



# Patient Engagement Advisory Panel

*January 14, 2015  
Arlington, VA*

Patient-Centered Outcomes Research Institute



# Recap of Day 1, Overview of Day 2

***Sue Sheridan, MIM, MBA, DHL***

*Director of Patient Engagement*

Patient-Centered Outcomes Research Institute

# Agenda for Jan 14

<b>9:00 – 9:15 a.m.</b>	<b>Recap of Day 1, Overview of Day 2</b>
<b>9:15 – 9:45 a.m.</b>	Ambassador Program - Update
<b>9:45 – 10:30 a.m.</b>	Pipeline to Proposal Awards - Update
<b>10:30– 10:45 a.m.</b>	BREAK
<b>10:45 – 11:15 a.m.</b>	Compensation Framework
<b>11:15 – 11:45 a.m.</b>	Privacy / Data and Safety Monitoring Board / Institutional Review Board - Discussion
<b>11:45 a.m. – 12:15 p.m.</b>	Call for topics
<b>12:15 p.m.</b>	Meeting Adjourned
	LUNCH



## Ambassador Program – Update

***Aingyea Kellom, MPA***

*Program Associate,  
Patient Engagement*

***Suzanne Schrandt, JD***

*Deputy Director,  
Patient Engagement*

Patient-Centered Outcomes Research Institute

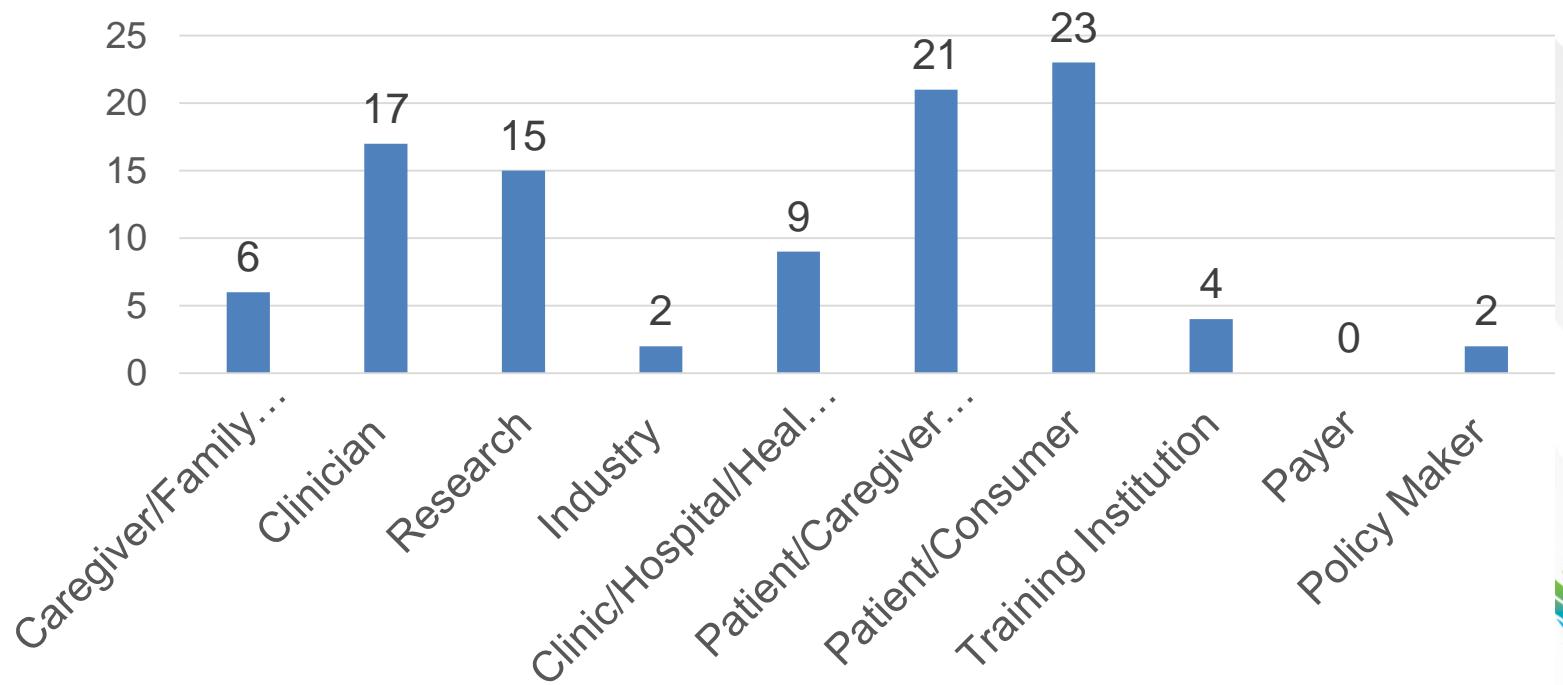
# Objectives

- Program Update
- Strategies for the Future: Action Plan

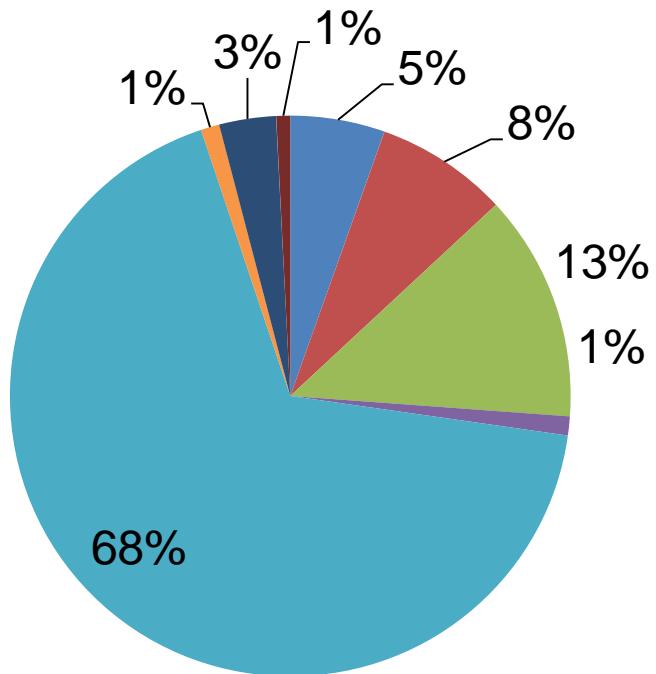
# Program Update

# Ambassadors by Stakeholder Group

- To Date: 99 Have Completed the Ambassador Training
  - 82 individual and 17 organizational

