

What Might Patient (Employee)- Centered Research Look Like?

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

MISSION STATEMENT

(adopted July 17, 2011)

The Patient-Centered Outcomes Research Institute (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.**

Working Definition of PCOR



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 risks 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?”**

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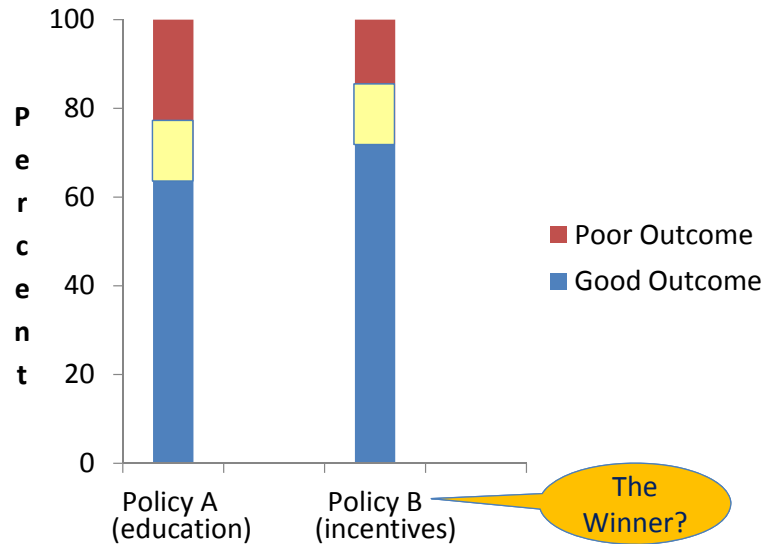


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Patient-Centered Outcomes Research (CER)

- ✓ The research addresses practical questions, of interest to patients, and is usually comparative
- ✓ The full range of outcomes important to patients are studied and compared
- ✓ The patients studied are representative and come from relevant settings – so that results generalize
- ✓ Possibilities of differences in effectiveness in various patient populations are examined

Two Ways to Think about Results:



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- **Population Approach**
 - Emphasis on results expressed as population proportions or means
 - Assumption that the approach with higher positive “response” is the preferred approach for everyone
 - Comes from the “placebo-controlled paradigm”
 - Has made remarkable progress in quality, outcomes, therapy
- **Patient (Employee-centered) Approach**
 - Emphasis is on examining results for various patient/employee subgroups
 - Assumption that different employees will respond differently to each of two reasonable approaches
 - Comes from the CER (two active comparator) approach
 - Holds promise of refining and improving policy-making and therapy, but benefits largely unproven

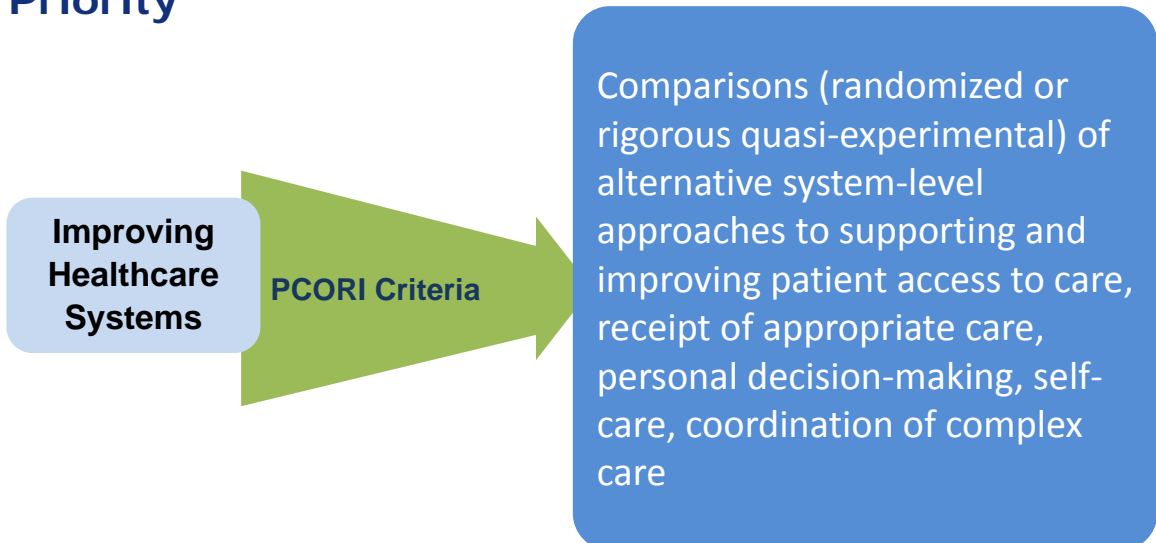
PCORI's Draft Research Priorities



Comparative Clinical Effectiveness	Comparing different prevention, diagnosis or treatment options to see which ones work best for which patient groups
Improving Health Care Systems	Improving the delivery of health care services so they match a person's needs and desired outcomes
Communication and Dissemination	Improving the information available to patients so they can make informed decisions along with their caregivers and clinicians
Fairness/Addressing Disparities	Making sure the needs of different patient groups are considered in any medical research study since treatments may not work the same for everyone
Accelerating Patient-Centered Research	Developing new ways to conduct quick, safe and efficient research that better involves patients and the health care community



Example of a Research Agenda item from a National Priority



Possible Content of PCORI Research Agenda



Comparative Clinical Effectiveness

- Comparisons of alternative clinical options
- Identifying patient differences in response to therapy
- Studies of patient preferences for various outcomes
- Outcomes studies of variation in practice (natural experiments)

Improving Healthcare Systems

- Improved delivery of evidence-based medicine
- Improved support of patient self-management
- Coordination of care for complex conditions

Communication & Dissemination

- Enhancing shared decision-making
- Alternative strategies for dissemination of evidence

Fairness/ Addressing Disparities

- Understanding differences in effectiveness across groups
- Understanding differences in preferences across groups
- Identifying optimal clinical options for population groups

Accelerating Patient-Centered Research

- Improving methods for longitudinal follow-up studies
- Building and improving clinical data networks
- Methods for training researchers, patients to participate in PCOR
- Facilitating the study of rare diseases

Likely Emphases in PCORI Research



- Studies of questions raised by patients (employees)
- Studies that examine differences in policy/treatment effectiveness in patient/employee subgroups
- Studies that aim to identify or understand differences in patient preferences for various policies, treatments, outcomes
- Studies that apply this understanding of patient differences in preferences or outcomes to improve outcomes overall and to eliminate disparities in outcomes