Welcome, Introductions & Review Agenda

Sue Sheridan, MIM, MBA
Director of Patient Engagement

Suzanne Schrandt, JD
Deputy Director of Patient Engagement

Charlotte W. Collins, JD
Chair

Darius Tandon, PhD
Co-Chair
### PCORI Advisory Panel on Patient Engagement

- Charlotte Collins
- Stephen Arcona
- Paul Arthur
- Kimberly Bailey
- Steven Blum
- Marc Boutin
- Kristin Carman
- Perry Cohen
- Amy Gibson
- Regina Greer-Smith
- Bruce Hanson
- Lorraine Johnson
- Julie Moretz
- Melanie Nix
- Sally Okun
- Laurel Pracht
- Lygeia Ricciardi
- Darius Tandon
- Sara van Geertruyden
- Saul Weingart
- Leana Wen
## Agenda for January 13

<table>
<thead>
<tr>
<th>Time</th>
<th>Agenda Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:15AM – 11:25AM</td>
<td>Welcome, Introductions and Review Agenda</td>
</tr>
<tr>
<td>11:25AM – 12:00PM</td>
<td>Update on the Engagement Rubric</td>
</tr>
<tr>
<td><em>Informational</em></td>
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<tr>
<td>12:00PM – 1:00PM</td>
<td>Update on Pipeline to Proposals Awards</td>
</tr>
<tr>
<td><em>Informational</em></td>
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<tr>
<td>1:00PM – 2:00PM</td>
<td>LUNCH</td>
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<tr>
<td>2:00PM – 3:00PM</td>
<td>Discuss Engagement Awards</td>
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<tr>
<td>3:00PM – 3:45PM</td>
<td>Review PCORI’s Evaluation Framework</td>
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<tr>
<td>3:45PM – 4:00PM</td>
<td>BREAK</td>
</tr>
<tr>
<td>4:00PM – 5:00PM</td>
<td>Discuss Position Statement on Parity in Compensation in Research</td>
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<tr>
<td><em>Create committee</em></td>
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<tr>
<td>5:00PM – 5:30PM</td>
<td>Update on Ambassadors Program</td>
</tr>
<tr>
<td><em>Informational</em></td>
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<tr>
<td>5:30PM – 6:30PM</td>
<td>Reception</td>
</tr>
<tr>
<td>6:30PM – 8:00PM</td>
<td>DINNER</td>
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</tbody>
</table>
Update on the Engagement Rubric

*Informational*

Sue Sheridan, MIM, MBA
Director of Patient Engagement

Suzanne Schrandt, JD
Deputy Director of Patient Engagement

Charlotte W. Collins, JD
Chair

Darius Tandon, PhD
Co-Chair
Objectives for Rubric Discussion

- To revisit the genesis and the purpose of the rubric and confirm that it aligns with PCORI Methodology Standards, PCOR engagement principles, and values.

- To share the current version of the rubric and the processes of approval and refinement that have taken place since the last PEAP meeting.

- To discuss implementation of the rubric in various PCORI programs and next steps.
Methodology Standards Associated with Patient-Centeredness

PC-1 Engage people representing the population of interest and other relevant stakeholders in ways that are appropriate and necessary in a given research context. Stakeholders can be engaged in the processes of:

- Formulating research questions;
- Defining essential characteristics of study participants, comparators, and outcomes;
- Identifying and selecting outcomes that the population of interest notices and cares about (e.g., survival, function, symptoms, health-related quality of life) and that inform decision making relevant to the research topic;
- Monitoring study conduct and progress; and
- Designing/suggesting plans for dissemination and implementation activities.
Engagement Principles

The rubric specifically focuses on patient and family engagement in research to help illustrate promising practices emerging in this relatively new area of engagement in research. The term used in the rubric, “patient partners”, is intended to include patients (those with lived experience), family members, caregivers and the organizations that represent them who are representative of the population of interest in a particular study.

There is an expectation that engagement of other stakeholders (e.g., clinicians, payers, or hospital administrators) that are relevant to a particular study will also have a parallel and similar review.

The rubric is to provide guidance to applicants, merit reviewers, awardees and engagement/program officers (for creating milestones and monitoring projects) regarding patient and family engagement in the conduct of research. It is not intended to be comprehensive or prescriptive.

The rubric is based on the promising practices identified in the first three rounds of PCORI awards. It is also consistent with PCORI’s Methodology Standards for patient-centeredness and its PCOR Engagement Principles.

