

Patient-Centered Outcomes Research Institute

National Patient and Stakeholder Dialogue

**The National Press Club – Washington, D.C.
February 27, 2012**



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Introduction to the National Patient and Stakeholder Dialogue

Joe Selby, MD, MPH, Executive Director

The National Patient and Stakeholder Dialogue
Washington, D.C.
February 27, 2012



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Receiving and Incorporating Public Input

Sharon Levine, MD, Member, PCORI Board of Governors

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Process for Public Input on National Priorities and Research Agenda

- **Formal Public Comment Period** (January 23 – March 15)
 - Submit formal comments at www.pcori.org/provide-input.
 - All comments are displayed on the website in real time.
- **Additional forums to obtain input**
 - Patient, caregiver and clinician focus groups.
 - Individual meetings with diverse mix of stakeholders.
- **Incorporating input received**
 - PCORI will review all input received and publish a report with explanation of how it led to changes in priorities and agenda.
 - Revised National Priorities and Research Agenda will be adopted by Board of Governors during a special public meeting in April.

National Priorities and Research Agenda

Harlan M. Krumholz, MD, SM, Member, PCORI Board of Governors

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Welcome to the PCORI team!





The best way to predict the future is to invent it.

Alan Kay, 1971









Science

October 9, 1998



*Science 9 October 1998:
Vol. 282 no. 5387 pp. 245-246*

Outcomes Research: Measuring the End Results of Health Care

Carolyn M. Clancy and John M. Eisenberg



“Outcomes research—the study of the end results of health services that takes patients' experiences, preferences, and values into account—.”



“Outcomes research—the study of the end results of health services that takes patients' experiences, preferences, and values into account—is intended to provide scientific evidence relating to decisions made by all who participate in health care.”

The Patient Protection and Affordable Care Act



Subtitle D—Patient-Centered Outcomes Research

SEC. 6301. PATIENT-CENTERED OUTCOMES RESEARCH.

(a) IN GENERAL.—Title XI of the Social Security Act (42 U.S.C. 1301 et seq.) is amended by adding at the end the following:—

“(c) PURPOSE.—The purpose of the Institute is to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of evidence con-

“COMPARATIVE CLINICAL EFFECTIVENESS RESEARCH

“SEC. 1181. (a) DEFINITIONS.—In this section:

42 USC 1320c

“(1) BOARD.—The term ‘Board’ means the Board of Governors established under subsection (f).

“(2) COMPARATIVE CLINICAL EFFECTIVENESS RESEARCH: RESEARCH.—

“(A) IN GENERAL.—The terms ‘comparative clinical effectiveness research’ and ‘research’ mean research evaluating and comparing health outcomes and the clinical effectiveness, risks, and benefits of 2 or more medical treatments, services, and items described in subparagraph (B).

“(B) MEDICAL TREATMENTS, SERVICES, AND ITEMS DESCRIBED.—The medical treatments, services, and items described in this subparagraph are health care interven-



time for **CHANGE**



The PCORI 4 Questions

- “Given my personal characteristics and conditions, what may happen to me?”
- “What are my options and the benefits and harms of those options?”
- “What can I do...?”
- “What can the health system do...?”





Shoulda, Coulda, Woulda: Patriots Edition

Here were the Patriots' chances of winning in the late moments of Super Bowl XLVI—both in reality and if different events had happened.

Events	Patriots' odds of winning
Actual event: Bradshaw scores on 2nd down	4.5%
What if: Patriots let him score on 1st down	10.3
What if: Bradshaw takes a knee on 2nd down	1.9
Actual event: Giants called for 12 men on field	12.2
What if: Time restored after penalty	20.4









Priorities and Agenda

**What is important and
what will we do?**

National Priorities and Research Agenda

Must be approved before major funding can begin

National
Priorities

Research
Agenda

Funding
Announcements

National Priorities for Research



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

“The Institute shall identify national priorities for research, taking into account factors of **disease incidence, prevalence, and burden in the United States** (with emphasis on chronic conditions), **gaps in evidence in terms of clinical outcomes, practice variations and health disparities in terms of delivery and outcomes of care**, the **potential for new evidence** to improve patient health, well-being, and the quality of care, the **effect on national expenditures** associated with a health care treatment, strategy, or health conditions, as well as **patient needs, outcomes, and preferences**, the **relevance to patients and clinicians** in making informed health decisions, and priorities....”

“The Institute shall establish and update a research project agenda for research to address the priorities identified under subparagraph (A), taking into consideration the **types of research that might address each priority** and the **relative value (determined based on the cost of conducting research compared to the potential usefulness of the information produced by research)** associated with the different types of research, and such **other factors** as the Institute determines appropriate.”

PA

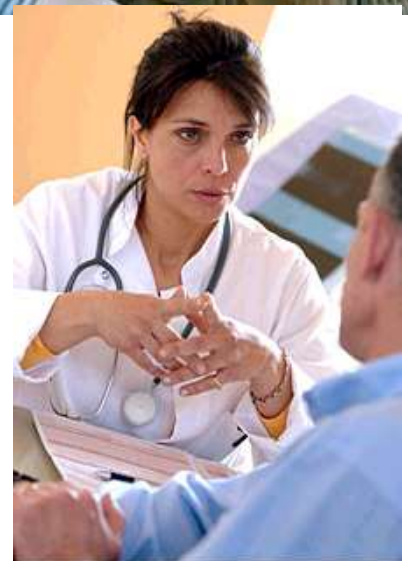


To what extent will PCOR be CER?

