Assessment of Patient and Stakeholder Engagement in the PCORI Pilot Projects

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Introduction to Data Collection
Engagement refers to patients and stakeholders taking an active role in the research process in a way other than as subjects of research (Hanley et al. 2003, Telford 2002)

Positive suggested impact: producing research that is more relevant and more able to address their healthcare needs (Shippee 2013, Staley 2009, Entwistle 1998, Caron-Flinterman et al. 2005)

Despite growing interest, limited descriptive information (Workman 2013)
Research Objectives

- Characterize patient and other stakeholder engagement in PCORI Pilot Projects
- Identify early lessons learned
- Lay groundwork for future assessments of research engagement
- Answer questions of use to PCORI, its awardees and the PCOR community
Study Design and Methods

AcademyHealth and PCORI developed the self-report instrument to characterize engagement:
- Domains of interest: types of stakeholders engaged, stages and levels of engagement, facilitators and barriers, contributions of engagement, and lessons learned.
- Administered through an online survey platform in Summer – Fall 2013 to all 50 principal investigators.
- Quantitative and qualitative analyses.
Results Overview

- Responses from 47 of the 50 projects (94%)
- Majority of projects report engaging at least one stakeholder community (83%)
- Stakeholders were most commonly engaged as consultants or collaborators
- Additional insights from qualitative data
Characterizing Stakeholder Engagement (Quantitative Data)
Engagement of Stakeholder Communities

Stakeholder Engagement in the Pilot Projects (n = 39)

- Patient(s)/Consumer(s) (unaffiliated individuals) - 90%
- Caregiver(s)/Family Member(s)/ of Patient (unaffiliated individual) - 41%
- Patient/Consumer/Caregiver Advocacy Organization(s) - 41%
- Clinician(s) - 87%
- Clinic/Hospital/Health System Representative(s) - 44%
- Purchaser(s) - 3%
- Payer(s) - 3%
- Industry Representative(s) - 10%
- Policy Maker(s) - 18%
- Other - 10%
Patient and Clinician Engagement

Patient (n=34) & Clinician (n=29) Engagement by Research Stage

- Topic solicitation/agenda setting: 50% (Patients), 53% (Clinicians)
- Question development/framing: 69% (Patients), 76% (Clinicians)
- Proposal development: 41% (Patients), 56% (Clinicians)
- Methods/study design: 59% (Patients), 63% (Clinicians)
- Data collection: 56% (Patients), 66% (Clinicians)
- Data analysis: 24% (Patients), 38% (Clinicians)
- Results review/interpretation/translation: 41% (Patients), 47% (Clinicians)
- Dissemination: 24% (Patients), 28% (Clinicians)
- Other: 6% (Patients), 6% (Clinicians)
Commonly reported early tangible contributions of engagement include:

- Changes to project outcomes or goals
- Changes to project methods
- Enhanced access to populations or study settings
- Refinement of instruments and interview questions
- Interpretation and dissemination of results

“I can say with confidence that our project (the methods and even the project goals) has evolved, in some cases dramatically, based on our collaborations with stakeholders.”

“They have pilot tested our patient interview tool and provided very valuable feedback about the content and process we are using to interview patients.”
Early lessons learned identified by respondents include:

- Seek genuine partnership
- Select stakeholders strategically
- Involve stakeholders continuously
- Define expectations and roles
- Adapt to the practical needs of stakeholders
- Meet in person to build relationships

“Their participation was enhanced because they quickly realized that their role was not symbolic in nature but was integral to the project’s development in many ways.”

“Stakeholder engagement is project specific. Think wisely about what stakeholders are needed and which ones are missing.”

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Limitations and Strengths

Limitations

- First time fielded
- Potential for response bias
- Administered early into projects
- PI perspective only

Strengths

- Systematic data collection tool
- Provides comprehensive descriptive information on a topic for which there is a limited evidence base
Conclusions and Implications

- PIs report engaging a variety of stakeholder groups across multiple stages of research.
- PIs recognize the contributions of engaged stakeholders including changes to the research.
- Systematic characterization of engagement at multiple stages research is needed to further build the evidence base around promising practices for, and effects of, engagement.
Thank you!

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Citations


