



# **Advisory Panel on Improving Healthcare Systems**

*May 8, 2014*

*9:00 a.m. – 5:45 p.m. EDT*

Patient-Centered Outcomes Research Institute



## Welcome & Introductions

*Steve Clauser, PhD, MPA*

*Director, Improving Healthcare Systems*

Patient-Centered Outcomes Research Institute

# Housekeeping

- Today's webinar is open to the public and is being recorded.
- Members of the public are invited to listen to this teleconference and view the webinar.
- Anyone may submit a comment through the webinar chat function, although no public comment period is scheduled.
- Visit [www.pcori.org/events](http://www.pcori.org/events) for more information.

# Panel Leadership

- Steven Clauser, PhD, MPA
  - IHS Director, PCORI
- Trent Haywood, MD, JD
  - IHS Advisory Panel Chair
- Doris Lotz, MD, MPH
  - IHS Advisory Panel Co-Chair

# Advisory Panel Members

- **Andrew Adams, BBA *(Not Attending)***  
*MBA Candidate, The Wharton School of the University of Pennsylvania*
- **Leah Binder, MA, MGA**  
*President & CEO, The Leapfrog Group*
- **Mary Blegen, RN, MA, PhD, FAAN**  
*Adjunct Professor, College of Nursing, University of Colorado at Denver*
- **David Bruhn, PharmD, MBA**  
*Health Outcomes Liaison, National Accounts, GlaxoSmithKline*
- **Daniel C. Cherkin, MS, PhD**  
*Director, Bastyr University Research Institute  
Senior Scientific Investigator, Group Health Research Institute*
- **Alan B. Cohen, MS, ScD**  
*Professor, Health Policy and Management, Boston University School of Management*
- **Elizabeth D. Cox, MD, PhD**  
*Associate Professor, Departments of Pediatrics and Population Health Sciences, University of Wisconsin-Madison*
- **Susan Diaz, MPAS, PA-C**  
*Physician Assistant, Liver Transplant, Mayo Clinic in Florida*
- **Michael R. Dueñas, O.D.**  
*Chief Public Health Officer, American Optometric Assn.*
- **John A. Galdo, PharmD, BCPS**  
*SClinical Pharmacy Educator, Barney's Pharmacy*
- **Eve A. Kerr, MD, MPH *(Not Attending)***  
*Director, Ann Arbor Center for Clinical Management Research*
- **Joan Leon, BA**  
*Retired Health Consultant*
- **Tiffany Leung, MD, MPH**  
*Postdoctoral Fellow, Medical Informatics, Center for Innovation to Implementation, VA Palo Alto Health Care System Center for Health Policy/Center for Primary Care &*
- **Outcomes Research (CHP/PCOR), Stanford University**  
**Annie Lewis-O'Connor, NP-BC, MPH, PhD**  
*Nursing Scientist Director - Women's C.A.R.E Clinic Brigham and Women's Hospital*
- **John Martin, MPH**  
*Senior Director, Research Operations, Premier Inc.*
- **Lisa Rossignol, MA**  
*Graduate Student, Health Communication, University of New Mexico*
- **Anne Sales, RN, PhD**  
*Professor, School of Nursing, University of Michigan*
- **Jamie Sullivan, MPH *(Not Attending)***  
*Director of Public Policy, COPD Foundation*
- **Leonard Weather Jr., MD, RPH**  
*Director, Omni Fertility and Laser Institute*



# PCORI IHS Staff

- Lynn Disney, PhD, JD, MPH
  - Senior Program Officer
- Alex Hartzman, MPH, MPA
  - Program Associate
- Lauren Holuj, MHA
  - Program Associate
- Hannah Kampmeyer
  - Senior Administrative Assistant
- Beth Kosiak, PhD
  - Contractor



# Today's Agenda

- Setting the Stage (9:15 – 10:10 a.m.)
- Break (10:10 – 10:20 a.m.)
- Topic Presentations and Discussion (Topics # 1 – 3) (10:20 – 11:45 a.m.)
- Conflict of Interest Discussion (11:45 a.m. – 12:00 p.m.)
- Working Lunch - Funding Updates and New Opportunities (12:00 – 1:00 p.m.)
- Group Picture (1:00 – 1:10 p.m.)
- Topic Presentations and Discussion (Topics # 4 – 9) (1:10 – 3:45 p.m.)
- Break (3:45 – 3:55 p.m.)
- Open Discussion of All 9 Topics (3:55 – 4:35 p.m.)
- Panelists Enter Scores / Rank Topics (4:35 – 4:45 p.m.)
- Topic Presentations and Discussion (Insurance Features) (4:45 – 5:30 p.m.)
- Closing Remarks / Review Day 2 Agenda (5:30 – 5:45 p.m.)
- Adjourn (5:45 p.m.)
- Dinner – The St. Gregory Hotel (6:30 – 8:30 p.m.)

# Meeting Objectives

- Address Issues Raised in Our Last Meeting
- Update Panelists Regarding the Status of IHS Funding and Other Initiatives
- Inform Panelists Regarding New Opportunities
- Prioritize Topics for Future Funding
- Develop a Plan for the Year Ahead



## Setting the Stage

*Trent Haywood, MD, JD*

*Doris Lotz, MD, MPH*

*IHS Advisory Panel Co-Chairs*

Patient-Centered Outcomes Research Institute

# Issues Raised Last Meeting

- Clarity of Roles and Responsibilities
- Communication / Information Flow
- Administrative Duties
- IHS Strategic Framework

# Clarity of Roles and Responsibilities:

## *Q&A Session with PCORI Leadership*

- Outcomes of the April 28<sup>th</sup> Q&A Session with PCORI's Executive Director and Board Member
  - Major issues discussed
  - Outstanding issues
  - General feedback regarding the value of this session

# Clarity of Roles and Responsibilities:

## *Review of Role Definitions Document*

### Review Role Definitions Document

- Co-Chairs worked with IHS staff
- We are now seeking input from all panelists

### Open Discussion

- Do the roles make sense?
- Which do you agree with and disagree with?
- Can we clarify any of these further?
- What is missing?

### Operationalizing This Document

- Will this influence how our panel functions moving forward?

### Other Ideas for Clarifying Roles?

# Communication / Information Flow

- Quarterly Newsletter Distributed April 1<sup>st</sup> included:
  - Panel updates
  - Upcoming meetings / opportunities
  - Topic-specific research activities update
    - Included all topics previously prioritized by the Advisory Panel
  - Broad portfolio updates
    - Number and size of projects funded by the IHS program so far
    - Full list and description of those studies
  - Other general advisory panel updates (for all panels)
- Does This Seem to Meet Your Information Needs?

