Agenda for Today

Recap from 10/15 meeting:
- Status updates
- Communicating about PCORI evaluation work

Focus on topic capture and research prioritization
- Process to date
- Evaluation planning

Key take-away points
HISTORY OF THE PCORI EVALUATION GROUP

Dec 2013 In-person Kick-off:
- Brainstorming and prioritizing evaluation questions
- Metrics for strategic goals

Jan 2014:
- Measuring engagement and its impact in PCORI projects

Feb 2014:
- Metrics for strategic goals
- Evaluation Framework and prioritization of evaluation questions

March 2014:
- Measuring engagement and its impact in PCORI projects
- CER Surveys: researchers, patients, & clinicians

April 2014:
- Measuring goal #1: useful information

May 2014:
- Overview of current data collection plans
- CER survey: Researchers

June 2014:
- PCORI Dashboard: metrics & visuals

July 2014:
- Need for an external evaluation for overall impact of PCORI?
- Methods for evaluating merit review

October 2014:
- Communicating PCORI’s Evaluation Activities
- Lessons learned for evaluation: Pronovost & Jha, 2014 (NEJM)
PCORI Evaluation Goals

- Steering PCORI: Determine progress against 3 PCORI goals
- Provide the public a framework for evaluating PCORI progress and provide progress updates
- Meet GAO requests
Status update: Measuring Progress on PCORI Strategic Goals

Goal 1: Useful information
- Applying usefulness criteria to the CER portfolio

Goal 2: Uptake of information
- Tracking early indicators of dissemination

Goal 3: Influence research
- Building repository of examples of PCORI’s influence

Future activities:
- Track additional metrics as study findings are available and implemented

PEG Meeting, November 5, 2014
Status update: PCORI Evaluation Framework

Evaluation questions, metrics, and data sources outlined and prioritized to guide evaluation projects

- What is the impact of PCORI’s approach to Topic Generation and Research Prioritization? → discuss at this meeting
- What is the Impact of PCORI’s Approach to Communication, Dissemination, and Implementation of information from funded research? → to discuss after release of PCORI’s D&I framework (Dec 2014)
Status Update: PCORI Dashboard

Used for quarterly reporting to PCORI Board of Governors
   ▪ Improvements in data to populate the dashboard and the visual presentation

Future activities:
   ▪ Update dashboard as more advanced metrics of PCORI strategic goals are available
PCORI Data Collection and Evaluation

Impact of PCORI Portfolio

Merit Review

Best Practices in Research Engagement

Patient and Other Stakeholder Knowledge, Attitudes and Behavior

PCORI Events

PEG Meeting, November 5, 2014
Agenda for Today

Recap from 10/15 meeting:
- Status updates
- Communicating about PCORI evaluation work

Focus on topic capture and research prioritization
- Process to date
- Evaluation planning
1. What is the impact of PCORI’s approach to Topic Generation, Prioritization, and Selection (inclusion of patients and other stakeholders, methods for ranking and selection) on:
   - perspectives incorporated into topic selection process,
   - the topics selected for funding, and
   - PCORI projects filling identified research gaps?

2. Compared to broad funding announcements, what is the effect of targeted funding announcements on the impact of information?

3. Compared to funding opportunities developed with input from scientists only, what is the effect of funding opportunities developed based on multi-stakeholder input on the impact of information?
Model: Topic Capture and Research Prioritization Evaluation Questions

PCORI Way

Topic Generation and Research Prioritization

- Perspectives Incorporated into Topic Selection Process
- Topics Selected for Funding

Patient-Centered CER

- Useful Information
- Uptake of Information

IMPACT
- Health Decisions
- Health Care
- Health Outcomes

PEG Meeting, November 5, 2014
1. What is the impact of PCORI’s approach to Topic Generation, Prioritization, and Selection on:

- perspectives incorporated into topic selection process:
  - Describe perspectives captured through public topic solicitation and engagement outreach
  - Tracking of progress of topics through prioritization by stakeholder category
  - Comparison of submissions against funded portfolio, by stakeholder category
 Patients don’t have research questions, they have questions
There are research questions others have identified that PCORI should address
Provide tracking of progress of topics through prioritization
The Advisory Panel meeting gave me the opportunity to provide input on PCORI's research topics.
The research prioritization process allowed me to systematically rank research topics.

