Agenda for Today

- Review Plans for Measuring Engagement in PCORI-funded Projects
  - Discuss Engagement Activity Inventory

  And, if time allows,

- Review Plans to Survey Patients, Clinicians, and Researchers
  - Discuss Draft Items for Patients and Clinicians
Model for Evaluating the Overall Impact of PCORI

PCORI Way
- Topic Generation and Research Prioritization
- Merit Review
- Infrastructure for Patient-Centered CER
- Development of PCOR Community
- Research on Methods for PCOR and CER

Patient - Centered CER
- Engagement in Research
  - Methods Standards
- Intensive Portfolio Management
- Dissemination & Implementation Efforts
- Use of Information
- Uptake of Information

IMPACT
- Health Decisions
- Health Care
- Health Outcomes

Influence Others
Model for Evaluating Engagement in Research

Patient – Centered CER

Studies that Matter to Patients
- Changes to research questions, processes, & design
- Study participants’ experiences in the research
- Recruitment
- Retention
- Study Completion

Study Quality

Useful Information

Uptake of Information

Engagement in Research:
- Who is involved
- When engagement occurs
- Type of engagement
- Engaged partners perceived influence
- Experiences of engaged partners
- Principles of engagement

To whom & how results are disseminated

Trust in Information

Understanding Information

Patient-Centered Outcomes Research Institute
Multiple Purposes for Measuring Engagement

**Describe** engagement in PCORI funded projects
- Enhances communication with awardees, other researchers and potential research partners, external stakeholders

**Evaluate** engagement in PCORI funded projects
- Determine effect of engagement on PCORI strategic goals and other key outcomes of interest
- Evaluate Engagement Rubric
- Identify best practices for Engagement
- Inform PCORI funding requirements for engagement
Challenges for Measuring Engagement

- Engagement is a relatively new concept
- Measurement of engagement in the literature is limited
- Complex set of behaviors
- Subjective
- Dynamic
Domains of Interest for Describing Engagement

- Who is engaged
- Partnership characteristics – how formed, length, frequency of engagement, etc.
- Level of engagement
- When in research process are they engaged
- Perceived level of influence of partners
- Effects of engagement on research questions, study design, study implementation, and dissemination of results
- Challenges, facilitators
- Lessons learned for engagement
- PCOR principles (respect, co-learning, etc.)
ENgagement ACTivity Inventory (ENACT)

- Self-report tool intended to describe engagement in funded projects

- Versions developed for:
  - PCORI Pilot Projects
  - CER projects
  - PCORnet projects (to describe engagement of patients and other stakeholders in network development)
Development of the ENgagement ACTivity (ENACT) Inventory

Spring 2013
- Initial measurement tool developed by PCORI & Academy Health

July 2013
- Tool fielded with Pilot Project PIs

Fall 2013
- Engagement Rubric developed

Jan 2014
- Webinar with Pilot Project awardees re: initial findings

Fall 2013 to present
- Revisions to tool based on:
  - Rubric
  - Pilot project data collection and PI input
  - PCORI Evaluation Group
  - Patient Engagement Advisory Panel
  - PCORnet
  - Pipeline Intermediate Funder
Data collection decisions

- Collect multiple perspectives
  - ≥1 each of scientist, patient and stakeholder partners (as applicable)
  - Identified via proposal, PCORI program staff, and PI/partner inquiry as needed

- Field at baseline and 12, 24, and 36 months post-contract execution (for 3 year projects)

- Minimize time burden
  - Electronic skip patterns
  - Brief data updates following baseline data collection
Measuring impact: *Changes to research questions, process, and study design*

Perceptions of scientists and patient and stakeholder partners provided via the ENACT Inventory

- Perceived level of impact on:
  - each stage of the research process (question framing, study design, recruitment, etc.)
  - the way researchers and partners work together on this project
  - Research projects, other work, or relationships outside this specific project

- Description of specific impacts of engagement on each of the above
# Measuring Impact: Recruitment, Retention, and Study Completion

<table>
<thead>
<tr>
<th>Primary indicator</th>
<th>Recruitment</th>
<th>Retention</th>
<th>Study completion</th>
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</thead>
<tbody>
<tr>
<td>Recruitment proportion: % of those eligible who enroll</td>
<td>Retention proportion: % of participants enrolled who complete the study</td>
<td>Recruitment completion: enrollment completed (Y/N)</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other indicators</th>
<th>Recruitment</th>
<th>Retention</th>
<th>Study completion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment timing: % of projects ahead of, consistent with, and behind planned recruitment schedule</td>
<td>Retention proportion- hard-to-reach: % of hard-to-reach participants enrolled who complete the study</td>
<td>Recruitment completion – hard-to-reach: enrollment completed for hard-to-reach populations (Y/N)</td>
<td></td>
</tr>
<tr>
<td>Recruitment proportion-hard-to-reach: % of those eligible who enroll among hard-to-reach populations</td>
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<td></td>
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<tr>
<td>Eligibility: % of people presenting to study who are eligible</td>
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Measuring Other Impacts

What is the effect of patient and stakeholder engagement:

- On the functioning of the *Study Team*?
- On *Study Design*?
- On the Experience of *Study Participants*?
Next Steps

- Finalize ENACT
- Administer to studies at the 12 month mark
- Report initial results at end of year
- Incorporate ENACT into project start-up (baseline) and routine monitoring (yearly progress reports)
- Develop additional metrics for impact of Engagement
- Develop study protocols
Scientific Survey Project: Objectives