# Administrative Duties

- Panel Meetings Scheduled for the Term Year
  - May 8-9; Sept. 29-Oct. 2; Jan. 12-15
- Co-Chairs Meeting with PCORI Staff Monthly
  - Please raise issues you feel we need to discuss
- Distribution of Meeting Materials / Topic Briefs
  - Well in advance of the meeting

# IHS Strategic Framework

- Advisory Panel Subcommittee met Monday to review and discuss the current strategic framework, and opportunities for improvement
  - IHS Goal Statement
  - Healthcare System Definition
  - IHS Strategic Framework
- Next Steps:
  - Review models in the literature for potential incorporation
  - Add to the “Healthcare System Definition”
  - Incorporate a systems engineer’s perspective
  - Consider additional “drivers of health system change”
- Review updated version with Panel at September meeting

# Discussion



## Break

10:10 – 10:20 a.m. (EDT)

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## Topic Presentations (# 1 – 3)

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# Topic 1: Health IT and Treatment Adherence in Chronically Ill Patients

*Presented by Tiffany Leung*

- Compared to usual care alone, what is the effect of the addition of information technology (e.g., personal health record/patient portals and decision support) on chronically ill patients' adherence to treatment plans?

# Topic 1: Health IT and Treatment Adherence in Chronically Ill Patients

Presented by Tiffany Leung

## Overview of topic

- Poor adherence to treatment plans for chronic disease lead to poor outcomes.
- Personal health records (PHR), patient portals, and decision support systems (DSS) may be an opportunity to improve adherence and health outcomes.
- CER on optimal IT features is lacking. IT features are heterogeneous, as are patient populations (e.g. multiple morbidity, technological proficiency, etc.).

## Significance (from your perspective)

- Health IT adoption among providers and patients is rapid and ongoing.
- There is significant opportunity here for CER to inform the use of health IT.

# Topic 1: Health IT and Treatment Adherence in Chronically Ill Patients

Presented by Tiffany Leung

## What questions need to be answered?

- What are optimal health IT features of PHRs, patient portals, and DSS?
- How are patient outcomes affected by health IT?
- How are health disparities, including literacy, affected by health IT?
- What are patients' preferences for health IT features and their satisfaction?
- What health IT implementation methods are most effective?

## Timeliness – why should PCORI take this up now?

- Health IT is evolving quickly, its adoption rapid and ongoing.
- CER would inform optimal applications of health IT for chronic disease.

# Topic 2: Multicomponent Interventions and Medication Adherence in Chronically Ill Patients

*Presented by David Bruhn and Jake Galdo*

- What are the comparative effects of multicomponent interventions on chronically ill patients' adherence to their prescribed medications?

# Topic 2: Multicomponent Interventions and Medication Adherence in Chronically Ill Patients

Presented by David Bruhn and Jake Galdo

- Most common disease states in US (in order)
  - Obesity, Hyperlipidemia, Depression, Asthma, Diabetes, COPD, Heart Disease
  - ~42% of Americans have a chronic condition
- Treatment adherence (taking medications, following diet/exercise plans) is about 50 percent in developed countries
  - Non-adherence to treatment plans is expected to cause ~125,000 deaths/year
- Comparative effects of multicomponent interventions on chronically ill patients' adherence to therapy (medications)

# Definition

- Various types of multicomponent interventions found in the literature
  - Provision of tools to improve medical adherence
  - Patient motivation, education, and training interventions
  - Treatment and medication adherence-related reminders

# Questions to Answer

- What is known about the relative benefits and harms of available multicomponent interventions
- What new research comparing multicomponent interventions contribute(s) to achieving better PCO
- Have recent innovations made research on this topic especially compelling
- What are the benchmark multicomponent interventions from which to conduct comparative effectiveness research

# Timeliness- why should PCORI take this up now?

- Understanding why people are not adherent to treatment plans is a complex process, but necessary to ensure that any interventions developed and measured address these core reasons
- Identifying barriers to nonadherence may be a relevant and timely topic for consideration
- Timeliness of comparing multicomponent interventions will be challenge, but not insurmountable

# Topic 3: Communication Technologies and Patients with Chronic Conditions

*Presented by Elizabeth Cox and Anne Sales*

- What are the comparative effects of different communication technologies (e.g., mobile health, telehealth, Skype) used in care management on the outcomes of patients with chronic conditions?

# Topic 3: Communication Technologies and Patients with Chronic Conditions

Presented by Elizabeth Cox

## Overview of topic

- >130M (42%) with chronic condition; 25% have more than 1 chronic condition
- Profound effects on QOL and functional capacity
- Many strategies with variable characteristics (e.g. real time vs asynchronous)
- Used to educate and monitor primarily, less so with consult/diagnosis

## Significance

- Current acute care model inadequate
- Numerous studies demonstrating wide ranging benefits, limited long term outcomes
- Uncertainty about which technologies and for whom
- Long drives to care for many with complex, severe, pediatric, or rare chronic illness

# Topic 3: Communication Technologies and Patients with Chronic Conditions

Presented by Elizabeth Cox

## What questions need to be answered?

- What are the comparative effects of different communication technologies used for care management of chronic illness?
- Patient-level barriers/facilitators, especially with hard to reach populations
- System-level incentives for healthcare providers to engage with these technologies
- Which outcomes matter?
- Resource allocation

## Timeliness?

- Connectedness is ever growing
- Younger folks communicate this way so our face-to-face care model may not work well for them now or as they develop chronic illnesses
- Overburden primary care workforce
- Many ongoing and planned studies



# Topic 3: Communication Technologies and Patients with Chronic Conditions

Presented by Anne Sales

- Overview of topic
  - Common health problems ranging from obesity to cancer
  - Most require ongoing interactions with health care providers/system
- Significance (from your perspective)
  - Affects a lot of people
  - High burden
  - High cost
  - Huge hassle factor and likelihood of people dropping through gaps
- What questions need to be answered?
  - What is effective?
    - And for what purpose?
  - What will patients and providers use and/or accept?
    - What will it take to get both to use specific forms?
  - How to use asynchronous communication safely?
- Timeliness – why should PCORI take this up now?
  - There are a number of research projects underway funded by other agencies
  - Unclear how patient-centered these are
  - Patient-centeredness and engagement are keys to patient acceptance and use
    - However, this is not enough; must be uptake on provider side also





## Conflicts of Interest

*Jayne Jordan*

*Special Assistant to the General Counsel*

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## Working Lunch - Funding Updates and New Opportunities