The rubric is structured into four sections; planning the study, conducting the study, disseminating the study results, and global PCOR principles.

The rubric provides guidance to help applicants “show their work” when describing the details of how patient and family input will be incorporated throughout the entire research process.
## Planning the Study

### Formulating Research Questions and Study Design

<table>
<thead>
<tr>
<th>Patient partners participate in:</th>
<th>Examples:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identifying the topic and developing the research question to be studied.</td>
<td>• Epilepsy study: the patients and parents of patients with epilepsy pose the question: which anti-epileptic drugs best preserve sufficient cognition to go to work or school and function normally, while still preventing seizures adequately?</td>
</tr>
<tr>
<td>• Creating the intervention to be studied (if applicable) and identifying comparators.</td>
<td>• Asthma study: the patients and patients’ parents help create the paper asthma tracker tool being compared to the e-asthma tracker tool.</td>
</tr>
<tr>
<td>• In identifying the goals or outcomes of the interventions to be studied.</td>
<td>• Cancer study: patient partners determine that all women with breast cancer would be eligible for the study versus only women who had completed active treatment.</td>
</tr>
<tr>
<td>• Defining essential characteristics of study participants.</td>
<td><strong>How can you demonstrate this in your proposal?</strong></td>
</tr>
<tr>
<td>• Other study design and preparation.</td>
<td>• Provide letters of support from patient partners that clearly describe the origin of the study topic, the role of the patient partners in defining the question, outcomes, comparators, and goals/outcomes, etc.</td>
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<tr>
<td></td>
<td>• Include the patient partners in all relevant sections of the application, such as the biosketches, the budget, and the dissemination and implementation assessment.</td>
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<tr>
<td></td>
<td>• Avoid relying <strong>entirely</strong> on patient partners who have dual roles on the project, e.g., relying on stakeholders or researchers who also happen to be patients. Including one or more patient partners who have no other role on the project is important.</td>
</tr>
</tbody>
</table>
## Conducting the Study

| Participating in and monitoring the conduct of the project | Patient partners participate in and monitor the conduct of the research project. | Examples:  
- Chronic pain study: the informed consent document is developed with patient partners to make it understandable to study participants.  
- Epilepsy study: patient partner (and parent of patient) suggest that an adult survey tool be adapted for children to answer, and they help develop one.  
- Depression study: patient partners advise researchers to substitute the term, “emotional well-being,” for the term, “mental health,” to enhance the recruitment of study participants.  

How can you demonstrate this in your proposal?  
- Provide letters of support from patient partners that clearly describe the role of the patient partners in conducting and monitoring the study.  
- Clearly articulate in the application the roles of the patient partners in each component of the study, (e.g., helping to draft survey tools and focus group questions, reviewing participant materials for readability, etc.), including the dissemination and implementation assessment. |
## Conducting the Study (continued)

| Participating in and monitoring the conduct of the project | Patient partners participate in the recruitment and data collection from the study participants. | Examples:  
- Depression study: patient partners are trained to go out into the community to recruit study participants and to conduct interviews with them.  
- Depression study: patient advocacy groups assist with recruitment through their patient networks—the “book club” model.  

**How can you demonstrate this in your proposal?**  
- Provide letters of support from patient partners that clearly describe the role of the patient partners in interacting with study participants, if appropriate.  
- Clearly articulate in the application the roles of the patient partners in interacting with study participants (e.g., recruiting participants, conducting interviews, leading focus groups, etc.). |
**Conducting the Study** (continued)

| Participating in and monitoring the conduct of the project | The research team, including patient partners, actively evaluate patient engagement throughout the project. | Example:  
- ER study: The PI regularly asks the patient partners if they feel that they are truly involved in the research and if they think that their involvement is contributing to the research.  

**How can you demonstrate this in your proposal?**  
- Include in your application a plan for “check-ins” with patient partners to monitor their perceptions of the extent to which a) they are meaningfully involved in the study and b) their participation is contributing to the study.  
- Also include a plan for “check-ins” with the other research team members to monitor their perceptions of the extent to which a) patient partners are meaningfully involved in the study and b) their participation is contributing to the study. |
Disseminating the Study Results

Helping to plan the dissemination of the study’s results.

Patient partners are involved in plans for disseminating the study’s findings to patient, stakeholder, and research audiences so that the findings are communicated in understandable, usable ways.

