



Request for Proposal:

Analysis of Input Received on Working Definition of “Patient-Centered Outcomes Research”

Background and Introduction

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, non-profit research organization created by the Patient Protection and Affordable Care Act of 2010. PCORI helps people make informed health care decisions – and improves health care delivery and outcomes – by producing and promoting high-integrity, evidence-based information – that comes from research guided by patients, caregivers and the broader health care community. 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.

On September 2, 2011, the Patient-Centered Outcomes Research Institute (PCORI) will complete, a 45-day [public input period](#) on the working definition of “patient-centered outcomes research,” the unique type of research that is the focus of PCORI’s work. Through this input period, the Methodology Committee working group that created the definition sought general feedback and specific feedback on four questions:

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? A link to the statute is provided above.
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](#)?

This project will synthesize the input so that the Methodology Committee can refine the working definition. It will also provide the starting point for further efforts to ensure the definition reflects the values and preferences of representative samples of U.S. patients and the public.

Statement of Objectives and Scope of Project

The overall goal of this project is to summarize public input that PCORI has received on the working definition of Patient-Centered Outcomes Research and seek input from patient and lay audiences on the working definition (once revised by the Methodology Committee). Specifically, this project aims to synthesize public input provided to PCORI about its working definition of Patient-Centered Outcomes Research, identify compelling and recurring suggestions, recommend questions that should be researched with patient and lay audiences, propose methodologies for getting feedback from patient and lay audiences, and conduct the recommended research with patient and lay audiences. The end result, after the reports are submitted to the

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Methodology Committee for its consideration, will be a revised definition of Patient-Centered Outcomes Research which will be used as the basis to help guide future PCORI research.

Opportunity

Phase I:

In this solicitation, PCORI seeks a vendor to summarize the input received and identify key issues or questions that should be considered in modifying the working definition. Approximately 140 responses have been received thus far. Without making recommendations for changes, the vendor shall identify consistent themes, quantify frequencies for recurring suggestions, and link these themes and suggestions to previous research work on patient engagement.

Based on this summary report, the vendor should make recommendations on specific questions or issues that should be researched with patient and lay audiences and appropriate methodologies for that research, which may include focus groups, quantitative surveys or other methods. The Methodology Committee will revise the working definition of PCOR before Phase II research is conducted.

Phase II:

The ideal vendor for Phase I will also be able to execute the patient and lay audience research it recommends. This is the work of PHASE II. Following this research, the vendor shall produce another report that summarizes the findings and identifies key issues or questions that should be considered in modifying the working definition. A brief report written of study findings that is understandable to patients and clinicians and contains the elements described above for Phase I is also required.

After PCORI has modified the definition following the patient and lay audience research, the vendor will provide a report suitable for publication in a scientific journal that summarizes all of the input process and research findings with reference to the rationale document and initial working definition.

Applicants can submit proposals for Phase I and/or Phase II, but we note a preference for proposals that cover both Phase I and Phase II.

Applicants should consider how to seek input from populations mentioned in the statute such as racial and ethnic minorities, women, and people across the age range. It should propose as an option seeking feedback from Spanish-speaking patients/consumers.

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Methodologies

Phase I of the project will consist of qualitative research to analyze the input received and plan future research. It is anticipated that Phase II of the project will involve focus groups with patient and lay audiences and/or representative surveys of patient/lay audiences.

Deliverables

The deliverables will include a report at the completion of Phase I (with a synthesis of public input, identification of recurring themes, and questions to elicit patient input) and a report at the completion of Phase II (summary of the input process, research findings, with reference to the rationale document and initial working definition). The latter report should be suitable for publication in a scientific journal.

For each phase, a brief (two-page) non-technical summary of study findings, written in language understandable to patients and providers, is also required. This summary must include the following:

- a. A brief summary of the study methods, key findings, and interpretation of the relevance of findings to patients and clinicians.
- b. Specific discussion of any suggestions that patient perspectives or approaches may differ for patient subgroups defined by age, gender, race/ethnicity, socio-economic, clinical, or genetic makeup (if studied).
- c. A discussion of the limitations of study findings.
- d. Suggestions for next steps for research in the specific area studied.

Total Contract Amount

The total contract amount will be up to \$15,000 (direct costs) for Phase I and up to \$50,000 (direct costs) for Phase II.

Please note that PCORI's indirect cost rate is 40% of total direct costs. The NIH salary cap applies to any salaries of researchers.