*Steve Clauser, PhD, MPA*

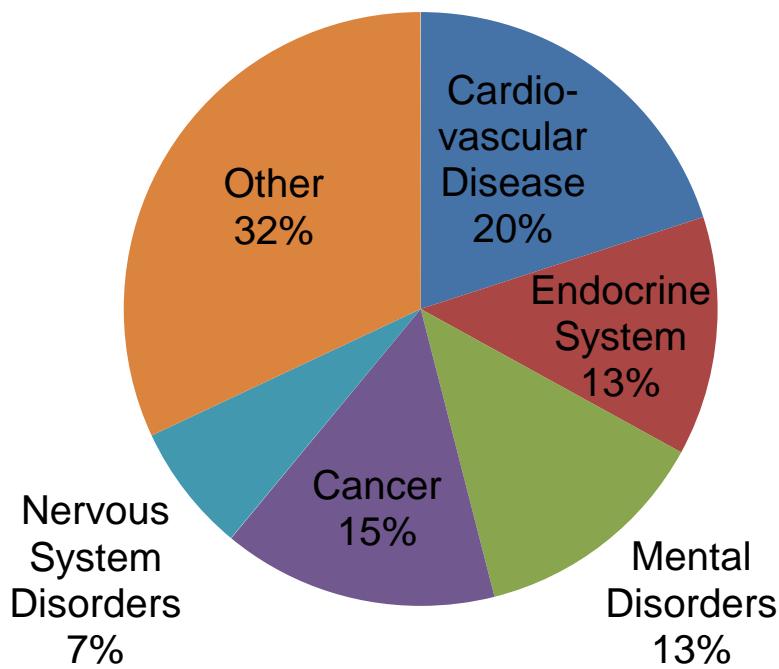
*Director, Improving Healthcare Systems, PCORI*

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# IHS Broad Portfolio to Date

Projects that address critical decisions that face healthcare systems, the patients and caregivers who rely on them, and the clinicians who work within them.

## By Primary Health Topic



Broad Funding Cycle	Number of Projects Funded by IHS	Total Funding Allocated
Cycle I	6	\$15.8 million
Cycle II	13	\$19.5 million
Cycle III	13	\$24.5 million
August 2013 Cycle	9	\$16.7 million
<b>Total</b> <i>(as of March 2014)</i>	<b>41</b>	<b>\$76.5 million</b>

# Targeted Funding

## Preventing Injuries from Falls in the Elderly

- Single \$30 Million award to be announced Spring 2014

## The Effectiveness of Transitional Care

- 4 / 23 LOIs invited to submit full applications
- 4 applications received 5/6/14
- Merit Review in August 2014

## Patient Empowering Care Management

- Staff working with the John A. Hartford Foundation
- Developing a model of empowering care for older adults with multiple chronic conditions
- *Joan Leon please add a few words about your experience*



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# Targeted Funding Continued

## Perinatal Care

- Working with the Addressing Disparities team
- MOU to be signed with NICHD / Aiming to write a funding announcement for anticipated release in Fall 2014

## Integration of Mental Health and Primary Care

- Pragmatic Clinical Studies and Large Simple Trials
- Applications Due August 2014

## Health Insurance Features

- Pragmatic Clinical Studies and Large Simple Trials
- Applications Due August 2014
- New Topic Brief Developed – Discussion this afternoon



# Spring 2014 Cycle: Available Funding

## Broad Funding Announcements

Assessment of Prevention, Diagnosis, and Treatment Options	\$32 Million
Improving Healthcare Systems (Large and Small)	\$16 Million
Communication and Dissemination Research	\$8 Million
Addressing Disparities	\$8 Million
Improving Methods for Conducting PCOR	\$17 Million

## Targeted Funding Announcements

Effectiveness of Transitional Care	\$15 Million
Obesity Treatment for Underserved Populations	\$20 Million

Pragmatic Clinical Studies and Large Simple Trials	\$90 Million
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Total Funding Available: \$206 Million



# Targeted Funding Announcements

- Ideal to assure that certain high priority questions are addressed in our research program
- Most Resource Intensive
  - **Time:** ~1 year from prioritization to announcement  
Prioritization → Landscape Review → Expert Workgroup → SOC Committee → BOG Approval → Write Announcement
  - **Budget:** \$10 - \$30 Million for one or more studies
- Transitional Care is the only Advisory Panel-prioritized topic (PCORI-wide) to complete this entire process

# Partnerships with Outside Organizations

- Partnerships defined in a memorandum of understanding (MOU)
  - PCORI provides research funding and expertise to assure adherence to PCORI's requirements, mission, and overall objectives in the study. Outside organizations provide expertise, resources, and in kind support.
  - Ideal for targeted or focused projects that require specific expertise and resources available from outside organizations.
  - Time:** MOU signed within a few months and fiscal year \$ allocated
  - Budget:** Allocate \$20 - \$30 Million

## Example Partnerships

- PCORI / NIA – Falls Injuries Prevention Partnership
  - \$30 million to fund a clinical trial of a multifactorial fall-injury-prevention strategy in older persons.
- PCORI / NICHD – Perinatal Care Partnership
  - IHS and AD working to develop a funding announcement in collaboration with NICHD

# Pragmatic Clinical Studies and Large Simple Trials

**Number of Anticipated Awards: 6 - 9**

**Funding Available: \$90 Million**

**Maximum Direct Costs Per Project: \$10 Million**

**Maximum Project Duration: 5 years**

Identifies research topics of interest, but allows investigator to select research questions, designs and methods.

Improving Healthcare Systems (IHS) included three IHS Advisory Panel designated priority areas:

- Integration of Mental and Behavioral Health Services in Primary Care
- Health Insurance Features
- Adherence to Medication Regimens

Other IHS-relevant research topics included in IOM's Top 100 Topics for CER or AHRQ's Future Research Needs.



## New Opportunities

*Choosing Wisely: An Initiative  
of the ABIM Foundation*

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# New Opportunities

## Choosing Wisely: An Initiative of the ABIM Foundation

- In 2012, the American Board of Internal Medicine (ABIM) enlisted medical specialty societies to identify 5 clinical procedures, tests or therapies of questionable value to promote appropriate care and encourage greater efficiency
- Some 60 medical societies have endorsed more than 230 recommendations to date.
- The categories of topics include:
  - Excessive imaging
  - Unnecessary screening or diagnostic tests
  - Unwarranted medications
- The campaign's goal is to facilitate conversations between physicians and patients concerning the appropriateness of such interventions

# New Opportunities

## Choosing Wisely: An Initiative of the ABIM Foundation

- Consumer Reports has created consumer friendly resources, and Robert Wood Johnson Foundation provided \$2.5 million that ABIM distributed to 21 medical and state societies and regional health collaboratives
- ABIM has approached PCORI about collaborating on CER to engage patients, clinicians and health systems. Possible research questions include:
  - Which approaches work best to improve patient/physician communication, and lead to better patient outcomes, such as improved quality of care, reduced harm, and increased patient involvement in decisions about their care?
  - What types of health system interventions are useful to achieve these outcomes in a more effective and efficient patient-centered way?
- This initiative would be a collaborative research initiative between IHS and PCORI's Communication and Dissemination Research program.

# Discussion



## Break – Group Picture

1:00 – 1:10 PM (EDT)

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## Topic Presentations (# 4 – 9)

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# Topic 4: Patient and Caregiver Engagement in Chronic Mental Illness

*Presented by Susan Diaz and Michael Duenas*

- Compared to usual care, do treatment strategies that involve both patients and their families/caregivers improve outcomes among patients with chronic mental illness (e.g., bipolar disorder and major depression), including members of historically underserved populations?

# Topic 4: Patient and Caregiver Engagement in Chronic Mental Illness

Presented by Susan M. Diaz

## Overview of topic

- Chronic Mental Illness (CMI) is the leading cause of disability in the US. Lack of diagnosis, variability of treatment options, disparities and burden on caregivers are significant burdens on society.