Examples:
- Chronic pain study: patient partners co-author manuscripts, present at scientific and lay conferences, and share study findings through their networks.
- Cardiac study: a Patient Dissemination Board is helping to craft the dissemination plan and advise the research team on how to best share study findings.

How can you demonstrate this in your proposal?
- Provide letters of support from patient partners that clearly describe the role of the patient partners in planning the dissemination of the study’s results.
- In the application, clearly identify the role of patient partners in planning the dissemination of the study’s findings.
### Global Principles

<table>
<thead>
<tr>
<th>Reciprocal Relationships</th>
<th>The roles and decision-making authority of all research partners, including patient partners, are clearly stated.</th>
<th>Examples:</th>
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<tr>
<td></td>
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<td>• Many applications state that patient partners are co-investigators, and that decisions about the study are made by consensus among all the research project partners.</td>
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<td>• Many applications describe patient partners as key personnel, and their biosketches illustrate how the skills and experiences of the patient partners prepare them to function effectively in this role.</td>
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</table>

<table>
<thead>
<tr>
<th>Co-learning</th>
<th>The application includes plans to ensure that the patient partners will understand the research process and the researchers will understand patient centeredness and patient engagement.</th>
<th>Examples:</th>
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<tr>
<td></td>
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<td>• Training and educational opportunities are provided such as patient partner training in human subjects protection.</td>
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<td>• Training is provided by patient advocacy organizations, patient/survivor, and clinician/caregiver for the researchers providing the intervention (e.g., training in better communication with patients, led by patient instructors).</td>
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</table>
## Global Principles (continued)

| Partnership | Time and contributions of patient partners are valued and demonstrated in fair financial compensation, as well as reasonable and thoughtful time commitment requests. When the patient partners represent unique populations, the research team proposes to accommodate their cultural diversity and/or disability. | Examples:  
• Compensation for patient partners is included in the budget at market rates for consultants.  
• In a study focused on a Latina population, several members of the research team are Hispanic and fluent in Spanish.  
• In a project with a patient partner with a disability, the research team selects sites for team meetings that are accessible. |
| Trust, Transparency, Honesty | a) Major decisions are made inclusively and information is shared readily with all research partners,  
b) Patient partners and research partners express commitment to open and honest communication with one another.  
c) The study team commits to communicate the study’s findings back to the study community in a meaningful and usable way. | Example:  
• Commitments to trust, transparency, and honesty are stated in many applications – and supported by descriptions of how the research team will communicate with each other frequently, and make decisions about the study by consensus. |
## Rubric Template

<table>
<thead>
<tr>
<th>Global Principles</th>
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<tbody>
<tr>
<td>Reciprocal Relationships</td>
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<tr>
<td>Co-learning</td>
<td></td>
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<tr>
<td>Partnership</td>
<td></td>
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<tr>
<td>Trust, Transparency, Honesty</td>
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</table>

<table>
<thead>
<tr>
<th>Formulating Research Questions and Study Design</th>
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<tbody>
<tr>
<td>Participating in and monitoring the conduct of the project</td>
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<tr>
<td>Helping to plan the dissemination of the study’s results.</td>
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</table>
Implementation Plan

- Incorporate the rubric in the PCORI Funding Announcement (PFA), application guidelines, and research template in next cycle of funding in January/February 2014.

- Incorporate the rubric in Merit Review and Awardee training so that applications will be reviewed with the rubric as guidance and that Awardees are knowledgeable about engagement expectations.

- Establish PCORI Engagement Officers (EO) to effectively assure meaningful engagement in PCORI funded research. The EOs will use the rubric as a starting point for the establishment, monitoring and evaluation of the engagement milestones in a project.

- Utilize the rubric as an important training and evaluation tool for the Pipeline to Proposal awards program.

- Share the rubric through a robust PCORI Communications effort, through presentations at national conferences, and various publications to help achieve one of PCORI’s strategic goals to “Influence clinical and healthcare research funded by others to be more patient-centered.”

