use PCOR in your health care decisionmaking process? Did you use PCOR for a specific topic or was it for general knowledge?
- a. How long have you been using PCOR? (Probe for year, 6-9 months, longer than a year)
 - b. How often do you use PCOR? (Probe for: does he/she use it every time he/she goes to a doctor or just for a chronic or severe condition.)
12. If you brought PCOR to your provider's attention, how did your provider respond? Was your provider receptive?
13. How would you like to access the information? (Probe for Internet, physicians, TV, radio, brochures etc...)
14. Would you recommend a friend or family member use PCOR? Tell me about that?.
15. Do you feel you are likely to continue using PCOR in the future?
- a. Is there anything that would prevent you from using PCOR (Probe for severe illness, not enough research on that topic, physician recommendations, it didn't help them make decision last time)

Research Benefits (10 minutes)

Let's talk about some of the benefits of PCOR.

All of you shared that you have used PCOR. I want to present you with some scenarios, and let's talk about whether or not you see these situations as beneficial to you as a consumer. After I say each statement please respond by saying "green," "red," or "yellow." Green are for those statements that are a "go" or that you like; red are for those statements that are not a

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“go” or that you see as wrong; and yellow dots are for those statements that are a “maybe.” (Read major copy; allow 2 minutes for participants to respond.)

- You deserve the latest and best information about treating your illness or condition. With this research, you and your health care provider can work together to make the best possible treatment choices.
- Lots of treatments are advertised on TV, the radio, and in magazines. And new scientific research findings are being released every day. This research helps cut through the noise and gives you and your health care provider the facts so that you can decide if that newest, expensive pill or procedure is really the best way of treating your illness.
- Every patient is different—different circumstances, different medical history, and different values. The research doesn’t tell you and your health care provider which treatment to choose. Instead, it offers an important tool to help you and your health care provider understand the facts about different treatments.

Discuss participants’ votes.

16. Do you feel there are any disadvantages to PCOR? What are they? What would you tell friends, if they expressed concern /hesitation about PCOR?
17. How has the use of PCOR affected your health outcomes? (Probe for better, worse, or no difference.)

False Close (5 minutes)

Before we end, I’m going to check with the observers to see if there are any follow-up questions; meanwhile, please think about if there’s anything else you’d like to say about the discussion we had that has not yet been shared.

Closing

Ask questions from observers/listeners.
Does anyone have any comments?

Thank you so much for participating in the focus group. Your time is very much appreciated, and your insights have been very helpful. We will be mailing your incentive in the mail.

Thank you.