## Significance

- Patients are not getting the appropriate care for CMI due to lack of diagnoses.
- This leads to ED visits, decrease productivity of patients, morale issues in work environment due to sick days and stress on the caregivers.
- The stress and burden on all stakeholders lead to more stress on the healthcare delivery system for patients, caregivers and employers.
- The lack of consistent defined guidelines on how to help caregivers deal with CMI leads to poor outcomes and lack of understanding about CMI which creates further stress on people and society.

# Topic 4: Patient and Caregiver Engagement in Chronic Mental Illness

Presented by Susan M. Diaz

## What questions need to be answered?

- How does early and accurate diagnosis impact morbidity and mortality of patients with CMI?
- What simple tools can be used in the ED setting to assist providers who suspect CMI to diagnose it?
- How can the healthcare psychiatric community help general providers treat CMI and connect caregivers with appropriate resources?
- Are there sufficient appropriate resources for caregivers of patient with CMI?
- Do the resources available, address ethnic and cultural differences? If not, what resources are available to help ethnic groups?

## Timeliness – why should PCORI take this up now?

- To improve the healthcare delivery of CMI patients, patients with CMI continue to be “forgotten” due to the difficulty/burden/etc associated with CMI. The cost of CMI contributes to the burden of healthcare and the lack of studies on engagement supports this. CMI is a chronic disease just like DM, CAD, Asthma and HTN.



# Topic 4: Patient and Caregiver Engagement in Chronic Mental Illness

Presented by Michael Dueñas

## Overview of topic

- Includes; major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, Posttraumatic stress disorder (PTSD) and borderline personality disorder.
  - Leading cause of disability in the U.S.
  - Affects an estimated 26.2 percent of adult Americans in a given year.
  - Almost half of U.S. adults will develop at least one mental illness during their lifetime.

## Significance (from your perspective)

- High disease burden with lifelong personal, societal, family and occupational consequences.
- High disparities in potential and realized access to care.
  - Less than half of patients with mental disorders received any treatment in past 12 months (1/3 received minimal treatment).
- Limited multidisciplinary actions;
  - to reduce, comorbidities (e.g. *social isolation, falls, substance abuse, risky behaviors*).
  - to identify suitable and effective family/caregiver engagements.
  - to use mental health extenders (e.g. *community health workers*).



# Topic 4: Patient and Caregiver Engagement in Chronic Mental Illness

Presented by Michael Dueñas

- What questions need to be answered?
  - Do increased levels of empowered social support, provided patients and caregivers, lead to higher treatment satisfaction and improved therapeutic outcomes as compared to standard care?
    - Best and Expanding Methodologies (e.g. *building community connectedness, social capital*)
    - Secondary Benefits (e.g. *reduced comorbidities and reduced need for hospitalization or emergency care*)
- Timeliness – why should PCORI take this up now?
  - Strong potential to reduce high personal and societal mental health burden
  - Limited data from Randomized Trials and Patient-centered Outcomes Studies
  - Self-reported data support need for further study (*BRFSS*)

National Data Sets: BRFSS- Mental Illness and Stigma Module 2005-2013<sup>1</sup>

BRFSS 2007 (n= 202,065)	All Adults (Agreement)	Adults with Mental Health Symptoms (Agreement)
Treatment can help persons with mental illness lead normal lives	88.6%	77.6%
People are generally caring and sympathetic to persons with mental illness	57.3%	24.6%

<sup>1</sup> MMWR, Attitudes Toward Mental Illness-35 States, DC and Puerto Rico, 2007, May 28, 2010/59(20):619-625

# Topic 5: Rural and Frontier Trauma

*Presented by Lisa Rossignol and Elizabeth Cox*

- Compared to direct transportation to a regional trauma center, what is the effect of stabilization at a local hospital (followed by transfer to a regional trauma center) on survival and other patient-centered outcomes?

# Topic 5: Rural and Frontier Trauma

Presented by Lisa Rossignol

## Overview

- Severity of condition can be determined by NISS/ISS
- Preference of transfers given to children, elderly, pregnant women
- Destination determined by availability, proximity, triage

## Significance

- Injury is leading cause of death for people under the age of 45.
- Rural citizens are nearly 4 times more likely to die from severe injury.
- Very little in literature. What is there has questionable methods.

## Questions

- Would rural care centers have infrastructure to track this?
- Would rural/frontier care centers be able to implement change based on findings?

## Timeliness

- This is highly endangered population, there is very little currently being done to study, impact can be immense.



# Topic 5: Rural and Frontier Trauma

Presented by *Elizabeth Cox*

## ● Overview of topic

- Trauma is leading cause of death under age 45
- PCOs include return to work and ongoing disability
- 38M live >1 hour from certified trauma center
- Injury severity and mortality are double in rural areas

## ● Significance

- Variability in outcomes with limited focus on PCO
- Variability in care patterns--direct and indirect referral to definitive care
- Referral bias
- Lower mortality and costs with direct referral, although evidence is low quality



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# Topic 5: Rural and Frontier Trauma

Presented by *Elizabeth Cox*

## What questions need to be answered?

- Compared to direct transport to trauma center, what is the effect of local stabilization followed by transport for rural patients with trauma?
- What are the most effective strategies to improve outcomes after rural trauma?
  - Aftercare services?
  - How to overcome system-level barriers?

## Timeliness?

- Ongoing impact on our workforce and future
- Opportunity to focus PCORI efforts within hard to reach population

# Topic 6: Medical Homes versus Care Management for Chronic Conditions

*Presented by Joan Leon and Tiffany Leung*

- Compared to care management supported by insurance companies, what is the effect of care management provided by medical homes (including those with physicians and those with other types of providers e.g. community care, nurse practitioner, PA) on patient-centered outcomes among patients with multiple chronic conditions?

# Topic 6: Medical Homes versus Care Management for Chronic Conditions

Presented by Joan Leon

## Overview of topic

- Current research looks at the two approaches separately. Even so, it shows that both improve health outcomes for some conditions, leading to a better quality of life, and slightly lower health care costs. There are major differences, however, and comparative effectiveness studies are greatly needed.

## Significance

- Highest priority since research already suggests that many chronic conditions can be prevented, delayed or alleviated through improved care management .

# Topic 6: Medical Homes versus Care Management for Chronic Conditions

Presented by Joan Leon

## What Questions Need to be Answered?

- How do the two approaches differ in implementation of the CCM?
- Do patients find the self-management and decision support and clinical information system helpful? What would they change?
- What is the role of the community? Do patients think it is adequate, helpful?
- Does the delivery system design actually enable the patient to gain the information he/she needs to make choices?
- Do patients prefer one location of the care manager over the other?

## Timeliness – Why Take This Up Right Now?

- Possibility of immediate improvements.