![Bar chart showing responses from April 2013 (blue) and January 2014 (red) for Strongly Disagree, Somewhat Disagree, Neutral, Somewhat Agree, and Strongly Agree categories. The chart indicates a higher percentage of Strongly Agree responses in January 2014 compared to April 2013.]
I was able to objectively prioritize the research topics, without giving special preference to topics that are more relevant in my professional or personal life.
PCORI's method for research topic prioritization will help PCORI fund research that can inform health care decisions by patients.
Evaluation questions: 1 of 3

1. What is the impact of PCORI’s approach on:
   - perspectives incorporated into topic selection process,
   - the topics selected for funding, and
   - PCORI projects filling identified research gaps?

• Portfolio comparison PCORI vs …NIH
• Stakeholder rating of topic relevance
• Usefulness to end users
Evaluation Questions: 2 of 3

2. Compared to broad funding announcements, what is the effect of targeted funding announcements on the impact of information?

- Stakeholder rating
- Information use
Establishing metrics: Evaluation questions

- Is topic capture from the public yielding targeted PFAs and funded research proposals?
- How well does the PCORI research prioritization process address research gaps identified by scientists, patients, and stakeholders?
Submitted Topics by Disease/Condition*

- Allergies & Immune Disorders: 1.84%
- Blood Disorders: 0.08%
- Cancer: 9.55%
- Cardiovascular Health: 9.21%
- Dental Health: 0.50%
- Digestive Disorders: 0.25%
- Ear, Nose and Throat Diseases: 0.34%
- Eye Diseases: 0.42%
- Infectious Diseases: 2.60%
- Kidney Disease: 1.34%
- Liver Disease: 0.50%
- Mental/Behavioral Health: 16.33%
- Muscular and Skeletal Disorders: 8.04%
- Nervous System Disorders: 7.29%
- Nutritional and Metabolic Disorders: 10.05%
- Rare Diseases: 2.93%
- Reproductive and Perinatal Health: 10.39%
- Respiratory Diseases: 6.95%
- Skin Diseases: 1.09%
- Trauma/Injury: 7.04%
- Urinary Disorders: 0.67%

*Excludes topics where the disease/condition is “Unspecified”
**FUNDED PROJECTS BY DISEASE/CONDITION AND PROGRAM AREA (N=222)**

*excludes all Methods projects*

**NUMBER OF FUNDED PROJECTS**

- Allergies and Immune Disorders
- Cancer
- Cardiovascular Health
- Digestive System Diseases
- Infectious Diseases
- Kidney Disease
- Liver Disease
- Mental/Behavioral Health
- Multiple/co-morbid chronic conditions
- Muscular and Skeletal Disorders
- Neurological Disorders
- Nutritional and Metabolic Disorders
- Other or Non-Disease Specific
- Rare Diseases
- Reproductive and Perinatal Health
- Respiratory Diseases
- Skin Diseases
- Trauma/Injury
Submitted Topics (n=1163) v Funded Projects (n=189) by Disease/Condition*

*For topics, this does not include topics which do not specify a disease/condition. For projects, this does not include projects which are Methods, non-disease specific, or deal with multiple chronic conditions.
Spring 2013 Submitted Topics (N=923) & Prioritized Topics by Condition (N=33)*

*Excludes ‘Unspecified’ topics
(submitted N=556; prioritized N=13)
Comparison of submitted topics to IOM 100

EXACT MATCH
- The suggestion has the exact (or nearly exact) wording of the IOM 100, or the suggestion includes both the specific condition and intervention/comparators of an IOM 100.

SIMILAR
- The suggestion matches an IOM 100 disease/condition(s), or matches an IOM 100 intervention.

DISSIMILAR
- The suggestion does not match any of the disease/conditions or interventions of the IOM 100.

% Matching IOM 100 Topics

- Exact: 5.2%
- Similar: 16.6%
- Not Similar: 78.3%

PEG Meeting, November 5, 2014
Submitted Topics Matching IOM 100 Priorities by Condition (N=1200)*

*excludes ‘Unspecified’ topics N=603
Participating in the Advisory Panel meeting helped me to understand other peoples' perspectives on research.

*No data available for Jan-14
The Advisory Panel meeting gave me the opportunity to provide input on PCORI's research topics.
PCORI's method for research topic prioritization will help PCORI fund research that can inform health care decisions by patients.
April 2013 Prioritization by Stakeholder
APDTO Panel (1 of 2)
April 2013 Prioritization by Stakeholder APDTO Panel (2 of 2)
PCORI is evaluating topic capture and research prioritization along with other PCORI work.

