

August 29, 2011

Patient Centered Outcomes Research Institute 1701 Pennsylvania Avenue, NW, Suite 300 Washington, DC 20006

This letter reflects comments by the American College of Physicians (ACP) in response to your request for feedback on a "Working Definition of Patient Centered Research (PCOR)". The ACP represents 132,000 internal medicine physicians and students. Internists specialize in primary and comprehensive care of adolescents and adults. These comments were developed with the assistance of an Advisory Committee including the following: Mark Eckman, MD; Eric Larson, MD; Cynthia Mulrow, MD; Stephen Pauker, MD; Hal Sox, MD; and Steven Weinberger, MD.

The College supports the general structure used in the draft PCOR definition in which the first several lines on the top of the page provides a definition for the overall concept and the questions and answer below serve to clarify and elaborate on the overall concept.

The College suggests that the overall concept of PCOR as defined in the first few lines can be improved in the following ways:

- The definition should first indicate what <u>PCOR is</u> it is research---and only then reflect how it can be used.
- The definition should emphasize that the research can be conducted using various methodologies.
- The use of the term "voice" in the working definition is vague and we recommend a clearer delineation of the types of attributes that the PCOR research needs to reflect.
- The definition should place increased emphasis that the research recognizes the importance of the individual characteristics of each patient, including the patient's personal situation, clinical profile, preferences and willingness to assume risk.
- The definition should be consistent regarding the "patient centered" nature of this research and thus should use the term "patient" rather than person----person could refer to any of a large number of stakeholders who could be interested in this research and it appears the Board wants to emphasize the patient focus of its activities.

With these suggestions in mind, we offer the following modified wording as an example of how these suggestions can be incorporated:

Patient Centered Outcome Research (PCOR) compares, through the use of a variety of techniques, the value of health care interventions to individual decision makers. A fundamental attribute of PCOR is the consideration of patient characteristics, including patient situational circumstances, clinical characteristics including other illnesses, and preferences, that influence health outcomes and therefore are important to consider in individualizing decision-making.

In your questions and answers used to clarify and elaborate the overall concept, the College suggests you consider including the following:

- As noted above, refer to patient rather than person.
- When discussing the issue of "what to expect" (bullet 1 under Questions) refer to the issues of personal setting and time horizon.
- Indicate a number of potential forms the results of this research might take (e.g. patientcentered decision support tools, treatment guidelines that account for patient-to-patient variability in treatment response and in patient-specific preferences, etc.)
- Indicate that this information is not only important to the patient, but also to their everyday caregivers.
- Place increased emphasis in the answer section on the importance of the dissemination of this information in a meaningful and effective manner.

Thank you for this opportunity to comment of the PCOR draft definition. If you have any questions regarding these suggestions, please contact Neil Kirschner Ph.D. on our staff who is available at 202 261-4535 or <u>nkirschner@acponline.org</u>.

Respectfully,

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Don Hatton, MD, FACP Chair, Medical Practice and Quality Committee