- Collaborate with PCORI Evaluation Group (PEG) regarding validation of the engagement scale.
Update on Pipeline to Proposals Awards

*Informational*

Sue Sheridan, MIM, MBA
Director of Patient Engagement

Suzanne Schrandt, JD
Deputy Director of Patient Engagement

Patient-Centered Outcomes Research Institute
Pipeline to Proposal Awards

- Tier 1
  - Up to $15,000
  - Up to 9 month term

- Tier 2
  - Up to $25,000
  - Up to 12 month term

- Tier 3
  - Up to $50,000
  - Up to 12 month term

PCORI Funding Announcement

Researchers who unsuccessfully submitted a PFA and need to improve proposal

Or submissions to other PCOR/CER Funders
Intermediate Funders and Pipeline Regions

Census Regions and Divisions of the United States

Patient Engagement Advisory Panel, January 13, 2014
Western Region Pilot
Thirty Awardees Announced December 2013

- Creating Healthy Communities: Engaging Native American and Spanish-Speaking Families and Sharing Family Wisdom to Reduce Childhood Obesity
- Improving the Lives of Alzheimer's Patients and their Caregivers: A Patient Centered Statewide Approach
- Mobilizing Community Engagement for Health in a Southern New Mexico Border Region Colonia
- New Mexico LGBT Health Improvement Network
- Usefulness of Pre-diabetes Management in Breast Cancer Care
- The Hispanic Family Asthma Outcomes Research Network
- Building Capacity for Novel Screening Delivery for Chronic Conditions to Benefit Miners in New Mexico
- Culturally Appropriate Options for Diabetes Prevention and Care for Low-Income Latinos
- Citizen Pscientist
- Developing Infrastructure for Patient Centered Melanoma Research
Western Region Pilot
Thirty Awardees Announced December 2013

- Establishing a Patient-Centered Research Community for Cystic Fibrosis
- Sepsis Survivors Engagement Project (SSEP)
- Preventing Missed Appointments for HIV Patients
- Empowering Patients and Their Families to Improve Outcomes That Are Most Important to Them after Lung Cancer Surgery
- YOU COMPLETE ME! Demonstrating the Efficacy of An Innovative Medical Appointment Model to Support Aging Patients
- Healthy Outcomes for Older Foster Youth
- Addressing Obesity in Latino Adolescents with Spina Bifida
- Creating the Patient Centered Primary Care Council in the Highland Hospital Adult Medicine Clinic: Strengthening Primary Care Together
- Health Literacy and the Patient Perspective in Primary Care
- Engaging Communities in the Fight Against Preterm Birth
Western Region Pilot
Thirty Awardees Announced December 2013

- Connecting Research and Real Life: Building a Network in the Columbia River Gorge
- Taking Care of Our Parents: Improving the Coordination of Care for Elderly Community Members
- Development of Community Partnership for Patient Centered Outcomes Research in Type 2 Diabetes
- Patient-Centered Transitions for Episodes of Surgical Care
- Increasing Patient Engagement and Capacity Building between Community Stakeholders and Patients in order to Improve Diabetes Education and Management among School-Aged Children
- Puget Sound Asthma Coalition: A Community, Clinical, and Academic Partnership
- The 'CISE' Project for Family Caregivers
- Making Stomach Cancer a Health Priority among Asian Americans
- Building a Community of Safe Sleep for Infants
- Patient-Centered Outcomes for the Parkinson's Disease Community in Wyoming
Western Region Pilot, by State

- Idaho award includes New Mexico, Oregon, and Wyoming
- Two of the Oregon awards are multi-state;
  - Oregon and Utah
  - Oregon and Washington
- No awards in AK, HI, or NV
Next Steps

- Evaluate West region Tier I pilot, revise processes as necessary
- Identify South, Midwest, Northeast, and national Intermediate Funders (IFs)
- Open first round of Tier I Pipeline Awards for South, Midwest, Northeast and national IFs
- Open first round of Tier II Pipeline Awards for all five regions
- Open first round of Tier III Pipeline Awards for all five regions
1 Hour Break

*Lunch is served in the Colonnade on the lobby level. We reconvene at 2:00 pm.*
Discuss Engagement Awards

Anne C. Beal, MD, MPH
Deputy Executive Director and Chief Officer for Engagement

Orlando Gonzales, MPA
Chief of Staff for Engagement

Alicia Thomas, MHS
Special Advisor for Engagement
“Today the Engagement imperative is evident in all of PCORI’s work because Dr. Washington’s vision and leadership were so keen in bringing patients and stakeholders of the entire healthcare community into the work that we do.”

