Patient-Centered Outcomes Research Institute
Dissemination Workgroup
Methodology Committee

“Can You Hear Us Now?”

Board of Governors Meeting
Jacksonville, FL
January 18-19, 2012
Members of the Workgroup

<table>
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<tr>
<th>Carolyn Clancy, <em>Co-Chair</em></th>
<th>Freda Lewis-Hall</th>
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<td>Sharon Levine, <em>Co-Chair</em></td>
<td>Steve Lipstein</td>
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<td>Lawrence Becker</td>
<td>Brian Mittman</td>
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<td>Allen Douma</td>
<td>Robin Newhouse</td>
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<td>Howard Holland</td>
<td>Grayson Norquist</td>
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<td>Gail Hunt</td>
<td>Jean Slutsky</td>
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“(c) PURPOSE.—The purpose of the Institute is to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions ....and the dissemination of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services, and items described in subsection (a)(2)(B).

“(1) DISSEMINATION.—The Office of Communication and Knowledge Transfer (referred to in this section as the ‘Office’) at the Agency for Healthcare Research and Quality (or any other relevant office designated by Agency for Healthcare Research and Quality), in consultation with the National Institutes of Health, shall broadly disseminate the research findings that are published by the Patient Centered Outcomes Research Institute established under section 1181(b) of the Social Security Act (referred to in this section as the ‘Institute’) and other government-funded research relevant to comparative clinical effectiveness research. The Office shall create informational tools that organize and disseminate research findings for physicians, health care providers, patients, payers, and policy makers. The Office shall also develop a publicly available resource database that collects and contains government-funded evidence and research from public, private, not-for profit, and academic sources.”
Timeline of Activities

- Formal launch of WG
  - Oct 2011
- RAND Presentation to WG (12/1)
  - Dec 2011
- AHRQ Presentation to WG (10/26)
  - Nov 2011
- WG three-hour teleconference (1/6)
  - Jan 2012
PCORI Dissemination Assumptions

- “Success” for PCORI and AHRQ = impact on practice and patient outcomes

- PCORI will disseminate results of PCORI-funded and conducted research and PCORI will also fund research on dissemination, but will complement and supplement what AHRQ/NIH are doing, not duplicate efforts

- PCORI has unique opportunities – and leg requirements

- Dissemination is essential and requires investment, which could occur in multiple ways:
  - Encourage / require “dissemination accelerating components” in all PFAs
  - Provide rapid follow-on funding for dissemination for selected studies
PCORI Dissemination Assumptions (cont’d)

- PCORI has a related role and opportunity in creating demand for, and receptivity to, PCOR in anticipation of evidence/research findings

- Not a one-size fits all endeavor—translating results, and influencing behavior, is context-dependent

- PCORI will be most effective by establishing partnerships early (with AHRQ, NIH, NGO’s and private sector actors) and clarifying what PCORI will and will not do

- Effective patient and stakeholder engagement, early on in the research endeavor, is the first step in planning and executing dissemination, and facilitating uptake
First Steps: Learning from the Work of Others

- Defining “successful dissemination” and potential obstacles/barriers to success
- Identifying dissemination activities of other organizations, namely AHRQ, to determine potential gaps that PCORI may fill
- Lessons learned from dissemination studies that may be relevant to PCORI activities
- Brainstorming strategies and assumptions to review with the Board of Governors, to inform PCORI’s Dissemination Framework and Strategy
### Existing Hurdles to Evidence Dissemination in the Health Care System

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<th>Category</th>
<th>Description</th>
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<tr>
<td>Limitations of the scientific evidence</td>
<td>Gaps in the medical evidence due to the limits of scientific knowledge, limitations of study design, or both</td>
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<td>Constraints on practicing clinicians</td>
<td>Little or no time to consult evidence or colleagues, limited reimbursement for consulting evidence, and limited skills among some clinicians for consulting electronic data sources</td>
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<td>Constraints on patients</td>
<td>Limited understanding of health care issues among many patients, and limited capabilities to make health care choices comprehensible to patients</td>
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<td>Limited incentives for clinicians to change practices</td>
<td>Lack of (or weakness of) financial and professional incentives for clinician attention to evidence-based guidelines/adherence to protocols, clinician distrust of an over-reliance on evidence (&quot;cookbook medicine&quot;), and organizational inertia</td>
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<td>Limitations in the presentation of evidence</td>
<td>Unclear presentation, inconvenient formats, and lack of clear rationale for action by the clinician or patient</td>
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<tr>
<td>Limited access to evidence</td>
<td>Uneven distribution of health care IT infrastructure and other resources that make evidence available in convenient forms</td>
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Anticipated hurdles to CER Dissemination:

- The public perception of CER and its legitimacy, including clinicians’ trust in systematic reviews and observational studies
- Lack of standard methodologies
- Speed of change in the evidence base
- Strength of evidence
- Heterogeneity of treatment effects

Drivers of CER Dissemination:

- The “Learning Health Care System” concept and the contextualization of evidence
- Patient-centered health care
- Mass media

New England Healthcare Institute (NEHI)

Building a Coherent Strategy For Dissemination – Policy Choices

- Use consistent evidence ratings
- Create partnerships with stakeholder groups
- Select high priority targets for dissemination
- Integrate CER dissemination into the deployment of health care IT
- Utilize patient and clinician incentives to promote comparative clinical effectiveness
- Communicate directly with the public and with patients

Note: The WG acknowledges that there is an engine in place (AHRQ) to address some of these issues, and there are required activities established under legislation.