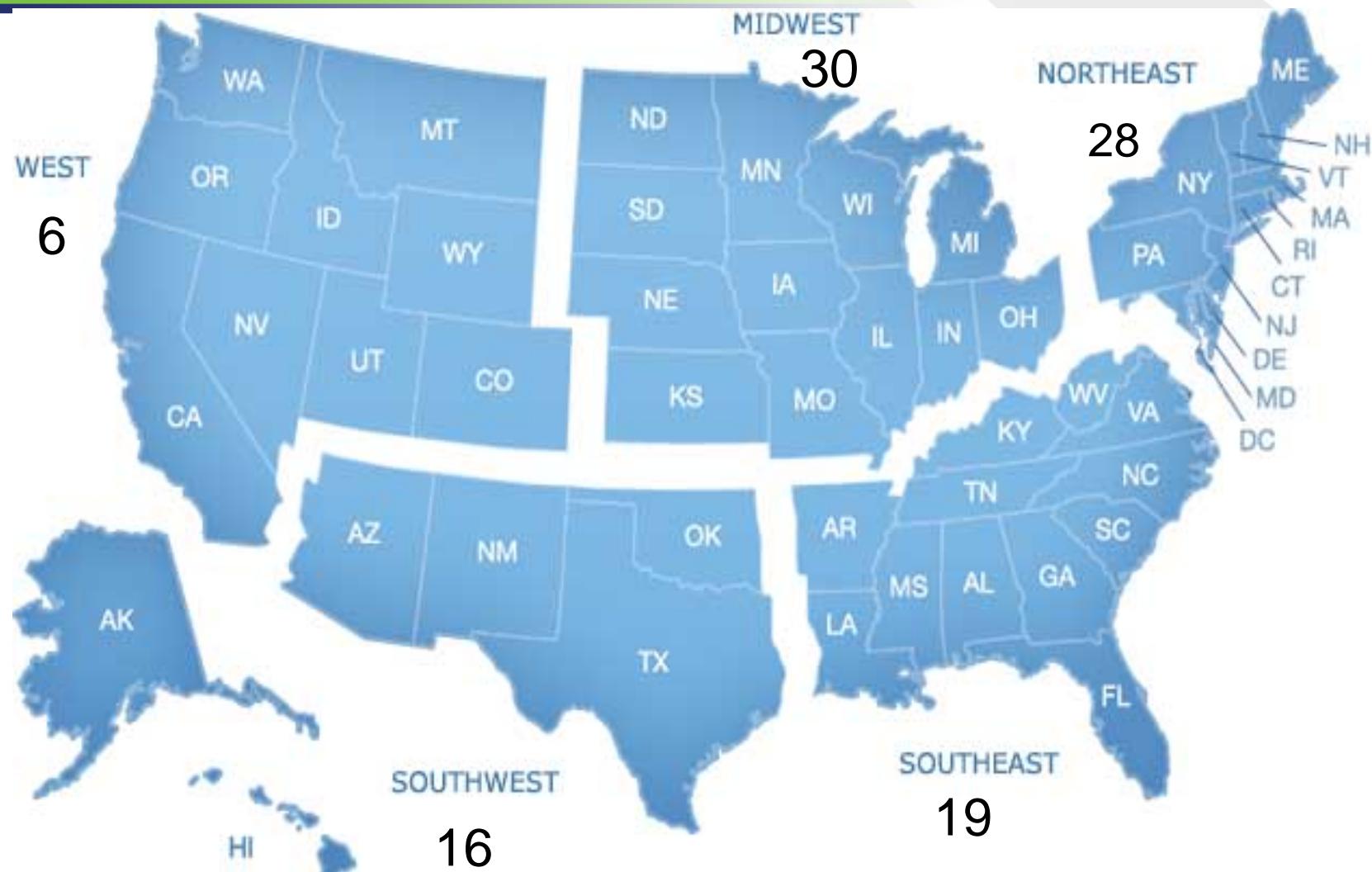


# Ambassadors by Ethnicity



- Asian (Not Hispanic or Latino)
- Black or African American (Not Hispanic or Latino)
- Hispanic or Latino American
- Indian or Alaska Native (Not Hispanic or Latino)
- White (Not Hispanic or Latino)
- Native Hawaiian
- Prefer Not to Answer
- Two or More Races

# Ambassadors by Region



# 17 Organizational Ambassadors by State

Organization	State
American College of Physicians	PA
American Heart Association	CA
American Occupational Therapy Association	MD
Association of Nurses in AIDS Care	PA
Association of Perioperative Registered Nurses	CO
Dia de La Mujer Latina	NY
Dia de la Mujer Latina (2 Representativas)	TX and NY
Epilepsy Foundation Central & South Texas	TX
FasterCures	DC
International Cancer Advocacy Network (ICAN)	AZ
Mercy Health Chicago	IL
National Association of Nurse Practitioners in Women's Health	WV
National Patient Advocate Foundation (NPAF)	CA
Patient-Centered Primary Care Collaborative	DC
The American Academy of Neurology	MN
The S.T.A.R. Initiative	IL
University of New Mexico - Department of Psychiatry	NM

# Refined Individual and Ambassador Roles



## **Individual Ambassador:**

Individuals with a personal interest in PCOR, a desire to be involved in PCOR activities, and a commitment to inform others about PCOR



## **Organizational Ambassador:**

A health or healthcare entity, typically represented by one or more individuals, that is interested in PCOR, is eager to partner in PCOR efforts, and has extensive reach into its networks

Individual Ambassadors and Organizational Ambassadors are committed to the PCOR engagement principles of reciprocal relationships, partnership, co-learning, trust, transparency, and honesty.



