



Patient-Centered Outcomes Research Institute
PCORI Seeks Your Input On...
Working Definition of “Patient-Centered Outcomes Research”

This opportunity for input is now closed.

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.

1. Does the definition place appropriate emphasis on, and convey the importance of, the “patient-centeredness” of the PCORI mission?
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)
3. Is the definition broad enough to include the range of research that PCORI should fund?
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)

PCORI accepted input on this working definition from July 20 to September 2, 2011. This opportunity for input is now closed.

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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.