PCORI Expert Interviews Project

Best Practices for Patient Engagement in Research

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March 6, 2012
Bethesda, Maryland

Introductions

- Pam Curtis, MS, *Principal Investigator*
- Valerie King, MD, MPH, *Co-Principal Investigator*
- Cathy Gordon, MPH, *Research Associate*

Introductions

Beth Church, *Administrative Coordinator*

Catherine Pettinari, PhD, *Evidence Consultant*

Katharine Ryan, MPH, *Research Associate*

Samantha Slaughter-Mason, MPH, *Program Administrator*

Aasta Thielke, MPH, *Research Associate*

Outline

- Project process
    - Advisory Panel
    - Expert Interviews
    - Facilitated Discussions
- Findings & Key Themes
- Standards

PCORI Expert Interviews

PROJECT PROCESS

Advisory Panel

- 11 members
- Input provided on:
  - ✓ Study protocol
  - ✓ Key informants
  - ✓ Key informant interview guide
  - ✓ Facilitation guide and materials
  - ✓ Stakeholder category definitions
  - ✓ Final report & standards

Expert Interviews

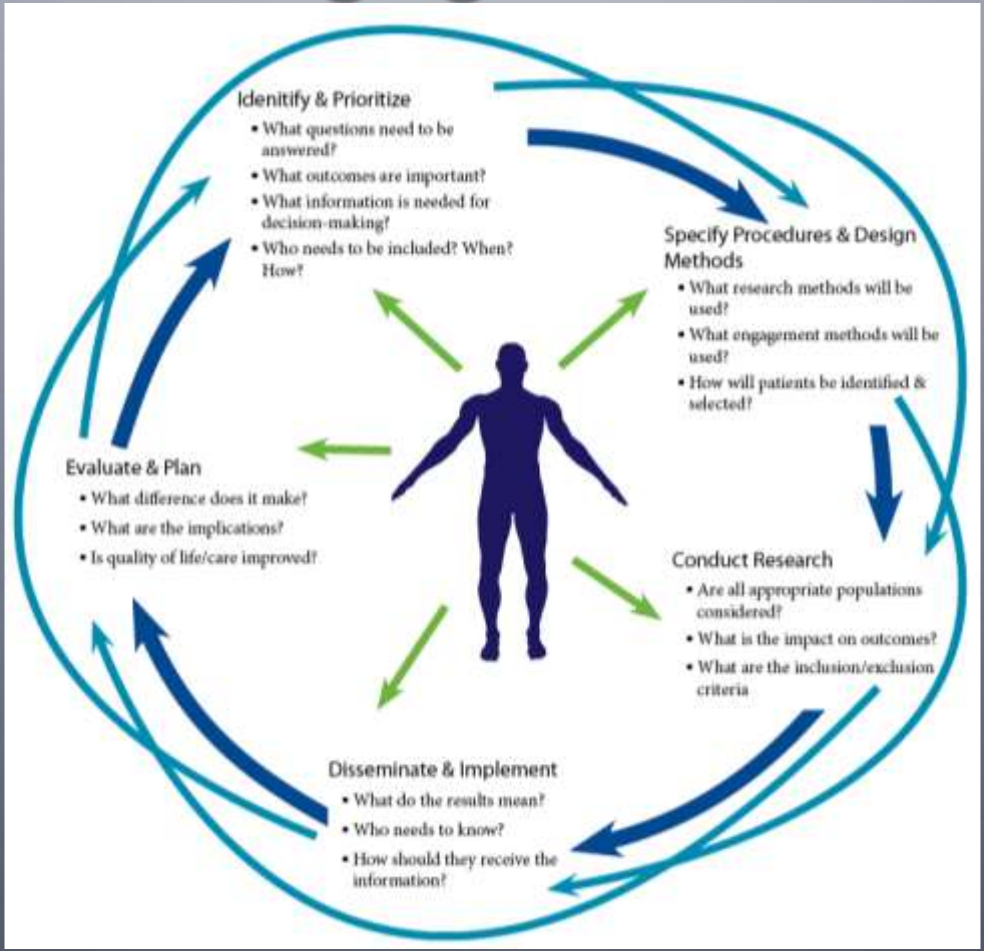
- 299 identified
    - Existing professional networks
    - Environmental scan
    - Snowball technique
- 128 contacted
- 87 completed
    - Phone
    - 30-60 minutes
    - December 12, 2011 – February 15, 2012

Facilitated Discussions

- PCI/UNCG partnership
- January 11 – February 9, 2012
- 123 participants
  - Patients
  - Caregivers
  - Public

FINDINGS & KEY THEMES

Points of Patient-Centered Engagement



Idenitify & Prioritize
- What questions need to be answered?
- What outcomes are important?
- What information is needed for decision-making?
- Who needs to be included? When? How?