- To understand patient, health care provider, and researcher
  - attitudes toward and perceptions of CER.
  - understanding of and attitudes toward patient and other stakeholder engagement in research.
- To understand barriers to and facilitators of use of CER results in health decisionmaking and clinical practice.
- To develop methods to facilitate use of CER in health decisionmaking and clinical practice.
Scientific Survey Project

- Guided by multi-stakeholder advisory board and sample specific working groups
- Development of flexible item pools to be used for this and other efforts

Project Timeline:
- Cognitive testing: April – May 2014
- Data collection: June – August 2014
- Results available: October – November 2014
Scientific Survey Project

Patient survey: nationally representative sample of patients with chronic or rare conditions
- N = 1,000 – 1,500

Clinician survey: nationally representative sample of Primary Care Clinicians (MDs, PAs, NPs)
- N = 1,400

Researcher survey: sampling plan under development
I. GENERAL PRACTICE
• Typical decision making process
• Typical methods of patient education
• Satisfaction with current patient education materials

II. USING MEDICAL RESEARCH FINDINGS
• Looked for medical research to aid patient care?
• Where provider looked for medical research
• Ways provider uses medical research
• Factors about medical research that are important to providers
• Did medical research meet provider’s needs
• Factors about medical research important for patient decision making
• Usefulness of various resources in decision making process
• How well medical research answered questions important to patients
• Value of resources to making treatment recommendations
III. COMPARATIVE EFFECTIVENESS RESEARCH (CER)
- Familiarity with CER
- Types of research that are valuable in creating CER
- Frequency provider uses CER
- Usefulness of CER for clinical practice

IV. MEDICAL RESEARCH ENGAGING PATIENTS & CLINICIANS
- Familiarity with research that involves patients and practicing clinicians
- Views on the impact of including clinicians on medical research team
- Views on the impact of including patients on medical research team
- Types of research provider thinks clinicians would be valuable in
- Have providers ever worked as part of a medical research team (by task)
- Interest in working as part of medical research team (by task)
- Overall interest in working as part of medical research team
- Facilitators to engaging in working as part of a medical research team
- Barriers to engaging in working as part of a medical research team
- Benefits of working as part of a medical research team
Feedback on Draft Patient and Clinician Surveys

- Did we capture the most important domains?

- Suggestions for improvement to increase question understandability? Flow? Etc.?
Appendix: selected results from initial data collection with pilot projects
Engagement of Patient and Other Stakeholder Communities (n = 39 Projects)

<table>
<thead>
<tr>
<th>Stakeholder Category</th>
<th>Percent Response</th>
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<tbody>
<tr>
<td>Patient(s)/Consumer(s) (unaffiliated individuals)</td>
<td>90%</td>
</tr>
<tr>
<td>Caregiver(s)/Family Member(s)/of Patient (unaffiliated individual)</td>
<td>41%</td>
</tr>
<tr>
<td>Patient/Consumer/Caregiver Advocacy Organization(s)</td>
<td>41%</td>
</tr>
<tr>
<td>Clinician(s)</td>
<td>87%</td>
</tr>
<tr>
<td>Clinic/Hospital/Health System Representative(s)</td>
<td>44%</td>
</tr>
<tr>
<td>Purchaser(s)</td>
<td>3%</td>
</tr>
<tr>
<td>Payer(s)</td>
<td>3%</td>
</tr>
<tr>
<td>Industry Representative(s)</td>
<td>10%</td>
</tr>
<tr>
<td>Policy Maker(s)</td>
<td>18%</td>
</tr>
<tr>
<td>Other</td>
<td>10%</td>
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### Nature of Patient Involvement

<table>
<thead>
<tr>
<th>Nature of Involvement</th>
<th>Percent Response</th>
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<tbody>
<tr>
<td>Consultant</td>
<td>35%</td>
</tr>
<tr>
<td>Collaborator</td>
<td>53%</td>
</tr>
<tr>
<td>Patient-led</td>
<td>6%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
</tr>
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Patient Engagement by Stage in the Research Process (n = 35)

- Topic solicitation/agenda setting: 50%
- Question development/framing: 76%
- Proposal development: 41%
- Methods/study design: 59%
- Data collection: 56%
- Data analysis: 24%
- Results review/interpretation/translation: 47%
- Dissemination: 24%
- Other: 6%
Initial Learnings on Engagement

Themes include:

- Importance of
  - Choosing the right stakeholders
  - Communicating genuine interest in engagement
  - Facilitators like transportation and face-to-face meetings

- Amount of time needed to build relationships

- Differences among stakeholder communities

- Overall positive experiences for researchers and stakeholders
Stakeholders Provide New Perspectives

Both patients and clinicians challenge and stimulate you in multiple ways. They offer ideas about alternative strategies to try when things did not work out as expected.

Engaging patients, family members, and clinicians offers many opportunities to shape the research project in ways that are relevant...and to get input and knowledge that only these stakeholders have.

Engagement is essential...our project methods and goals have evolved, in same cases dramatically, based on our collaborations with stakeholders.
Stakeholders Contribute to the Research Methodology

They helped us get the right questions into our instruments.

They taught us a lot about our expectations for our pilot in regard to outreach to low education groups.

They have pilot tested our patient interview tool and provided very valuable feedback about the content and process we are using to interview patients.
Patients and Other Stakeholders Want to Be Engaged

Although it is difficult to enroll subjects in an inpatient setting, our experience is that patients appreciate the opportunity to tell their story and explain their understanding of their illness and reasons for hospital reutilization.

Patients and other stakeholders are very interested in contributing to research endeavors as long as they feel it is not tokenism or the desire for involvement is not sincere.