**pcori**

# Strategies for the Future: Action Plan

# Strategy for the Future

## Areas for Growth:

- Aligning membership growth with scientific priorities, such as the conditions or populations of focus in the pragmatic clinical trials
- Working toward greater participation by our funded project teams
- Increasing participation of patient and stakeholder organizations

## Adding Value:

- Facilitating more Ambassador Program activity
- Increasing the use and benefit of social media
- Identifying/developing incentives for individual and organizational participation

## Opportunities for Cross-Fertilization:

- Syncing Ambassador activities with work ongoing across PCORI
- Collaborating with and learning from work going on across the healthcare system, such as that done by PFACs, IHI, FDA, NQF, CMS, AHRQ, and others

# Areas for Growth: Aligning with Science Priorities

- Identify Science funding priority areas, with a particular focus on pragmatics
- Connect current Ambassadors to Science workgroups
- Recruit future Ambassadors aligned with funding priorities

# Areas for Growth: Increasing Participation of Funded Projects

- Begin a tiered invitation approach starting with familiar projects, then incorporating invitations from Engagement Officers during kick-off and interim calls
- Ensure Pipeline and Engagement Awardees are aware of the opportunity to join
- Include information about Ambassadors to unsuccessful applicants who are still eager to be involved

# Areas for Growth: Increasing Organizational Involvement

- Refine description of Individual and Organizational Ambassador role, including “value proposition”
- Promote involvement to our contacts through social media and other marketing
- Hold activities relevant to targeted patient and stakeholder organizations