# Topic 6: Medical Homes versus Care Management for Chronic Conditions

Presented by Tiffany Leung

## Overview of topic

- Existing studies examine chronic disease *care management in a medical home model* and *care management supported by insurance* as two separate approaches.
- Studies provide an incomplete picture: both approaches improve health outcomes for some conditions, leading to a better quality of life, and slightly lower health care costs. CER for these approaches is missing.

## Significance (from your perspective)

- High priority. Many chronic conditions can be prevented, delayed or alleviated through improved care management.
- CER is needed to understand care management features and implementation that optimally benefit patient outcomes in chronic disease.

# Topic 6: Medical Homes versus Care Management for Chronic Conditions

Presented by Joan Tiffany Leung

## What questions need to be answered?

- How do the two approaches differ in implementation?
- What is the role of the community in these care management models? What is the optimal role of information systems, decision support, and self-management?
- How does the delivery system design enable the patient to gain the information he/she needs to make informed choices?
- What are patients' preferences about the roles, responsibilities, and location of the care manager?
- How will cost impact care management program design?

## Timeliness – why should PCORI take this up now?

- Patient-centered care for those with multiple chronic disease is increasingly desired and necessary for complex cases. CER would inform and impact care management for a significant portion of the patient population.

# Topic 7: Patient Engagement in Quality Improvement Projects

*Presented by Leah Binder and John Martin*

- Does the inclusion of patients in health systems' quality improvement projects lead to better patient outcomes than quality improvement projects that do not include patients as part of the quality improvement team?

# Topic 7: Patient Engagement in Quality Improvement Projects

Presented by Leah Binder

- **Overview:** Unlike other industries where successful businesses focus on satisfying customers, the financing of healthcare makes it unclear who the customer is. The delivery system is thus structured not around patients, who are not seen as the customers, but around the needs of providers and those who pay their bills, i.e. health plans, Medicare, and Medicaid.
- As a result, dramatic lapses in quality and safety emerge when the patient needs are not priorities from the perspective of providers or payors. For instance: hand-offs, hand hygiene, medication safety/reconciliation, and many others. One in four patients are harmed during a hospital stay.
- **Significance:** Good patient-centered outcomes cannot be achieved without good patient-centered inputs.
- **Timeliness** – In addition to satisfying the very core of PCORI's mission, changes in the financing of healthcare make this body of research even more urgent: today the patient is increasingly the payor. One in six workers were covered by a high deductible health plan in 2012, according to Kaiser/HRET, and the ACA exchanges will accelerate the private sector trend with many plan options featuring very high deductibles as well.

# Question: Which strategies of patient engagement are most effective in improving quality of care? i.e...

- Compare *methods* for obtaining patient feedback, i.e. real-time electronic vs. HCAHPs, vs. focus groups, cognitive interviews, etc.
- Compare *methods* for bedside collaboration, including open notes, teamwork strategies, family rounding.
- Compare *strategies* for engaging patients in institutional quality improvement leadership, such as physician and nurse peer review, quality improvement teams, root cause analyses, Board strategic planning, etc. Compare patient selection methods, patient education strategies, patient decision-making authority levels, in terms of their impact on quality of care.



# Topic 7: Patient Engagement in Quality Improvement Projects

Presented by John Martin

- Patient engagement has become more prevalent
  - Anecdotal evidence suggests pt. engagement improves patient reported outcomes
  - Many national and international initiatives to include patients in nearly every facet of care.
  - No rigorous evidence to support it has had an effect on outcomes or QI project results
  - No studies ongoing at the present time
  - Complex study because of QI process and many potential touch points with patient
- Significance: Sits at the crux of what PCORI is trying to accomplish
  - Many resources are dedicated to this topic, but there is a paucity of evidence to support it.
  - There is a growing trend to engage patients, but we need to know the best points to engage them.



# Topic 7: Patient Engagement in Quality Improvement Projects

Presented by John Martin

## What questions need to be answered?

- Does the inclusion of patients in health systems' quality improvement projects lead to better patient outcomes than quality improvement projects that do not include patients as part of the quality improvement team
- Do QI programs improve patient outcomes/patient reported outcomes?
- Does the addition of patient engagement activities marginally improve outcomes further?
- At what point(s) in the QI process should patients be engaged to get the maximal benefit?

## Timeliness – why should PCORI take this up now?

- There is no rigorous evidence to support a large, and growing trend in patient engagement
- Resource constraints for providers dictate they know how to best use resources.
- To support the ongoing, and future work of PCORI, the evidence needs to be established that this is beneficial to healthcare.

# Topic 8: Linkages between Providers and Community

*Presented by Mary Blegen and Annie Lewis-O'Connor*

- What are the effects of linkages between health care providers and community-based organizations on patients' health-related behaviors, such as weight management, compared with usual care?



# Topic 8: Linkages between Providers and Community

Presented by Mary Blegen

## Overview of topic:

- Improve health behaviors by integrating health care providers and community organizations that promote health
- Builds on history of health promotion in the community, workplace, schools, voluntary organizations
- Scant systematic research on this obvious and often recommended approach to improving the overall health of US residents

## Significance (from your perspective)

- While there is long-standing recommendations about improving health by supporting healthy behaviors in everyday life, it has rarely been more than an ideal
- Previous problems with financing the efforts when the outcomes are very long term and deal with the stubborn problems of behavior change
- ACA presents the opportunity to bring reality closer to the ideal



# Topic 8: Linkages between Providers and Community

Presented by Mary Blegen

## What questions need to be answered?

- How best to finance?
- Would recommendations and referrals from providers to these community organizations bring more success in behavior change?
- What kind of linkages/collaboration/integration between providers and these community/ workplace/ school settings promote the most effective change?
- How to measure the effects and challenges?
  - Process and Attitude measures exist; also disease specific outcomes IF truly successful will impact population morbidity and mortality

## Timeliness – why should PCORI take this up now?

- Recent background literature reviews and measurement suggestions from the AHRQ provides up-to-date foundation
- This could truly be patient centered and fits well with the goals of the ACA

# Topic 8: Linkages between Providers and Community

Presented by Annie Lewis-O'Connor

● **Overview of topic:** “Clinical-community linkages help to connect health care providers, community organizations, and public health agencies so they can improve patients' access to preventive and chronic care services.” AHRQ

- Few Ex. Visiting Nurses Programs, Public Health Nurses, Telemedicine for rural areas, Cardiac Care Coordination, Home visitation programs have shown significant decrease in child maltreatment, In-home therapy for behavioral health issues- increased compliance with treatment plans

● **Significance:** To improve health care delivery and health care outcomes across the continuum of care in patient informed manner.

- Aging population that is spending more time in the home
- Community partnerships offer the opportunity to provide wrap around services, compared to 'silo' care
- Engagement of community services provides an aspect of care not provided in the medical model- thus an opportunity to augment care exists when this partnership occurs



# Topic 8: Linkages between Providers and Community

Presented by Annie Lewis-O'Connor

## What questions need to be answered?

- What is the added benefit of community partners, specifically as it relates to health outcomes?
- How does Community Partnerships affect a Providers satisfaction with care delivery?
- What are potential measures for clinical-community relationships? (Clinical Community relationship Measure (CCRM)).