We are looking at the:
- types of stakeholders that submit topics
- contribution to prioritization by stakeholder type
- comparison of submitted topics to PCORI-funded topics.

What other information should we collect to evaluate the impact of our topic capture and research prioritization process?
Goal #1: Usefulness Criteria

User-Driven

- The end-users (patients, clinicians, payers, organizations, health systems etc.) of the information have been identified (e.g., in the literature, through engagement with partners).
- The end-users (patients, clinicians, payers, organizations, health systems etc.) have identified this information would fill a critical gap (e.g., end-users generated the research questions).
- The end-users have committed to using the information (e.g., systems administrators/clinicians/etc. have committed to implement the intervention).

User-Focused

- The research assesses options that are relevant for the end users of the information.
  - The end-users were involved in choosing or developing the options.
- The research assesses the outcome(s) that will comprehensively address the needs of the end-users.

Real-World Users

- Results can provide a clinically (in addition to statistically) significant answer. The study would provide a clear answer, rather than calling for further research.
- Results can inform decisions of end-user(s) with specific characteristics, conditions, and preferences.
- Results can be scaled/spread beyond the traditional study setting for a wider net impact.
Goal #2: Uptake

**Dissemination**  
(Measure for all PCORI funded studies)

- Results reported back to study participants
- Access to PCORI study report
- Presentations:  
  - Scientific/professional audiences  
  - Lay audiences
- Bibliometrics:  
  - # of Publications  
  - Time to publication  
  - Impact factor  
  - Citations
- Alternative metrics for key groups (patients, clinicians, payers, etc.):  
  - # manuscript downloads  
  - # manuscript bookmarks  
  - Media coverage  
  - Social media coverage

**Uptake and Use**  
(Measure for a subset of PCORI funded studies)

- Adoption of study findings in the study setting
- Incorporation into:  
  - Systematic reviews  
  - Patient and consumer education materials  
  - Graduate Medical Education (GME) or Continuing Medical Education (CME)  
  - Practice guidelines  
  - Decision making infrastructure (e.g. electronic decision aids, clinical reference tools)  
  - Payer policies  
  - Institutional, local, state, and national policy

**Impact: Changes in Health Decisions or Care and Outcomes**  
(Measure for small set of exemplar studies)

- Improvement in health decisions or health care quality and improved health outcomes in relevant populations

Note: Most of these metrics are typically not measurable until after study completion, and in many cases, are typically not measurable until several years after study completion.
Goal #3: Influence

We are now or soon will be measuring:

- Endorsement, Promotion, and Dissemination of PCORI work
- Use of PCORI Methodology Standards for Patient-Centeredness
- Use of PCORI approaches:
  - Topic Generation and Research Prioritization
  - Merit Review
  - Engagement
  - Communication and Dissemination
- Use of PCORI guidance re: Patient-Centered CER
- Use of PCORI-supported curricula or training
- Collaborations/Co-funding with other funders

We will have to wait a few more years to measure:

- Use of PCOR Methods evidence
- Use and support of PCORnet
Topic Capture and Targeted Funding

- Falls in the Elderly: Clinical Trial of a Multifactorial Fall Injury Prevention Strategy in Older Persons
- Treatment Options for Severe Asthma in African-Americans and Hispanics & Latinos
- Comparative Effectiveness Research on Medical and Surgical Treatment for Uterine Fibroids
- Obesity Treatment Options Set in Primary Care For Underserved Populations
- The Effectiveness of Transitional Care
Topics prioritized 1-5 by Advisory Panels, received pragmatic trial application

- Identifying lung cancer in people with lung nodules
- Ductal Carcinoma
- Interventions to Promote Tobacco Cessation Among Vulnerable Populations
- Integration of Mental and Behavioral Health Services into Primary Care Settings
- Care management of multiple chronic conditions
- Hepatitis C
- Treatment options for opioid substance abuse
- Migraine headaches
- Coronary Artery Disease
- Treatment options for autism
- Osteoarthritis
- Heart attacks among racial and ethnic minorities
- Proton beam therapy for breast, lung, and prostate cancer
Topics prioritized 1-3 by Advisory Panels, prioritized by at least 2 other stakeholders (e.g. IOM, AHIP)

- Ductal Carcinoma
- Integration of mental and behavioral health services into primary care settings
- Cancer management
- Palliative care management
- Treatment Strategies for Atrial Fibrillation
- Migraine headache
- Coronary Artery Disease
- Major depressive disorders
- Treatment options for autism
- Heart attacks among racial and ethnic minorities