# Adding Value: Facilitating More Ambassador Program Activity

- Update current Ambassador tool-kit materials
- Calendar of events
  - Ambassador-only monthly conference calls/webinars [with compelling guest speakers]
  - PCORnet's Grand Rounds: Rethinking clinical research webinars
  - PCORI public webinars and events
  - Publicizing/sharing information about non-PCORI events
- Newsletters
- Surveys and crowdsourcing opportunities

# Adding Value: Increasing Use and Benefit of Social Media

- Gather lessons learned from current Ambassadors and patients or stakeholders involved in successful (non-PCORI) social media campaigns
- Develop a list of essential social media activity trackers to be incorporated into the transition to Chatter
- Encourage Ambassadors to promote the program through their social networks
- Plan and execute more frequent and energized social media activity

# Adding Value: Incentives for Individual and Organizational Participation

- Training (CME/CE credit, college credit, etc.)
- Connection to PCOR community and research partnership opportunities
- Recognition

# Opportunities for Cross-Fertilization

- Connect Ambassadors to PCOR opportunities:
  - Merit review
  - Various PCORI activities such as workgroups, funded project activities, and advisory panel recruitment
  - Pipeline to Proposal application review
  - Contributions to the D&I Framework
- Facilitate connections and active collaboration between these various initiatives
- Serve as a platform for shared learning and dialogue between diagnostic, population, or other affinity groups

# Opportunities for Cross-Fertilization

- Collaborate with and learn from work going on across the healthcare system, such as that done by PFACs, IHI, FDA, NQF, CMS, AHRQ, and others
- Connect with and learn from other programs similar to the Ambassador Program

# Questions?



# Pipeline to Proposals Awards – Update

*Courtney Clyatt, MPH*

*Senior Program Associate on Patient Engagement*

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# Pipeline to Proposal Initiative Update Overview

- PAPOs Contracted
- Letters of Intent (LOI) for Tier I Cycle 2
  - Tier I Cycle 2 LOI period closed on 12/23/14
    - Received 298 LOIs
- Other activities
  - NAPCRG presentation
  - 11/7/14 End of Award Meeting for Tier I Cycle 1 Awardees
    - - Snippets of video interviews
  - Strategic planning session with Engagement Team
    - SWOT Activity



# Pipeline Award Program Offices by Region

East - Health Resources in Action

Midwest - Michigan Public Health Institute

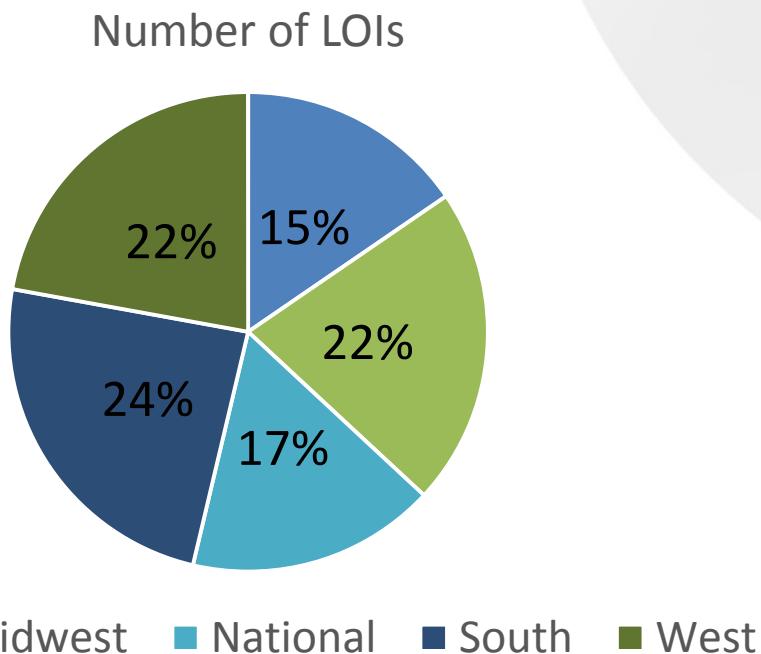
National - National Network of Public Health Institutes

South - Georgia Health Policy Center

West - Colorado Foundation for Public Health and the Environment

# Breakdown of LOIs Received by Region for Tier I Cycle 2

- 1) 46 – East
- 2) 64 – Midwest
- 3) 50 – National
- 4) 72 – South
- 5) 66 - West