Anne C. Beal, MD, MPH
Deputy Executive Director and Chief Officer for Engagement
Purpose of Engagement Awards

- Projects designed to provide “wrap-around” support and enhance impact of our major research awards
- NOT meant to be research, but meant to:
  - Support knowledge of PCORI’s work, and inform about our program efforts
  - Provide training and development of “non-usual suspects” and others
  - Disseminate the results of our research to promote implementation into practice
- Awards up to $250,000 total; products less than two years in length
- Project concepts provided in a Letter of Intent can be submitted on a rolling basis and will be reviewed periodically through the year
- Other objectives:
  - Engage new groups who have not previously been involved with PCORI
  - Develop new mechanisms for disseminating research findings
  - Promote research done differently by supporting the engagement and partnering
Engagement Priorities and Long Term Goals

Develop PCOR Community...

to successfully establish an infrastructure for patients, caregivers, and other stakeholders to increase comparative effectiveness research (CER) information and engage them in research, dissemination and evaluation

Engage Community in Research Process...

to influence research and establish trust and legitimacy for successful uptake of research findings

Promote Dissemination and Implementation...

so that patients, caregivers and other stakeholders have CER information they can use to make decisions that reflect their desired health outcomes and to speed implementation of our findings
## Enhancing the Impact of PCORI’s Research

<table>
<thead>
<tr>
<th>Activities</th>
<th>Knowledge Awards</th>
<th>Training and Development Awards</th>
<th>Dissemination and Implementation Awards</th>
</tr>
</thead>
</table>
| • Background papers  
  • Efforts to share information on PCORI and PCOR  
  • Gaining knowledge of the current state of comparative effectiveness research (CER) | • Develop a skilled “PCOR-ready” community  
• Data challenge  
• Researcher outreach  
• Identification of best practices for engagement | • Surveys and evaluation of current implementation practice  
• Dissemination collaborations  
• Any project to promote impact of PCORI’s findings |

| Goal | Develop PCOR community | Engage the community in research | Promote dissemination and research |
FY 2014 Proposed Budget

- $15.5M budget was approved by the PCORI board in November 2013.
- In 2014, most projects will focus on training and development.
- Pilots are currently in development in each award category.

- Knowledge Awards $5 million
- Dissemination Awards $2 million
- Training & Development Awards $8 million
Example Engagement Awards
Knowledge Awards Example: National Academy for State Health Policy

Awardee: National Academy for State Health Policy
- A non-profit and non-partisan organization, NASHP provides a forum for constructive work across branches and agencies of state government on critical health issues

Project title: PCOR/CER Roadmap for State Policymakers

Goal: promote use of PCORI’s findings by public payers
- Engage leaders of key state policymaker constituencies (e.g. state legislators, Medicaid directors, state employee health benefits administrators) in discussions of PCOR/CER
- Provide state policymakers a guide to understanding and use of PCOR/CER
- Uncover gaps in knowledge and PCOR/CER needs from state policymakers

Status: in progress
- Start date: August 15, 2013
- End date: May 14, 2014 (with three month PCORI option to extend)

Award amount: $291,272
Training and Development Awards Example: PhRMA Foundation

- **Awardee:** PhRMA Foundation
- **Project title:** PhRMA Foundation Comparative Effectiveness Research (CER) Education Conference
- **Goal:** influence development of PCOR training in several academic medical settings identified as leaders in the conduct of PCOR
- **Status:** in development
  - **Start date:** Q4 2013
  - **End date:** Q2 2014
- **Award amount:** TBD (~$25,000)
Training and Development Awards Example: Pipeline to Proposal Awards

**Tier I – Pre-Engagement/Community Projects**
- Purpose of Funding: Building of the community and capacity necessary to later develop a patient-centered comparative effectiveness research (CER) project addressing the issue of interest to the awardee.

**Tier II – Partnership and Infrastructure Development Projects**
- Purpose of Funding: Maturation of research partnerships with the goal of receiving PCORI or other CER project funding. The funds are to be used to strengthen the partnerships and further develop the infrastructure and governance structures laid out during Tier I and to lay groundwork for the ultimate drafting of a patient-centered CER proposal.

**Tier III - Proposal Development Projects**
- Purpose of Funding: Proposal development, targeting advanced potential research partnerships (those who are “almost there”) that could benefit from working with awardee partners to draft a strong patient engagement plan and a rigorous science proposal.
Dissemination Awards Example: Primary Care Physicians Survey

- Awardee(s): American Academy of Family Physicians, American College of Physicians, American Academy of Pediatrics, and American Osteopathic Association are working together to create a survey of their members.
- Possible title: Primary Care Physician Use and Understanding of PCOR/CER.
- Outcome: collaborate with primary care medical societies to develop understanding of their use and opinions related to CER/PCOR to inform future outreach efforts to the primary care physician community.
- Status: in development
  - Start date: Q4 2013
  - End date: Q2 2014
- Award amount: TBD (~$250,000)
Engagement Awards Brainstorming Session
Session Objectives

- Develop a shared understanding of specific **issues** and the types of **project** ideas that address the issue.
  - Clarify and add to the list of issues.
  - Provide input on additional projects to consider.