## Timeliness – why should PCORI take this up now?

- Timing and philosophical underpinnings of Patient and Family Centered Care align with this topic.
- Benefits have shown these linkages to improve care and outcomes.



# Topic 9: Multidisciplinary Treatment Approaches to Chronic Pain

*Presented by Dan Cherkin and Leonard Weather Jr.*

- Does a multidisciplinary treatment approach (e.g., including nutritionists, psychotherapists, physical therapists, holistic practitioners, and physicians) improve the management of chronic pain, compared to treatment from individual providers (usual care)?

# Topic 9: Multidisciplinary Treatment Approaches to Chronic Pain

Presented by Dan Cherkin

## Overview

Guidelines recommend multi-disciplinary approaches for difficult cases of chronic pain but not clear what disciplines/treatments to include

## Significance

An effective and pragmatic multi-disciplinary model could reduce suffering and the use of ineffective, costly and harmful treatments

# Topic 9: Multidisciplinary Treatment Approaches to Chronic Pain

Presented by Dan Cherkin

## Questions

Need research documenting value of specific spreadable multi-disciplinary models, e.g.,

- What disciplines should be included?
- How should they be integrated?

## Timeliness

- Need developmental studies to identify viable multidisciplinary treatment approaches that can be compared with each other or with usual care
- Not ready for PCORI funding



# Topic 9: Multidisciplinary Treatment Approaches to Chronic Pain

Presented by Leonard Weather Jr.

## OVERVIEW OF TOPIC

- According to the iom, chronic pain (cp) affects about 100 million American adults—more than the total affected by heart disease, cancer, and diabetes combined. Pain also costs the nation up to \$635 billion each year in medical treatment and lost productivity.
- Pain is typically defined as a subjective experience grounded in an unpleasant sensory and/or emotional perception associated with actual or potential tissue damage.
- Cp lasts more than several months (between 3 and 6) and adversely affects the individual's well-being. Additionally ahrq, has identified four types of pain: neuropathic, inflammatory, muscle and mechanical/compressive.

## SIGNIFICANCE

- The magnitude of suffering caused by pain and the limitations around response to pain constitutes “*a crisis in America.*”
- Effective pain management is a moral imperative.
- The pernicious effects of cp on physical health, daily activity, psychological health, employment and economical well being is immense.



# Topic 9: Multidisciplinary Treatment Approaches to Chronic Pain

Presented by Leonard Weather Jr.

## WHAT QUESTIONS NEED TO BE ANSWERED?

- Does a multidisciplinary treatment approach (e.g. Including nutritionists, psychotherapist, physical therapist, holistic practitioners and physicians) improve the management of cp compared with treatment from individual providers (usual care)?

## TIMELINESS – WHY SHOULD PCORI TAKE THIS UP NOW?

- Cp is a major driver for visits to physicians and other healthcare providers, a major reason for taking medications, a major cause of disability, and a key factor in quality of life and productivity. Given the burden of pain in human lives, dollars, and social consequences, more desirable ways of relieving pain should be expeditiously prioritized and rendered.



# Discussion / Prioritization

*Moderated by:*

*Trent Haywood, MD, JD – Chair*

*Doris Lotz, MD, MPH – Co-Chair*

# Insurance Approaches & Chronically Ill Patients

Presented by Trent Haywood and Doris Lotz

## Topic was Previously Prioritized by our Panel

- PCORI commissioned a new topic brief.
- Convened an Advisory Panel subcommittee.

## New Topic Brief Question:

- What are the comparative effects of recently developed health insurance approaches, specifically high deductible plans, bundled payments, and condition management plans, on chronically ill patients' access to care, use of care, and patient-centered outcomes?



# Insurance Approaches & Chronically Ill Patients

*Presented by Trent Haywood*

- Overview of topic: The relationship between new models of insurance features and patient-centered outcomes is not clearly established.
- PCORI research could provide significant guidance to the field in developing a framework or roadmap for future research.
- What questions need to be answered? The relationship between insurance features and patient-prioritized outcomes for patients with chronic conditions.
- Timeliness – why should PCORI take this up now? The results of the research could address current knowledge gaps and inform ongoing efforts to improve patient-centered outcomes through new or enhanced insurance features.



# Insurance Approaches & Chronically Ill Patients

*Presented by Doris Lotz*

- **Overview of topic:** Access to care is effected by payers and the design of health plans as they attempt to balance monetary resources, health services utilization, and health outcomes. Plan design effects the activities of providers (e.g., reimbursement via bundled payments), consumers (e.g., high deductible cost sharing) and payers (e.g., condition/disease management).
- **Significance:** The impact of health plan design and activities on patient centered outcomes is not well understood, yet ongoing resource constraints and a lack of high quality health outcomes continue to challenge health care systems.

# Insurance Approaches & Chronically Ill Patients

Presented by Doris Lotz

What questions need to be answered? What are the impacts of health plan designs on patient centered outcomes? Specifically, given defined patient outcomes related to chronic disease what are the impacts of:

- Characteristics of the health plan and the provider networks, such as various provider reimbursement strategies, network design?
- Various cost-sharing strategies, such as high deductibles, tiered payments and co-payments, or consumer-directed care?
- Manage care organizations programs, such as disease management, predictive modeling and case management?

Timeliness – why should PCORI take this up now? Monetary resources will continue to be scarce, health outcomes are inconsistent for populations and waste within health care delivery systems is notable. As more individuals seek care through health plans due to the ACA related changes, the role that health plans play in access to and the assurance of appropriate health services is critical to understand.



# Discussion

*Moderated by:*

*Trent Haywood, MD, JD – Chair*

*Doris Lotz, MD, MPH – Co-Chair*



## Closing Remarks

*Steve Clauser, PhD, MPA  
Director, Improving Healthcare Systems*

Patient-Centered Outcomes Research Institute

# Logistics

- Tomorrow we will review results of today's prioritization exercise
  - Opportunity to discuss and reprioritize
  - Be prepared to share your ideas
  - Half day meeting
    - Breakfast at 8:30 am; Meeting begins at 9:00; Adjourn at noon
- Dinner this Evening
  - St. Gregory Hotel at 6:30 p.m.

