

Expert Interview Project:

Best practices for involving patients & public in research processes

Curtis, P.¹, Slaughter-Mason, S.¹, Thielke, A.¹, Gordon, C.¹, Pettinari, C.¹, Ryan, K.¹, Church, B.¹ & King, V.¹

¹Center for Evidence-based Policy, Oregon Health & Science University

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Patient Protection and Affordable Care Act

The Patient Centered Outcomes Research Institute (PCORI) is an independent organization authorized by the US Congress as part of the US health care reform to conduct research on the best available evidence to help patients and health care providers make informed health care decisions.

October 2011

Methodology Committee Objectives

The Center for Evidence-based Policy (CEbP) at Oregon Health & Science University conducted the Expert Interview Project to assist the PCORI Methodology Committee efforts in developing research standards for patient-centered outcomes research. The Expert Interview Project aimed to identify:

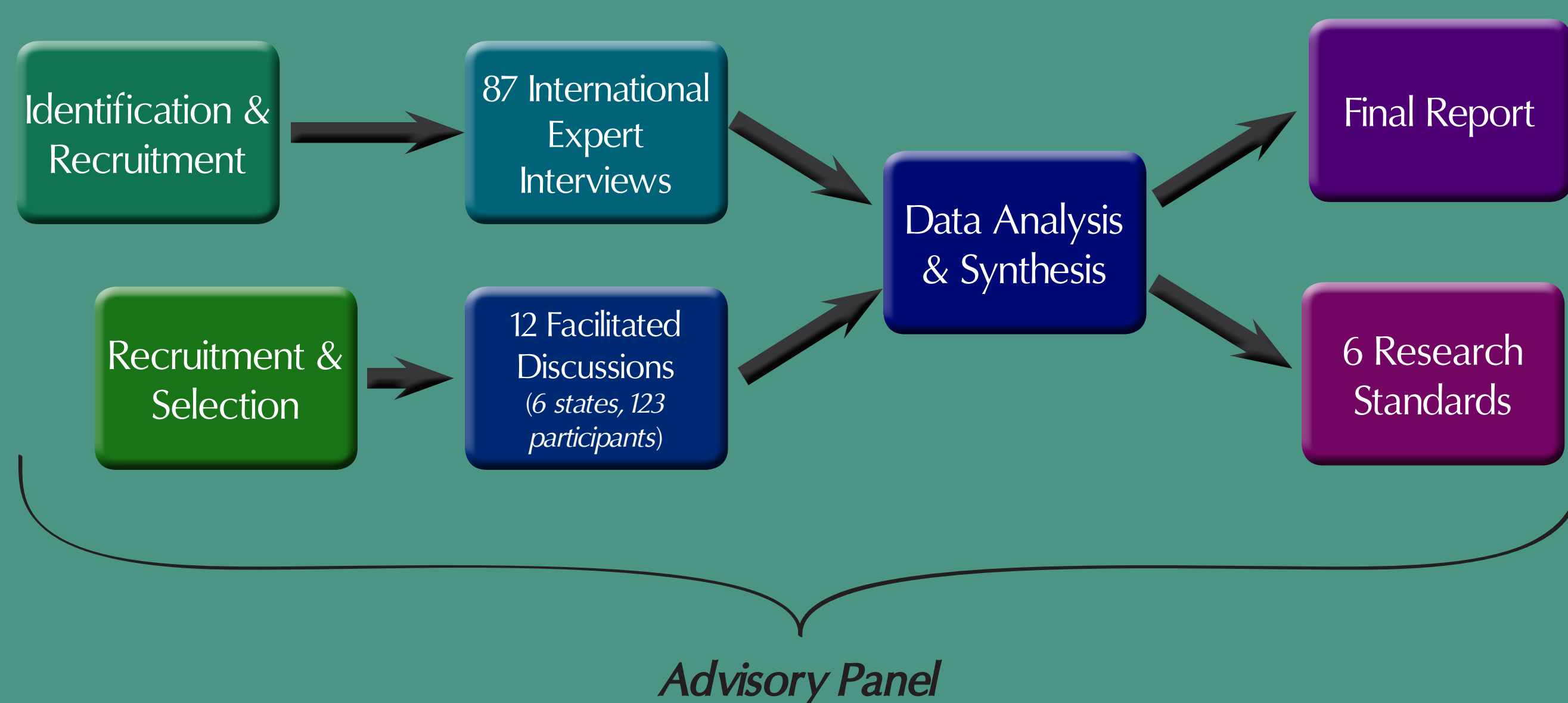
- Best practices and effective methods to identify, select, and involve patients in research processes
- Methods to elicit and incorporate these perspectives in research design and implementation

5%

Nov 2011 — Feb 2012

Project Implementation

Methods



Interviewees

Health researchers	21%
Advocates/organizations	16%
Health engagement professional	13%
Government	13%
Non-health researchers	9%
Health care providers	7%
Industry	6%
Patients	6%
Engagement pro.*	5%
Payers	3%
Caregivers	2%

Fields of Expertise

- Business
- Civic engagement
- Communications
- Criminal justice
- Environment
- Health
- Mental health
- Social services

Project Final Report

Analysis

To provide rapid turnaround, a qualitative analysis technique was utilized in which interview and discussion notes were coded in an online tool for high-level key themes.

Findings

The initial analysis of interviews and discussions revealed three key themes: respect, communication, and dedicated resources

Results

Patient engagement is a process, not a one-time event. Based on the project findings CEbP outlined an effective engagement process and recommended six research standards to the PCORI Methodology Committee.

Core Support

- Funding & Oversight
- Staffing
- General Outreach & Education
- Communication

Engagement Process



Draft Standards

- 1) Patient Involvement Across the Spectrum of Research Activities
- 2) Dedicated Resources for Patient & Other Stakeholder Involvement
- 3) Stakeholder Identification & Selection
- 4) Support for Patient Engagement
- 5) Communication with Patients & Other Stakeholders
- 6) Transparent Involvement Processes

Jul - Nov 2012

PCORI Methodology Report

The Expert Interview Project informed the development of PCORI's Draft Methodology Report (draft released July 2012 and approved November 2012), including standards for patient-centered outcomes research. For more information and access to the report, use the QR code.