- Highlight key **audiences** to which notice of the Engagement Awards program should be directed, as well as **mechanisms** by which to disseminate and promote this information.
Advisory Panel Potential Project Suggestions

- Knowledge Awards
- Training and Development Awards
- Dissemination, and Implementation Awards
### Knowledge Awards: Potential Project Ideas

<table>
<thead>
<tr>
<th>Issues/Needs</th>
<th>Projects</th>
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</thead>
</table>
| To further understand the role, importance, and usage of CER by various stakeholder groups (e.g. patients, primary care physicians, nurses, caregivers, etc.). | - Develop surveys of patients through a network of patient organizations and of primary care physicians through the specialty societies.  
- Catalog and promote CER’s “greatest hits.”  
- Develop a funding stream for patient groups to develop capacity. |
| To identify and address barriers in patient engagement in CER.               | Conduct a survey and other methods of identifying the barriers from all research participants. |
| Establish some differentiation for PCOR by highlighting the differences between PCOR and community-based participatory research (CBPR). | Commission a white paper |
| To understand how CER intersects with quality improvement and patient safety. |          |
# Knowledge Awards: Potential Project Ideas

<table>
<thead>
<tr>
<th>Issues/Needs</th>
<th>Projects</th>
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<tbody>
<tr>
<td>To address the most pressing health needs of various stakeholder groups.</td>
<td>Develop strategies for garnering meaningful CER-focused research topics and questions from various stakeholders.</td>
</tr>
<tr>
<td>To identify how much patient engagement makes a difference.</td>
<td>Evaluate and determining the scale for the engagement rubric.</td>
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# Training & Development Awards: Potential Project Ideas

<table>
<thead>
<tr>
<th>Issues/Needs</th>
<th>Projects</th>
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<tbody>
<tr>
<td>To enhance the capacity of non-researchers in PCOR.</td>
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<tr>
<td>Establish models for incentivizing researchers to partner with consumers to generate CER.</td>
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### Dissemination & Implementation Awards: Potential Project Ideas

<table>
<thead>
<tr>
<th>Issues/Needs</th>
<th>Projects</th>
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</table>
| Uncovering educational constructs related to CER from the patient/stakeholder perspective. | Commission a white paper whereby a contractor provides answers to these questions:  
  - What do patients need to understand, as it relates to CER?  
  - What is the process by which patients use CER and incorporate it into their medical decision-making? |
| To understand and identify well established patient groups that are well positioned to disseminate and spread CER research information. | Commission a landscape review identifying key patient groups. |
| To increase awareness on the value of CER, evidence based medicine and patient-centeredness. |
Target Audiences & Channels to Promote the Engagement Awards

- Identify key audiences to which notice of the Engagement Awards program should be directed?
- Which communication channels effectively target and engage these audiences?
- Who should we consider partnering with in promoting Engagement Awards?
The Engagement Awards will be launched on **February 13, 2014** through a live webinar.

- A formal portal through which project ideas may be submitted with debut during this webinar.

In the interim, advisory panel members can send additional Engagement Awards-related ideas/suggestions to PCORI staff at **ea@pcori.org**.
Thank you

As previously noted, you and your colleagues can ask additional questions or submit ideas to ea@pcori.org.
Evaluating Our Work

Lori Frank, PhD
Program Director, Research Integration and Evaluation Program

Laura P. Forsythe, PhD, MPH
Program Officer, Research Integration and Evaluation Program

Michele Orza, ScD
Senior Advisor to the Executive Director

Patient-Centered Outcomes Research Institute
Our Evaluation Activities

Our objective is to produce information that is useful to us and others to improve our work and advance the science and practice of Patient-Centered Outcomes Research.

We plan to conduct this work in a manner consistent with our values and methods – rigorous, focused on and engaging of stakeholders, efficient.