# Adjourn

**Thank you for your participation!**



# **Advisory Panel on Improving Healthcare Systems, Day 2**

*May 9, 2014*

*9:00 a.m. - 12:00 p.m. EDT*

Patient-Centered Outcomes Research Institute

# Today's Agenda

- Review of Prioritized Topics **(9:00 – 9:15 a.m.)**
- Discussion and Reprioritization **(9:15 – 10:30 a.m.)**
- Break **(10:30 – 10:50 a.m.)**
- Review of Final Ranking **(10:50 – 11:00 a.m.)**
- PCORI Ambassadors / Engagement in Research  
**(11:00 – 11:30 a.m.)**
- Housekeeping Items / Open Discussion / Next Steps  
**(11:30 a.m. – 12:00 p.m.)**
- Adjourn **(12:00 p.m.)**



## Review of Prioritized Topics

*Doris Lotz, MD, MPH – Co-Chair*

Patient-Centered Outcomes Research Institute

# Outcome of Yesterday's Prioritization Exercise (18 Responses)

Topic	Score*	Overall Rank
Patient Engagement in Quality Improvement	129	1
Linkages Between Providers and Community	126	2
Patient and Caregiver Engagement in Chronic Mental Illness	106	3
Communication Technologies and Patients with Chronic Conditions	93	4
Multidisciplinary Treatment Approaches to Chronic Pain	91	5
Medical Homes	82	6
Health IT and Treatment Adherence in Chronically Ill Patients	78	7
Multicomponent Interventions and Medication Adherence in Chronically Ill Patients	77	8
Rural and Frontier Trauma	28	9

\*Score is a weighted calculation. Items ranked first are valued higher than the following ranks, the score is the sum of all weighted rank counts.



## Reprioritization of Topics

*Moderated by:*

*Doris Lotz, MD, MPH – Co-Chair*

Patient-Centered Outcomes Research Institute

# Outcome of the Reprioritization Exercise: Final Results (16 Responses)

Topic	Score*	Overall Rank
Patient Engagement in Quality Improvement	78	1
Linkages Between Providers and Community	74	2
Patient and Caregiver Engagement in Chronic Mental Illness	55	3
Communication Technologies and Patients with Chronic Conditions	46	4
Multidisciplinary Treatment Approaches to Chronic Pain	44	5
Medical Homes	39	6

\*Score is a weighted calculation. Items ranked first are valued higher than the following ranks, the score is the sum of all weighted rank counts.



# Engagement in Research / PCORI Ambassadors

*Suzanne Schrandt, JD*

*Deputy Director, Patient Engagement, PCORI*

Patient-Centered Outcomes Research Institute

# What We Will Cover

- The genesis and launch of the Rubric and the role of Engagement Officers
- An overview of the Ambassador Program and current program status

# Patient and Family Engagement Rubric

## Why develop a rubric?

- The rubric is a response to frequent questions from the patient and research communities asking what we mean by “engagement in research.”

## What is the rubric?

- The rubric provides a variety of options for incorporating engagement, where relevant, into the research process.

## How will the rubric be used?

- The rubric will be used as a guide for applicants, merit reviewers, awardees and Engagement Officers.

# Rubric Development Process and Implementation

PEAP provides recommendations to PCORI Engagement staff on rubric development (September 20<sup>th</sup> , 2013)

PCORI Engagement staff review and refine with Scientific Program Directors and Executive Committee (November 2013)

PCORI Engagement team refine rubric with PEAP (December, 2013)

Rubric utilized in funding application (January/February, 2014), merit review and awardee training as well as establishment of engagement milestones and oversight of portfolio by Program and Engagement Officers

Rubric will ultimately be defined and redefined by the community of researchers, patients, caregiver and advocacy organizations

# Rubric Launch



## PCORI Patient and Family Engagement Rubric

### I. Overarching Concepts

- 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 "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.
- Although the rubric is called the *Patient and Family Engagement Rubric*, 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 be evaluated.
- The rubric is intended 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. Instead, it provides a variety of options to incorporate engagement, where relevant, into the research process. Applicants can choose to include some, but not all, activities, and can include additional innovative approaches not listed here.
- 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 PCOR Engagement 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.

*The rubric is intended 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 divided into four segments:*



### Planning the Study



### Conducting the Study



### Disseminating the Study Results



### PCOR Engagement Principles



# Rubric Snapshot

<b>Planning the Study</b>		
<b>Formulating research questions and study design</b>	<p>Patient partners participate in:</p> <ul style="list-style-type: none"><li>Identifying the topic and developing the research question to be studied.</li><li>Creating the intervention to be studied (if applicable) and identifying comparators.</li><li>In identifying the goals or outcomes of the interventions to be studied.</li><li>Defining essential characteristics of study participants.</li><li>Other study design and preparation.</li></ul>	<p><b>Examples:</b></p> <ul style="list-style-type: none"><li>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?</li><li>Asthma study: the patients and patients' parents help create the paper asthma tracker tool being compared to the e-asthma tracker tool.</li><li>Cancer study: patient partners determine that all women with breast cancer would be eligible versus only women who had completed active treatment.</li></ul> <p><b>How can you demonstrate this in your proposal?</b></p> <ul style="list-style-type: none"><li>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.</li><li>Include the patient partners in all relevant sections of the application, such as the biosketches, the budget, and the dissemination and implementation assessment.</li></ul>

# ENGAGEMENT TEMPLATE

Refer to the Patient and Family Engagement Rubric, included in the appendix, for guidance as you complete this template. Continuation pages may be used as needed. Limit 4 pages. Refer to the PCORI Application Guidelines, available in the [PCORI Funding Center](#), for additional guidance.

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## 1. Formulating Research Questions and Study Design

*Describe how patient partners will participate in relevant planning and study design activities.*

## 2. Participating in and Monitoring the Conduct of the Project

*Describe how patient partners will participate in relevant portions of the conduct of the research.*

## 3. Helping to Plan the Dissemination of the Study's Results

*Describe how patient partners will be 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.*

## 4. PCOR Engagement Principles:

- a. Reciprocal Relationships: *Describe the roles and decision-making authority of all research partners, including patient partners.*
- b. Co-Learning: *Describe plans to ensure that patient partners will understand the research process and researchers will understand patient-centeredness and patient engagement.*
- c. Partnership: *Describe how the time and contributions of patient partners are valued and demonstrated in fair financial compensation, as well as reasonable and thoughtful time commitment requests.*
- d. Trust, Transparency, Honesty: *Describe how major decisions<sup>96</sup> are made inclusively and information is shared readily with all research partners; patient partners and research partners express commitment to open and honest communication with one another; and the study team commits to communicate study findings to the community studied, in a meaningful and usable way.*

# Education and Training

- Town Hall meetings (Broad and Targeted PFAs)
- Presentations to key stakeholders (Drug Information Association/PCORI webinar, IOM roundtable and NIMH, etc.)
- Rubric is or will be incorporated into:
  - Merit Review training and process
  - Ambassador Program training
  - PFA applicant and awardee training
  - Pipeline to Proposal applicant and awardee training

# Engagement Resources



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## Engagement in Research

Since our establishment, PCORI has been committed to funding research that includes meaningful involvement of patients and other stakeholders in all steps of the process. Bringing together all stakeholders in the healthcare enterprise to set research priorities, with patients at the center, is our formula for ensuring we fund and conduct the most relevant research possible. We believe that including patients in the research process will lead to trustworthy and more usable information that will result in greater uptake of the research findings. We look forward to producing evidence to that effect through our portfolio of funded projects. In response to frequent questions about what we mean by "engagement in research," PCORI, with contributions from our Patient Engagement Advisory Panel, developed the Patient and Family Engagement Rubric to provide guidance to applicants, merit reviewers, awardees, and PCORI program staff, on meaningful engagement practices.

