Patient-Centered Outcomes Research Institute

PCORI Seeks Your Input On…

Working Definition of "Patient-Centered Outcomes Research"

What is the Patient-Centered Outcomes Research Institute?
The Patient-Centered Outcomes Research Institute (PCORI) is an independent, non-profit research organization created to help patients and those who care for them make better informed health decisions. PCORI will commission research that is responsive to the values and interests of patients and will provide patients and those who care for them with reliable, evidence-based information for the health care choices they face. To learn more about PCORI, visit our website: www.pcori.org.

Explanation of this input opportunity:
"Patient-centered outcomes research" is the type of research that will be the focus of PCORI's work. There are different opinions about what this research includes. PCORI has created a working definition, so that we can have a shared understanding to guide our work. PCORI wants your input to make sure the definition is appropriate. This opportunity is open to everyone. PCORI will review all of the input it receives and then update the working definition as needed based on the feedback provided.

When can you provide input:
You can provide input until 11:59 p.m. Eastern Time on Friday, September 2, 2011.

How to provide input:
There are three ways you can provide input:

1. You can complete this form and click "Submit" on the last page, which will send it to PCORI by email.
2. You can complete this form, print it out* and mail it to PCORI at:
   Patient-Centered Outcomes Research Institute
   Attn: PCOR Input
   5185 MacArthur Blvd., NW, Suite 632
   Washington, DC 20016
   **If your "Additional Comments" for any question extend beyond the visible space provided, please print out those comments on a separate page and return them with this form.*
3. You can complete this questionnaire on PCORI's website through this page: http://www.pcori.org/provideinput.html

You are NOT required to provide any personal identification in order to provide input. However, you may provide such information if you are willing to be contacted if PCORI has questions about your comments. PCORI's privacy policy, which explains how PCORI handles information it receives, is available on PCORI's website here: http://www.pcori.org/privacy.html.

Questions about this input opportunity may be directed to PCORI by email to info@pcori.org or by phone to 202-683-6690.

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Below you will find:

- the working definition of patient-centered outcomes research,
- four questions about the definition, where we would like your feedback,
- an opportunity for you to provide general feedback on the definition, and
- an opportunity for you to provide personal identification information, if you would like to.

You may provide input on any of the questions. You are NOT required to answer all the questions.

The working definition of patient-centered outcomes research is provided in the below box. The definition includes four questions the research answers and a list of ways the research can provide answers.

Patient-Centered Outcomes Research (Working Definition)

Patient Centered Outcomes Research (PCOR) helps people make informed health care decisions and allows their voice to be heard in assessing the value of health care options. This research answers patient-focused questions:

1. "Given my personal characteristics, conditions and preferences, what should I expect will happen to me?"
2. "What are my options and what are the benefits and harms of those options?"
3. "What can I do to improve the outcomes that are most important to me?"
4. "How can the health care system improve my chances of achieving the outcomes I prefer?"

To answer these questions, PCOR:

- Assesses the benefits and harms of preventive, diagnostic, therapeutic, or health delivery system interventions to inform decision making, highlighting comparisons and outcomes that matter to people;
- Is inclusive of an individual's preferences, autonomy and needs, focusing on outcomes that people notice and care about such as survival, function, symptoms, and health-related quality of life;
- Incorporates a wide variety of settings and diversity of participants to address individual differences and barriers to implementation and dissemination; and
- Investigates (or may investigate) optimizing outcomes while addressing burden to individuals, resources, and other stakeholder perspectives.

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Please provide PCORI your feedback on the working definition of patient-centered outcomes research below. The spaces provided for comments have an 8,000-character limit.

1. Does the definition place appropriate emphasis on, and convey the importance of, the "patient-centeredness" of the PCORI mission?

- (●) Yes
- ( ) No
- ( ) Don't Know/Not Sure

Additional Comments:

The American Occupational Therapy Association (AOTA) commends PCOR for emphasizing "patient-centeredness" in the working definition. In addition to "1. Given my personal characteristics, conditions and preferences, what should I expect will happen to me?" a patient may also ask about costs of these options. Another question that may arise is: "What is the likelihood of secondary conditions, complications, or positive/negative outcomes for each treatment option?"
AOTA is pleased to see that the individual's preferences and values are respected in this definition and rationale. As health care providers, we need to understand that individuals have different support systems and resources, which may influence which treatment option would be best.

2. Is the definition consistent with the intent of the statute that established PCORI? (The text of the statute is available on the PCORI website: http://www.pcori.org/images/PCORI_EstablishingLeg.pdf)

- (●) Yes
- ( ) No
- ( ) Don't Know/Not Sure

Additional Comments:

3. Is the definition broad enough to include the range of research that PCORI should fund?

- (●) Yes
- ( ) No
- ( ) Don't Know/Not Sure

Additional Comments:

The rationale for the definition of patient-centered outcomes research supports a variety of research methodologies. AOTA supports this focus on other research methodologies because one research design cannot answer all of our clinical questions, for all populations, and for all conditions. For rare conditions and certain vulnerable populations, we need to consider other study designs and funding sources can help influence this paradigm shift.

4. Does the definition adequately convey the rationale outlined in the rationale document?
(The rationale document is available on the PCORI website:
http://www.pcori.org/images/PCOR_Rationale.pdf)

- (●) Yes
- ( ) No
- ( ) Don't Know/Not Sure

Additional Comments:

5. Please use the following space to provide any additional comments you have about the definition.

Additional Comments:

Question 4 asks "How can the health care system improve my chances of achieving the outcomes I prefer?" AOTA commissions systematic reviews and produces practice guidelines like many other organizations but facilitating practitioners' to incorporate the latest evidence into practice is the challenge. Thus even if resources and strategies exist, health care providers may not be utilizing them. A patient may then wish to ask "What will the health care system do to improve my chances of achieving the outcomes I prefer"? This subtle change in semantics may spur action instead of contemplation.

Contact Information

Note: You are NOT required to provide any personal identification in order to provide input. However, you may provide such information if you are willing to be contacted if PCORI has questions about your comments.

First Name	Susan
Last Name	Lin
Organization	AOTA
Email Address	
Address 1	
Address 2	
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Zip	

Submit via email pcori