We are committed to sharing and using this information.
**Evaluation Framework: Our Questions and How We Will Answer Them**

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Metrics/Indicators</th>
<th>Methods</th>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do PCOR and PCORI stakeholders want/need to know?</td>
<td>For each question, what are we measuring and how will we measure it?</td>
<td>What approach will we take to answering this question?</td>
<td>From where will we get the data to answer this question?</td>
</tr>
</tbody>
</table>

Why would we do this evaluation – what is the objective? How would it fit into the bigger picture – our overall framework? What would we do with the results of this evaluation?
Developing Our Evaluation Framework
Guidance from PCORI's Methodology Report

PCORI’s Translation Framework for choosing research designs/methods:

- Keep the question and the methodology separate
- Focus on clarifying tradeoffs
- Place individual studies in the context of a program
- Have the choice of study design take into account state-of-the-art methodology
Our Strategic Framework/High-level Logic Model

<table>
<thead>
<tr>
<th>STRATEGIC IMPERATIVES</th>
<th>OUTPUTS</th>
<th>GOALS</th>
<th>IMPACT</th>
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<tbody>
<tr>
<td>How We Create</td>
<td>What We Create</td>
<td>What We Accomplish</td>
<td>Why We Do It</td>
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<tr>
<td>Engagement</td>
<td>Skilled Patient-Centered Outcomes Research Community</td>
<td>Increase Information</td>
<td>Better Informed Health Decisions</td>
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<td>Patient-Centered Outcomes Research Methods</td>
<td>Speed Implementation</td>
<td>Better Health Care</td>
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<td>Portfolio of Patient-Centered Outcomes Research Studies</td>
<td>Influence Research</td>
<td>Improved Health Outcomes</td>
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<td>Communication and Dissemination Activities</td>
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<td>Patient-Centered Research Networks</td>
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Patient Engagement Advisory Panel, January 13, 2014

Patient-Centered Outcomes Research Institute
2014 ENGAGEMENT ACTIVITIES

**Strategic Priority: Develop Community Skilled in PCOR**
- Refine PCORI's engagement infrastructure and plan
- Train an expanded cadre of patients and all other stakeholders
- Assess need for and expand training curriculum and opportunities
- Evaluate and refine training activities
- Expand on pilot Eugene Washington Engagement Awards for Knowledge building
- Launch PCORI Ambassadors Program

**Strategic Priority: Engage Community in Research Processes**
- Establish Rare Disease Advisory Panel
- Establish Communication and Dissemination Advisory Panel
- Establish additional multi-stakeholder groups as needed to guide topic generation, prioritization, and selection

**Strategic Priority: Engage Community in Dissemination**
- Establish plan and infrastructure for engaging stakeholders in PCORI's peer review, publication, and dissemination processes
- Expand on pilot Eugene Washington Engagement Awards for Dissemination

**Expected Outputs**

**Skilled PCOR Community**
- Advisory Panelists
- Merit Reviewers
- Ambassadors
- Engagement Awardees
- Training Curriculum
- Training Opportunities

**PCOR Methods**
- Tested Engagement Methods

**Portfolio of PCOR Studies**
- Stakeholder-driven Agenda
- Stakeholder-engaged Studies

**Communication and Dissemination Activities**
- Stakeholder-engaged:
  - Peer Review
  - Publishing
  - Dissemination Activities
- Engagement Awardee Activities

**Patient-Centered Research Networks**
- Patient-Powered Research Networks

**Goals**

- Substantially increase the quantity, quality, and timeliness of useful, trustworthy information available to support health decisions
- Speed the implementation and use of patient-centered outcomes research evidence
- Influence clinical and health care research funded by others to be more patient-centered

*Patient Engagement Advisory Panel, January 13, 2014*
The Big Questions

Does “Research Done Differently” make a difference? Is it worth it?
- In the usefulness of information? (First Goal)
- In the use of information? (Second Goal)
- In how others conduct research? (Third Goal)
- In health outcomes? (Impact)

What are the effects of “the PCORI way” on the quality of research and usefulness of the information that results? Is it worth it?
- Patient-centeredness
- Engagement
- Methodology Standards
- Active Portfolio Management (Prioritization, Merit Review, Oversight)
- Communication and Dissemination
- Infrastructure Building – The National Patient-Centered Clinical Research Network

If it works, what’s the best way to do it? For example, Engagement:
- Who needs to be engaged?
- In what should they be engaged?
- How should they be engaged?

What are the most effective ways to engage people?
Prioritizing Evaluation Questions

Right
For
PCORI

Uniqueness
Appropriateness
Capability

High
Collaborate
Lead

Low
Monitor
Coordinate
Facilitate
Fund

Low

Potential to Impact PCORI’s Work and the Field

Patient Engagement Advisory Panel, January 13, 2014
Getting More Specific, Example: How Does Engagement Affect Recruitment?