### The Patient and Family Engagement Rubric

The rubric was created by identifying promising practices of engagement within our first three funding cycles. While we are providing the rubric as a tool for applicants, we do not want to stifle innovation and encourage applicants to continue to bring their most creative engagement ideas forward. The rubric simply provides a variety of options for incorporating engagement, where relevant, into the research process, and is not intended to be prescriptive or comprehensive.



The Rubric: Genesis and Purpose

See More »

## Patient Partnerships



PCORI-funded researchers and their partners discuss the importance of research that's guided by patients.

Promising Practices of Meaningful Engagement in the Conduct of Research

PCORI-funded research and stakeholder partners share successful practices of patient and stakeholder engagement in all stages of the research process.

# Engagement Officers

Engagement Officers, working closely with Program Officers, will support active portfolio management by;

- Helping Awardees to outline engagement milestones
- Participating in the Awardees' kick-off and interim phone calls as well as in separate calls with key patient and stakeholder partners
- Facilitating communication between Awardees to troubleshoot engagement challenges
- Gathering promising engagement practices from the portfolio to feature in webinars and for use in updating or expanding the Patient and Family Engagement Rubric

# Ambassador 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

# Key Program Dates

- October 28, 2012
  - Program recommended by a *Transforming Patient-Centered Research: Building Partnerships and Promising Models* workshop attendee
- September 20, 2013
  - Inaugural Ambassadors invited to join the program
- October 25, 2013
  - Program webpage launched and invitations sent to merit reviewers, workgroup, roundtable, and regional event attendees
- December 10, 2013
  - Phase I of Training completed - Module 1: *Introduction to PCORI* and Module 2: *The Role of the Ambassador*
- March 25, 2014
  - Phase II of Training completed - Module 3: *Basics of PCOR for Ambassadors*, Module 4: *Meaningful Patient and Stakeholder Engagement and the Research Team*, and Module 5: *How PCORI-Funded Research Teams Work Together*



# Program Opportunities

## Benefits:

- Receiving PCORI Ambassador communications tools and PCOR science training
- Being recognized as a “PCOR Science-Trained Ambassador” on the PCORI Ambassador webpage
- Co-authoring publications, submitting guest blogs, or participating in other media opportunities
- Being highlighted for work in patient-centered research in PCORI e-newsletters
- Learning of opportunities to serve as PCORI reviewers or participate in working groups and on survey panels
- Collaborating and serving as a panelist with PCORI or others on events such as webinars, conferences, and panels

# Program Status

- 67 individual and 14 organizational ambassadors
- Training: 36 completed
- First quarterly newsletter distributed
- Annual Meeting June 18<sup>th</sup> -19<sup>th</sup>



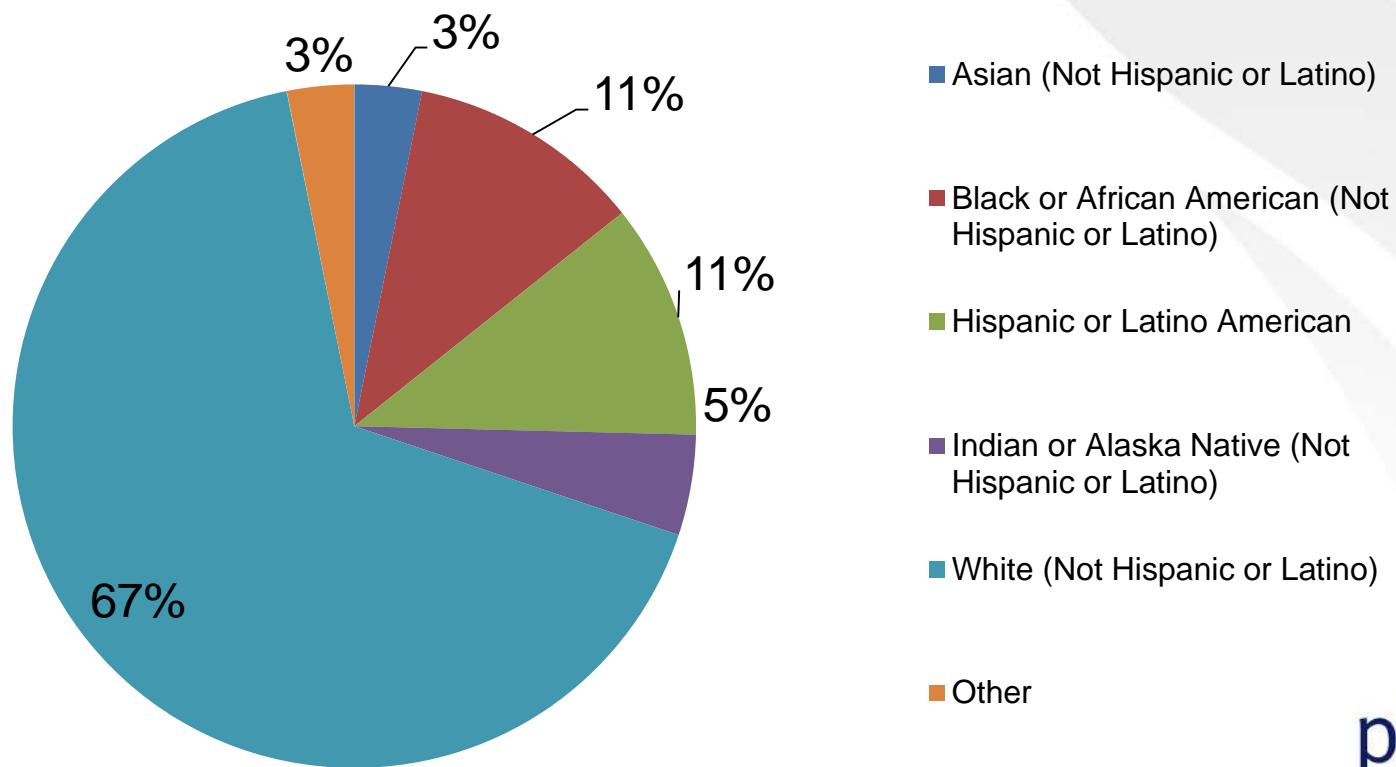
Become an Ambassador today at: [www.pcori.org/ambassador](http://www.pcori.org/ambassador)



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# Program Status

## Demographic characteristics:



# Next Steps

- Continue to grow the Ambassador Program and identify new methods for connecting patients, stakeholders, and researchers interested in PCOR
- Evaluate and refine the Ambassador Program and the Patient and Family Engagement Rubric as needed
- Build a repository of promising practices of patient and stakeholder engagement in research for shared learning

# Questions?



## Housekeeping Items / Open Discussion / Next Steps

*Steve Clauser, PhD, MPA*

Patient-Centered Outcomes Research Institute

# Next Steps

- Develop the prioritized topics into future funding announcements
- Meet with Subcommittees regarding Strategic Framework and the Insurance Features topic
- Send quarterly newsletters to keep all of you informed

# Adjourn

**Thank you for your participation!**