

Moderator’s Topic Guide -Those who report no awareness of CER.

ROAD MAP of Discussion

Introduction and Warm-Up	10
General Perceptions	10
Awareness of Research	30
Awareness of Understanding	10
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 or using research to understand health care options and discuss these options with your health care provider to make decisions.
- (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.

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(c) Procedure

(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
- Tell me 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 and Understanding of the Research (30 minutes)

I want to talk now about something that is called 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 so participants can see it.)

3. Now that you know what PCOR is, do you think your doctor provided you with medical treatment research options? What could your doctor have said or done to make your options clearer? What could he/she have said differently to better convey your options or to educate you about PCOR? (Probe for materials, research findings, etc...)
4. Again, now that you know what PCOR is, do you think you have been exposed to PCOR from another source other than your doctor, such as TV, radio, print, advertisement, social media, conference, membership organization, Web sites, friend, or family member? What would make the message about PCOR clearer? (Probe for better visuals, word choice, time of day, Web site.)
5. Are you familiar with the Effective Health Care Program, also known as 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 Q4 above).
 - i. (If they are familiar with EHCP) Have you been to the EHCP Web site? If not, do you think you would visit it? Tell me about more about that?
 - ii. (If they have been exposed to PCOR through Web sites mentioned in Q4) 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?

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- 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. Were you aware that a PCOR media campaign occurred in the last 3 months, in the last 6 months, last year? (Probe for time of day [i.e., something aired during the day while participant worked]; language barrier, no TV/Internet; self-admittance of non-recall; if print, they do not get the publication; if online, they do not use online/that particular site; vacation/out of town; other.)

7. Now that we are talking about some ways that PCOR may have been communicated to you, do you recall any such information? If so, can you tell what that is and when you may were exposed to it?

8. Would you like to learn about or use PCOR the next time you have to make decisions about your health care?

9. If you wanted to use PCOR, how would you prefer to learn about it (i.e., health care provider, TV, radio, brochure in provider's office)?

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. Now that you are aware of PCOR, that is, research designed to help you make health care decisions by comparing different treatment options, do you think you would use it to help make health care decisions? If you had to make a medical decision, would you use the AHRQ Web site to help you make your decision?
 - a. If yes, why?
 - b. If no, why?

Are there any particular topics you are interested in learning about?

Research Benefits (10 minutes)

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

12. What do you think would be the benefits of using PCOR?

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13. Do you feel there are any disadvantages to PCOR? What are they? What would you tell friends, if they expressed concern/hesitation about PCOR?

14. Do you think using PCOR could affect your health outcomes? If so, how?

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 "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.

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.