**ENGAGEMENT**
- Role on Study Team
- Question Development
- Study Design
- Recruitment
- Data Collection
- ???

**RECRUITMENT**
- Pace of Recruitment
- Eligibility Rate
- Completion of Recruitment
- Retention Rate
- ???

Patient Engagement Advisory Panel, January 13, 2014
We Need Your Help!

Identify and Prioritize Evaluation Questions

Determine how to characterize and measure:

- The PCORI Way – for example, Engagement (Relates to discussion of engagement rubric)
- PCORI’s Goals – for example, Usefulness (Following-up on this morning’s discussion)

Think about the appropriate comparators for PCOR and PCORI
The Big Questions

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Appendix: Evaluation Activities Underway

Pilot Project Learning Networks

Evaluations of:
- Engagement by Awardees
- Application Process
- Merit Review
- PCORI Events (Roundtables, Workshops, etc.)

Surveys of Stakeholders

Evaluation Component of PCORnet

Performance Monitoring (Dashboard)
15 minute break

*Refreshments in the hall*
Discuss Position Statement on Parity in Compensation in Research

*Create committee*

Sue Sheridan, MIM, MBA
Director of Patient Engagement

Suzanne Schrandt, JD
Deputy Director of Patient Engagement
Update on Ambassadors Program

*Informational*

Sue Sheridan, MIM, MBA
Director of Patient Engagement

Suzanne Schrandt, JD
Deputy Director of Patient Engagement

Aingyea Kellom, MPA
Program Associate, Patient Engagement
Program Overview

The volunteer initiative that trains, equips, and mobilizes patients, caregivers, organizations and other stakeholders to share PCORI’s vision, mission and PCOR principles with their respective communities, participate as full partners in research and to help assure the sharing and uptake of information generated from PCORI funded projects.

Train….Ambassador Training: Five modules of training focused on PCORI, their role, PCORI funding, and working in research teams

Equip….Ambassador Toolkit: Provides support material such as talking points, presentation template, social media guide

Mobilize…Ambassador Yammer Community: Online community that encourages the exchange of best practices in different communities
Session Objectives

- **Provide an update on the status of the program**
- **Training:** To share an update on PCOR Training
- **Equip:** To receive feedback on current materials and the need for other tool-kit materials
- **Mobilize:** To provide a brief update of Ambassadors in Action
- To share the implementation plan of evaluation strategy
Important Program Dates

- **September 20, 2013**: Inaugural Ambassadors invited to join.
- **October 25, 2013**: Program webpage launched and sent invites to merit reviewers, workgroup, roundtable, & regional event attendees.
- **December 10, 2013**: Phase I of Training Live: Module 1: Introduction to PCORI & Module 2: The Role of the Ambassador.
Ambassador Interest by Region and Ethnicity

- Asian (Not Hispanic or Latino): 6%
- Black or African American (Not Hispanic or Latino): 9%
- Hispanic or Latino American: 72%
- Other: 2%

Region Breakdown:
- WEST: 7%
- SOUTHWEST: 11%
- SOUTHEAST: 19%
- MIDWEST: 21%
- NORTHEAST: 42%

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Which of the following is your primary community?
Part I of training launched on December 10th

- Feedback: Issues logging in using different devices, more testing of knowledge, and release of training in parts

Part II of training will launch on January 31

Ambassadors will be listed on the PCORI website after they complete Part II of training
Tool-kit Materials

- We currently have template PowerPoint, social media guide, talking points, FAQs, and leavebehinds

- Have you found the materials useful? What else is needed?
Ambassadors In Action

Yammer
- 48 users currently, averaging 11 engaged user per month

Ambassadors have....
- Completed presentations in their communities
- Applied or recommended an individual to be considered as a panelist for the two new advisory panels
- Joined as a patient partner for a funded project
- Been featured as a PCORI blogger or in a webinar
- Joined PCORI workgroup
Program Evaluation

Evaluation of two populations:

- Ambassadors
  - Web Interest Form
  - Activity Report
  - Mid- and one-year survey

- Organizations that hosted a PCORI Ambassador speaking engagement
  - Activity Report Follow-up
Q&A
Reception and Dinner

*In the Colonnade on the lobby level.*

*We reconvene tomorrow at 8:30 am*