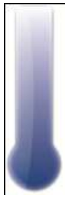
Specify Procedures & Design Methods
- What research methods will be used?
- What engagement methods will be used?
- How will patients be identified & selected?

Conduct Research
- Are all appropriate populations considered?
- What is the impact on outcomes?
- What are the inclusion/exclusion criteria

Disseminate & Implement
- What do the results mean?
- Who needs to know?
- How should they receive the information?

Evaluate & Plan
- What difference does it make?
- What are the implications?
- Is quality of life/care improved?

Strength of Evidence

Evidence Scale	
Strong 	Finding was consistently reported by experts from three or more disciplines, regions or countries, and/or participants from a majority of facilitated discussion groups. Practice or method is widely viewed as significantly contributing to successful engagement of stakeholders, and is broadly accepted as a best practice; or conversely, is widely viewed as ineffective and should not be used in engagement activities. Strong evidence may also include unique practices or methods that have deep support within two or fewer disciplines, regions or countries, and are based on extensive cumulative expert experience (e.g., engagement professionals have successfully employed the practice over several years).
Moderate 	Finding was regularly reported or recommended by experts from more than one but fewer than three disciplines, regions or countries, and/or participants in several facilitated discussion groups; or conversely, is widely viewed as ineffective and should not be used in engagement activities. Moderate strength of evidence may also include deep support within one discipline or region/country.
Weak 	Finding was supported by one or more experts but was not widely identified or used either within or across disciplines, regions, or countries, and participants in two or fewer facilitated discussion groups. Practices or methods with weak evidence may include new or innovative approaches to engagement where there is promise, but variation in application or experience.
Insufficient 	Finding was only identified by one or a few engagement experts or facilitated discussion participants and is new to practice and therefore lacks information on effectiveness.

Key Themes

- Respect
- Communication
- Dedicated Resources

Respect

- Trust
- Commitment to meaningful engagement
- Everyone possess expertise

Communication

- Knowledge exchange
- Listening to patients & keeping the patient perspective in mind
- Flexibility
- Transparency
- Two-way training & capacity building

Dedicated Resources

- Process
- Facilitation
- Funding & financial support

STANDARDS

Proposed Standards

1. Involve patients across the spectrum of research activities
2. Dedicate 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

Involve Patients Across the Spectrum

PCOR should strategically and systematically involve patients and other stakeholders in all stages of planning, conducting and implementing research. The goals, objectives and level of patient involvement at each phase will depend on the needs of the project and should be clearly articulated in all research projects. A patient engagement plan will be submitted as a required component of all proposals. PCOR projects that do not include patient and stakeholder involvement should provide rationale for exclusion. Research projects should report on all involvement activities including an evaluation of methods used.

Dedicate Resources for Patient & Other Stakeholder Involvement

PCOR should provide evidence of dedicated resources to support patient involvement activities in the conduct of research, including a stand-alone description of dedicated resources such as staff, budget, patient incentives and other items. Specific resources will vary depending on the particular research project and the level and depth of involvement. PCOR projects that do not include dedicated resources for patient involvement should provide rationale for exclusion. Research projects should evaluate and report on the use of these resources.

Stakeholder Identification & Selection

PCOR should demonstrate systematic and formal processes by which to identify, recruit, screen and select patients and other stakeholders to participate in PCOR activities. Research projects should evaluate and report methods for selecting patients and other stakeholders.

Support Patient Engagement

PCOR should have processes in place that support patients and other stakeholders involved in all phases of research. Processes should be broad enough to allow researchers flexibility in designing patient engagement activities and substantially directive enough to avoid tokenistic patient involvement. Institutional and organizational processes should provide direction on appropriate orientation, training, and general support for researchers, patients, and other stakeholders engaged in research.

Communication with Patients & Other Stakeholders

PCOR should demonstrate patient-centered communication styles and modes, including but not limited to consideration of culturally and linguistically appropriate language, impact of different interpersonal communication styles and use of facilitators skilled at eliciting patient perspectives.

Transparent Involvement Processes

PCOR should be conducted in an open and transparent manner. Research projects should provide clear and complete information regarding the purpose, goals, policies, timeline and processes by which they will engage patient and other stakeholders. PCOR projects should also provide clear and complete information regarding researcher, patient, and other stakeholders' roles and expectations for participation, as well as a description of decision making processes and dissemination plans. Information on processes regarding data use, management and ownership should be disclosed.

QUESTIONS

Questions for Discussion

1. How will patients, experts and others participating in this research receive feedback?
2. How can we make “patient engagement” sustainable in a non-system?
3. How can we change the culture of research, researchers, incentives, etc.?

Questions for Discussion

4. How do we implement local on a global scale?
5. How will PCORI reflect these findings?
6. Where’s the “death panel”?

Questions from PCORI