Eligibility

The following institutions and individuals are eligible to submit a proposal:

Individuals

Higher Education Institutions:

- Public/State Controlled Institutions of Higher Education
- Private Institutions of Higher Education

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Nonprofits Other Than Institutions of Higher Education

- Nonprofits with 501(c)(3) IRS Status (Other than Institutions of Higher Education)
- Nonprofits without 501(c)(3) IRS Status (Other than Institutions of Higher Education)

For-Profit Organizations

- Small Businesses
- For-Profit Organizations (Other than Small Businesses)

Governments

- State Governments
- County Governments
- City or Township Governments
- Special District Governments
- Indian/Native American Tribal Governments (Federally Recognized)
- Indian/Native American Tribal Governments (Other than Federally Recognized)
- Eligible Agencies of the Federal Government
- U.S. Territory or Possession

Other

- Independent School Districts
- Public Housing Authorities/Indian Housing Authorities
- Native American Tribal organizations (other than Federally recognized tribal governments)
- Faith-based or Community-based Organizations
- Regional Organizations
- Non-domestic (non-U.S.) Entities (Foreign Organizations) (Provided that the benefit to the US health care system and US efforts in the area of patient centered research is apparent)
- Foreign (non-U.S.) components of U.S. Organizations (Provided that the benefit to the US health care system and US efforts in the area of patient centered research is apparent)

Review Criteria

Evaluation criteria to be used in determining the successful proposals are as follows:

- Understanding of the project and of comparative effectiveness research and patient-centered outcomes research
- Experience in eliciting feedback from patients and laypersons (Phase II)

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- Coherent, thoughtful, and thorough responses to the specifics of the RFP
- Well-qualified staff with required expertise to complete the project
- Evidence of capacity to meet PCORI timelines
- Experience with similar projects

About PCORI Policies

Conflict of Interest – PCORI requires disclosure of any potential conflicts of interest (see attached form) as part of the application. This input will be considered during the review process.

Publication Policy -- The reports generated under this contract become the property of the PCORI. PCORI retains the rights to publish these materials in whole or in part. Contracted authors are free to publish other paper(s) derived from work conducted under this contract, with or without participation of PCORI representatives, but they cannot publish the Report or parts of the Report. The contracted authors must acknowledge PCORI funding in any such publication. The contracted author must also state explicitly that the work does not necessarily represent the views of PCORI unless the publication includes PCORI representatives as co-authors and has been reviewed and approved by PCORI.

Use of research findings – PCORI considers the sharing of unique research resources developed through PCORI-sponsored research an important means to enhance the value and further the advancement of the research. When resources have been developed with PCORI funds and the associated research findings published or provided to PCORI, it is important that they be made readily available for research purposes to qualified individuals within the scientific community. If the final data/resources are not amenable to sharing, this must be explained in the application.

How to Apply

Submission

Proposals (no longer than 6 pages) must be submitted by 3:00 p.m. on September 9, 2011, and must include the following information:

- a) Proposed plan for conducting Phase I (synthesis of input, identification of questions for Phase II, proposed methodology for Phase II, report) and/or proposed plan for conducting Phase II (seeking patient and layperson input, report)
- b) Summary of Proposed Staff Qualifications and CV's
- c) Proposed budget with justification
- d) List of professional references – beginning with most recent professional references and their contact information
- e) Three examples of relevant experience
- f) Completed Conflict of Interest Disclosure Form

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In your proposal, please clearly label each section as listed above.

The proposal should be sent by the deadline by mail and email: It should be e-mailed to Gail Shearer (gshearer@pcori.org) and two copies sent by US Postal Service to:

Gail Shearer
Patient-Centered Outcomes Research Institute (PCORI)
ATTN: PCORI Request for Proposal – PCOR Definition Synthesis
1701 Pennsylvania Ave., NW, #300
Washington, DC 20016

We anticipate that the author of the accepted proposal will be notified by phone by September 16, 2011.

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Key Dates

Step	When
Issue RFP (and reach out to potential applicants)	August 24, 2011
Deadline for applications	September 9, 2011
Complete review of applications	September 16, 2011
Complete contract with chosen contractor	September 19, 2011
Submit Phase I findings and draft questions for focus groups	September 30, 2011
PCORI completes revision of PCOR Definition	October 26, 2011
Revise questions for focus groups	November 9, 2011
Focus Groups (or other way of seeking patient input)	November 18, 2011
Report due to PCORI	December 16, 2011 (with preliminary report in time for December 8 meeting)
PCORI completes further revisions of PCOR Definition	January 15, 2012
PCORI Board considers revised PCOR Definition	January 18, 2012

Contact Information

Questions about the PCOR definition input synthesis project should be directed to Gail Shearer, gshearer@pcori.org or 202 683-6690.

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE Conflict of Interest Disclosure Statement

1. Name: _____
2. Date Submitted: _____
3. List the nature of any conflict of interest:

The undersigned hereby affirms that he/she has disclosed any conflicts of interest that may have the potential to bias or has the appearance of biasing their obligations under the Services Agreement.

Signed: _____

Print Name: _____

Title: _____

Date: _____

Definition:

“Conflict of interest”. The term “conflict of interest” means an association, including a financial, business, or personal association, that has the potential to bias or has the appearance of biasing an individual in matters related to the Patient-Centered Outcomes Research Institute (PCORI) or the conduct of PCORI activities.