## Other P2P Activities

● NAPCRG Presentation

● P2P Webinar

● End of Award Meeting for Tier I Cycle 1  
Awardees

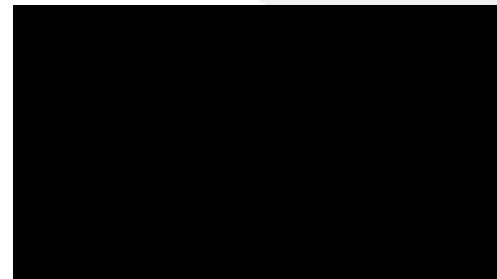
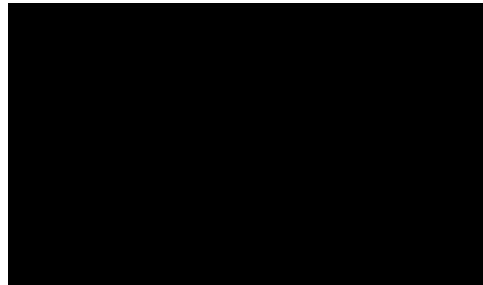
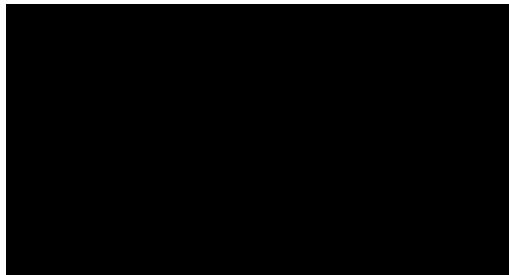
- Snippets of video interviews

● Strategic Planning Session with Engagement  
Team

- SWOT – Activity focusing on opportunities

# Video Interviews with Pipeline Awardees

- Patient,  
Katie Wilkes
- Stakeholder,  
Suzanne Pak
- Researcher,  
H. Bryant Nguyen



# Strategic Planning Session with Engagement Team

- Affirming where P2P fits into the PCORI Research Enterprise
- SWOT - focusing on opportunities moving forward
- Tier III

# Opportunities

- Align P2P with Science funding priorities
- Improve communication about P2P
- Program development
  - Develop dissemination structure
  - Define Tier III
  - Cross pollinate with other areas of PCORI

# Align P2P with Science Funding Priorities

## Course of action:

- Identify Science funding priority areas
- Develop targeted P2P funding announcements

# Improve External Communication about P2P

## External

### Course of Action:

- Develop a national and regional targeted outreach plan (aligned with science and priority patient/stakeholder communities)
- Publish pre-engagement promising practices from P2P

# Program Development for P2P

## Course of action:

- Develop and incorporate dissemination concept into P2P structure
- Strategically build out Tier III
- Identify where and how P2P aligns with or contributes to other PCORI programmatic areas (Ambassadors, Science, Engagement Awards, training, rubric development, etc.)

# Future Direction of P2P

- Patient and other stakeholders groups will be strategically targeted for the Pipeline to Proposal Awards Initiative (community clinics, junior researchers, underserved patient populations, rare disease)
- Opportunities to cross-pollinate with other program areas in PCORI including Ambassadors, EAs, training, learning networks, merit review and others that will be identified
- Pipeline to Proposal Awards Initiative will be structured to incorporate dissemination projects
- Pipeline to Proposal Program Awards will be aligned with PCORI's future research funding priorities
- Promising practices on community engagement and partnership development will be shared with broader research community

# 15 Minute Break

*Refreshments outside.*



# Compensation Framework - Finalization and Approval

***Charlotte W. Collins, JD***

*Chair, Compensation Subcommittee*

***Suzanne Schrandt, JD***

*Deputy Director of Patient Engagement*

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# **Privacy / Data and Safety Monitoring Board / Institutional Review Board - Discussion**

***M. Suzanne Schrandt, JD***  
*Deputy Director, Patient Engagement*

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# Goals

- Provide a quick refresher on IRBs, DSMBs, and privacy concepts
- Share updates from our work
- Discuss the potential for forming a subcommittee and the functions of such a body

# Institutional Review Boards

- What they are/what they do
- Unique elements of PCORI-funded research that may be new to IRBs
- What we are learning from our portfolio
- Ideas for providing guidance or information sharing

# Data Safety Monitoring Boards

- What they are/what they do
- Unique elements of PCORI-funded research that pertain to DSMBs
- What we are learning from our portfolio
- Ideas for providing guidance or information sharing

# Privacy and Confidentiality

- What these concepts mean
- Elements of PCORI-funded research that create unique privacy questions
- Ideas for providing guidance and information sharing



# Call for Topics

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## Wrap-Up & Adjourn

***Sue Sheridan, MIM, MBA, DHL***

*Director of Patient Engagement*

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Thank you!  
Lunch in  
Crystal Ballroom Salon A.  
Safe travels home.