PA



**To what
extent will
our priorities
and agenda
be problem
specific?**







Priorities

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE



**Improving Patient and
Caregiver Decisions**

**Improving Health
Care Systems**

**Addressing
Disparities**

**Improving
Communication and
Dissemination**

**Accelerating PCOR
and Methodological
Research**

**Emphasis on
comparing strategies**

Developing PCORI's Research Agenda

Proposed PCORI Criteria

Potential to Influence Decision Making

Improved Health Care System Performance

Probability of Improvability via Research

Current Health Disparities

Address Current Gaps in Knowledge

Address Variation in Care

Impact on Health of Individuals and Populations

Efficient Use of Research Resources

Novel Use of Technology

Priority
Themes



Proposed
PCORI
Criteria



PCORI
Research
Agenda

In Statute

From Board

Research Agenda Item From a National Priority

**Improving
Patient and
Caregiver
Decisions**

PCORI Criteria

**...compare strategies
where better evidence is
needed to support
decision-making by
patients, caregivers, and
health care professionals.**



PCORI's Path from Priorities to Research Patients can Use



Future priorities and agendas will be informed by the development process, ongoing stakeholder engagement, and PCORI's research results.

-----Original Message-----

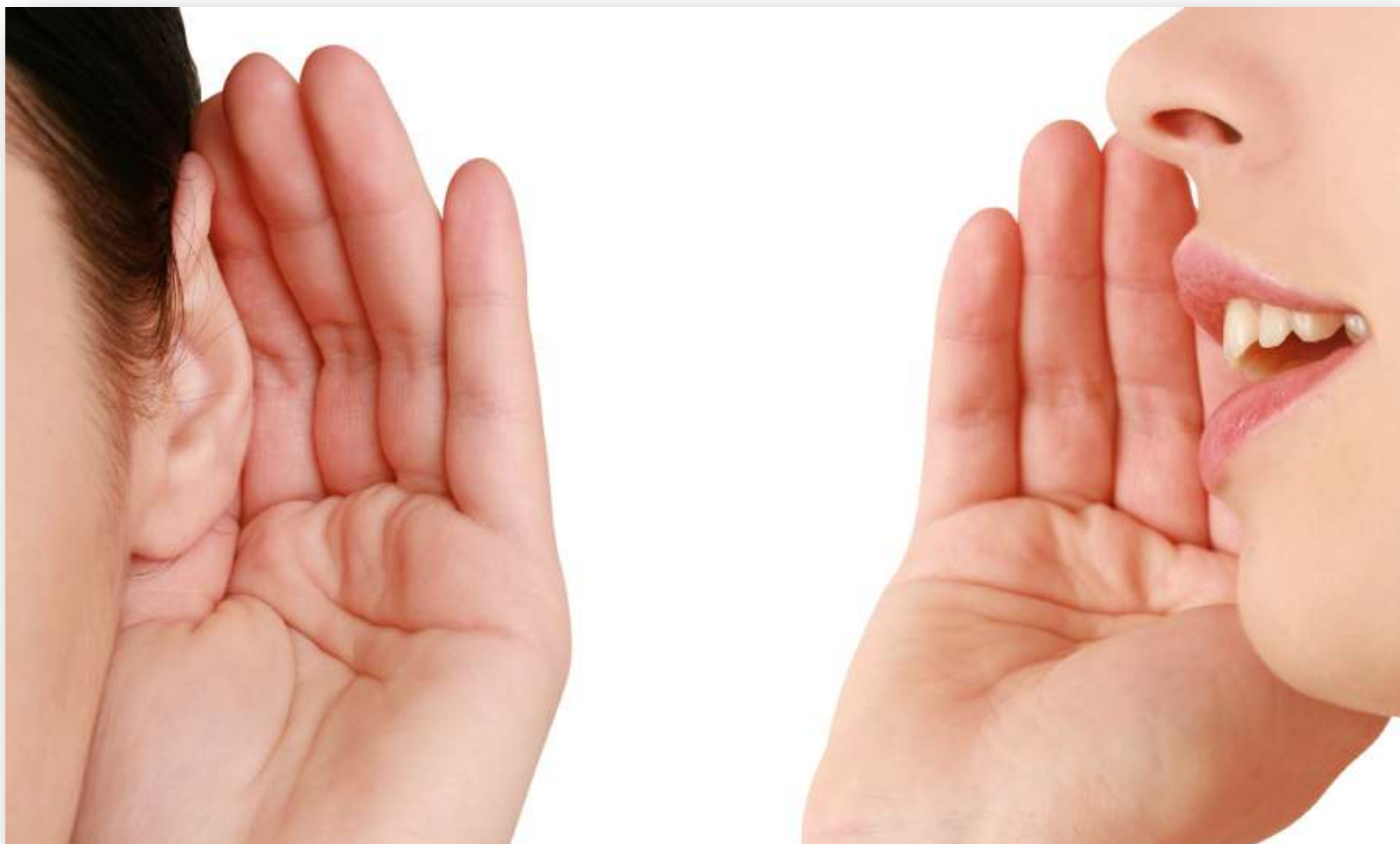
From: xxxx

To: Krumholz, Harlan

Subject: PCORI Pilot Grants

"...it fundamentally changed the way we think about patient engagement in research, from being passively observed subjects to thinking creatively how to engage them in the design of our research - the way we design the study, how we craft our interventions and what outcomes we measure."







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Introduction to the Public Comment Period

Gail Hunt, Member, PCORI Board of Governors

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Observations from PCORI Board Members

Larry Becker, Member, PCORI Board of Governors

Harlan Weisman, MD, Member, PCORI Board of Governors

Ellen Sigal, PhD, Member, PCORI Board of Governors

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