AHRQ’s PCOR Activities

Goals

– Dissemination, translation, and implementation goals include fostering awareness and use of PCOR, informing professional and consumer audiences about AHRQ’s Effective Healthcare Program, and driving towards a greater degree of shared decision-making

Target Audience

– Audience is broad and includes healthcare providers, consumers, patients, caregivers, decision makers, policymakers, business leaders, and advocates
– Audiences are diverse and information needs to be framed differently for different audiences

Effective Health Care (EHC) Program

– EHC offers continuing education and other resources, and does a robust job of developing and testing various formats (received $300 M for PCOR activities under ARRA)
– Emphasis on user-driven synthesis; has produced more than 100 products for clinicians, patients and families, and policy makers
– EHC conducts research on dissemination and partnerships

http://www.nehi.net/publications/47/from_evidence_to_practice_making_cer_findings_work_for_providers_and_patients
AHRQ’s PCOR Activities

**Community Forum Project**
- Its purpose is to improve and expand public and stakeholder engagement in PCOR or CER
- It will identify useful and effective ways to engage stakeholders and the general public in AHRQ Programs

**iADAPT**
- Develop innovative ways to adapt and disseminate summary guides for health consumers.
- Supports Clinical Decision Support Systems, Culturally Tailored/Health Literacy, Communication/Marketing, Academic Detailing/CME

**Dissemination Contracts**
- Support national awareness building, establishment of regional partnerships, providing online continuing education, conducting academic detailing, and a systematic program evaluation

**Evaluation**
- Evaluate effectiveness of publicity centers, regional offices, continuing education, and academic detailing
- Determine the level of awareness, understanding, behavior change/use, and benefits of PCOR among targeted audiences

[http://www.nehi.net/publications/47/from_evidence_to_practice_making_cer_findings_work_for_providers_and_patients](http://www.nehi.net/publications/47/from_evidence_to_practice_making_cer_findings_work_for_providers_and_patients)
Important Take-Away Messages for PCORI

- Programs are most successful when they are audience-centered and use the audiences’ preferred formats and channels
- Credentials are important in gaining access to healthcare providers
- Health plans, health systems, and large medical groups are valuable sources of access to clinicians
- Clinicians want unbiased and balanced information from a trusted and credible source
- Disseminating new research differs from disseminating systematic reviews
RAND Briefing to PCORI

RAND Study Objectives

1. Developing a Dissemination Framework for assessing barriers and enablers to CER translation into practice

2. Identifying barriers to and enhancers of CER translation

3. Developing recommendations for more effective CER translation
### Case Study Topics and Results

- **CATIE:** Conventional antipsychotics had similar effectiveness and side effects vs. atypical antipsychotics

- **COURAGE:** Optimal medical therapy (OMT) provided equivalent survival benefit and comparable relief of angina to OMT + Percutaneous Coronary Intervention

- **COMPANION:** Compared to optimal medical therapy, both cardiac resynchronization therapy (CRT) and CRT + defibrillator reduced hospitalization rates, improved functional status, and improved survival

- **SPORT:** Surgery for lumbar spinal stenosis had better outcomes that non-operative treatment in a cohort study

- **CPOE:** Computerized Physician Order Entry significantly reduced the incidence of serious medication errors vs. paper-based entry
Based upon literature review/environmental scan, RAND developed a conceptual framework that included four phases of translation.
Little to no practice change, even when interventions were favored by results (i.e., implementation of results would have resulted in more aggressive or expansive practice).

For each of 5 studies, RAND assessed factors that prevented or slowed uptake into practice and root causes of incomplete translation were identified.

- Misalignment of financial incentives
- Ambiguity of CER results
- Cognitive biases
- Failure to address the needs of end users
- Inadequate use of decision support by patients and clinical professionals
Important Take-Away Messages for PCORI

- Potential for CER results to influence practice is not yet fully realized
- Current translation process is still ad hoc and post hoc with some exceptions
- Significant barriers to CER translation may be addressed through a variety of policy levers, namely building CER-enabling infrastructure with a focus on governance, standards, financing, appeals to professionalism, education and marketing, and research and evaluation
- Prospective studies of the CER translation process based on the proposed framework could guide future improvements
Important Take-Away Messages for PCORI (cont’d)

- CER results are sometimes outdated by the time the study ends—is there a way to get answers faster?
- Current under-appreciation for the roles of specialty societies in changing clinical practice
- Additional information on best practices, but also the rate of diffusion, is needed
- Need to create demand on the front end—this could be written into PCORI solicitations
- PCORI may want to engage cognitive psychologists

Dissemination and Adoption of CER Findings when Findings Challenge Current Practices

Eric Schneider
Justin Timbie

PCORI Dissemination Work Group
December 1, 2011
Developing an Overall Framework: Strategic Issues Raised by Presentations

- How can PCORI, building on AHRQ’s work, also work to address the “black box” between dissemination and uptake identified by RAND?

- Several of the areas identified by RAND for additional infrastructure focus are areas where PCORI could be involved: generation of CER; more effective translation; evaluation of impact; transparent governance

- Can we learn from examples of where translation works well?
  - Can we prospectively study both infrastructure and sociological factors that make things work?
  - How do we incorporate elements that work into design?
Developing an Overall Framework: Strategic Issues Raised by Presentations (cont’d)

- How do we set up a platform for dissemination that works and allows us to customize strategy to meet the needs of different audiences, given audience heterogeneity (diverse research, multilevel and multidimensional barriers, channels for dissemination)?

- What can be required component of all funding announcements that can accelerate dissemination—e.g., requirement for stakeholder engagement in a strategic and planned way?

- Can we provide additional, follow-on funding for dissemination and (?) implementation when studies have meaningful findings?

- How to anticipate and address potential resistance early in process?
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Next Steps

- Feedback from the Board at early stage (today; via COEC and PDC ongoing)
- Building a framework for PCORI dissemination
- Commissioning landscape review
- Articulating potential ‘dissemination acceleration components’ for PFA’s released in May, 2012