



Patient Engagement Advisory Panel

September 20, 2013
Washington, DC

Patient-Centered Outcomes Research Institute



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

Patient-Centered Outcomes Research Institute

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 September 20

1:30-1:45 p.m. Welcome, Introductions and Review Agenda

1:45-2:15 p.m. Present Engagement Strategic Plan

2:15-3:00 p.m. Discuss Ambassadors Program

3:00-3:15 p.m. **Break**

3:15-4:00 p.m. Discuss the Ambassadors Program (cont'd)

4:00-5:15p.m. Discuss the Pipeline to Proposals Awards

5:15-5:30 p.m. Wrap-up

5:30-6:30 p.m. **Break**

6:30-8:00 p.m. Dinner with the Advisory Panel on Assessment of Prevention, Diagnosis, and Treatment Options



Engagement Strategic Plan

Sue Sheridan, MIM, MBA

Director of Patient Engagement

Patient-Centered Outcomes Research Institute

Session Objectives

- *Informational Item*
- To share an overview of the Engagement Team's strategic plan and how it aligns with PCORI's organizational priorities
- To set the stage for continual dialogue and accept recommendations for future revisions

PCORI Strategic Plan

Our Values

Patient-
Center-
edness

Useful-
ness

Trans-
parency

Inclusive-
ness

Evidence

Our Strategic Imperatives

Engage patients, caregivers, and all other stakeholders in our entire research process, from topic generation to dissemination and implementation of results

Develop and promote **methodological knowledge**, standards, and best practices

Fund a comprehensive agenda of high quality patient-centered outcomes **research** and evaluate its impact

Disseminate patient-centered outcomes research to all stakeholders and support its uptake and implementation

Promote and facilitate the development of a sustainable **infrastructure** for conducting patient-centered outcomes research

Our 2013 Priority Activities

Fund research through broad solicitations on assessing options; improving systems; addressing disparities; research methods; and communication and dissemination

Fund research on targeted topics

Develop the framework for evaluating our work and establish baselines

Develop a skilled community to participate in our research processes

Establish programs to build capacity of patient groups and to match patients with researchers

Develop dissemination for implementation plan and infrastructure in collaboration with AHRQ

Launch PPRN, CDRN, and a coordinating center

Establish multi-stakeholder advisory panels and work groups

Launch dissemination for implementation plan to promote methodology standards

Implement portfolio planning, management, and evaluation system to maximize our research

Our Goals

Increase
Information

Speed
Implement-
ation

Influence
Research

Our Mission

PCORI helps people make informed health care decisions, and improves health care delivery and outcomes by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader health care community.

Our Vision

Patients and the public have information they can use to make decisions that reflect their desired health outcomes.



From Strategy to Activities

PCORI Strategic Plan

Mission

PCORI helps people make informed health care decisions, and improves health care delivery and outcomes by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader health care community.

Vision

Patients and the public have information they can use to make decisions that reflect their desired health outcomes.

Goals

Increase Information

Speed Implementation

Influence Research

Strategic Imperatives

Engage patients, caregivers, and all other stakeholders in our entire research process, from topic generation to dissemination for implementation of results

Develop and promote **methodological knowledge** standards, and best practices

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Engagement Priorities

Develop PCOR Community

Engage Community in Research

Promote Dissemination for Implementation

Theory

of

Change

What Are We Trying to Achieve

Facilitators

Activities

PCORI Engagement



Develop PCOR Community	<p>Introduce PCORI to key patients, stakeholders, and the organizations that represent them, and develop engagement processes</p>	<p>Implement structures and internal processes to bring together patients and stakeholders around PCORI and PCOR; conduct activities to identify promising practices and thought leadership for engagement</p>	<p>Fold newly interested patients and stakeholders into PCORI community; continue refining methods to maintain community's engagement</p>	<p>Refine methods to maintain community's engagement; continue to expand PCORI community</p>	<p>Large, diverse PCORI community established with broad reach into other patient and stakeholder communities</p>
Engage Community in Research Process	<p>Establish programs to bring patients and stakeholders into PCORI's research process</p>	<p>Provide ongoing opportunities for involvement in PCORI's research process and develop additional PCOR-field capacity</p>	<p>Ensure understanding of PCOR; continue opportunities for community involvement in research</p>	<p>Refine activities to expand opportunities for community's engagement in research process</p>	<p>Large, diverse PCORI community actively engaged in all aspects of the research process</p>
Promote Dissemination for Implementation	<p>Establish patient/stakeholder relationships to develop future pathways for D&I</p>	<p>Begin development of D&I thought leadership, creative new pathways, facilitators, and infrastructure</p>	<p>Develop mechanisms and processes to assure that all D&I materials are understandable, relevant, accessible and culturally appropriate</p>	<p>Disseminate learnings through new and traditional pathways that are understandable, relevant, accessible, and culturally appropriate</p>	<p>Have successfully created trust, legitimacy and uptake of PCORI research findings within a well-developed D&I infrastructure</p>

Develop PCOR Patient Community



What Are We Trying to Achieve?

- Increase PCORI's knowledge of the community
- Increase the community's knowledge of PCOR and PCORI
- Build trust in PCORI
- Build a “sense” of community

Engage Patient Community in Research



What Are We Trying to Achieve?

- Move thinking from “partners in care” to “partners in research”
- Develop a well-informed, trained, collaborative community
- Create a research culture that connects patient/caregiver community with research community
- Facilitate PCOR readiness
- Ensure meaningful patient engagement in PCORI research process

Promote Dissemination for Implementation (D & I)



What Are We Trying to Achieve?

- 🌱 Develop thought leadership, best practices and create a customized and coordinated D&I infrastructure
- 🌱 Identify and develop creative new pathways and facilitators for D&I
- 🌱 Promote and produce materials that are utilized because they are understandable, relevant, accessible and culturally appropriate
- 🌱 Create trust, legitimacy and uptake of PCORI research findings

Engagement Activities



- Ambassadors
- Roundtables
- Webinars
- Pipeline to Proposals
- Workshops
- *Patient Engagement Advisory Panel*
- Training
- Development of rubric on meaningful engagement in research
- Engagement/Science active portfolio management
- Communications/social media plan
- Evaluation
- Dissemination for Implementation blueprint



PCORI Ambassador Program

Sue Sheridan, MIM, MBA

Director of Patient Engagement

Suzanne Schrandt, JD

*Deputy Director of Patient
Engagement*

Aingyea C. Kellom, MPA

*Program Associate on Patient
Engagement*

Patient-Centered Outcomes Research Institute

Session Objectives

1. Provide an program overview
2. Review webpage draft and Yammer Community
3. Review components “PCOR Science” training
4. Are you ready to be an inaugural PCORI Ambassador? If yes, are you interested in helping in the creation of the first quarterly newsletter?

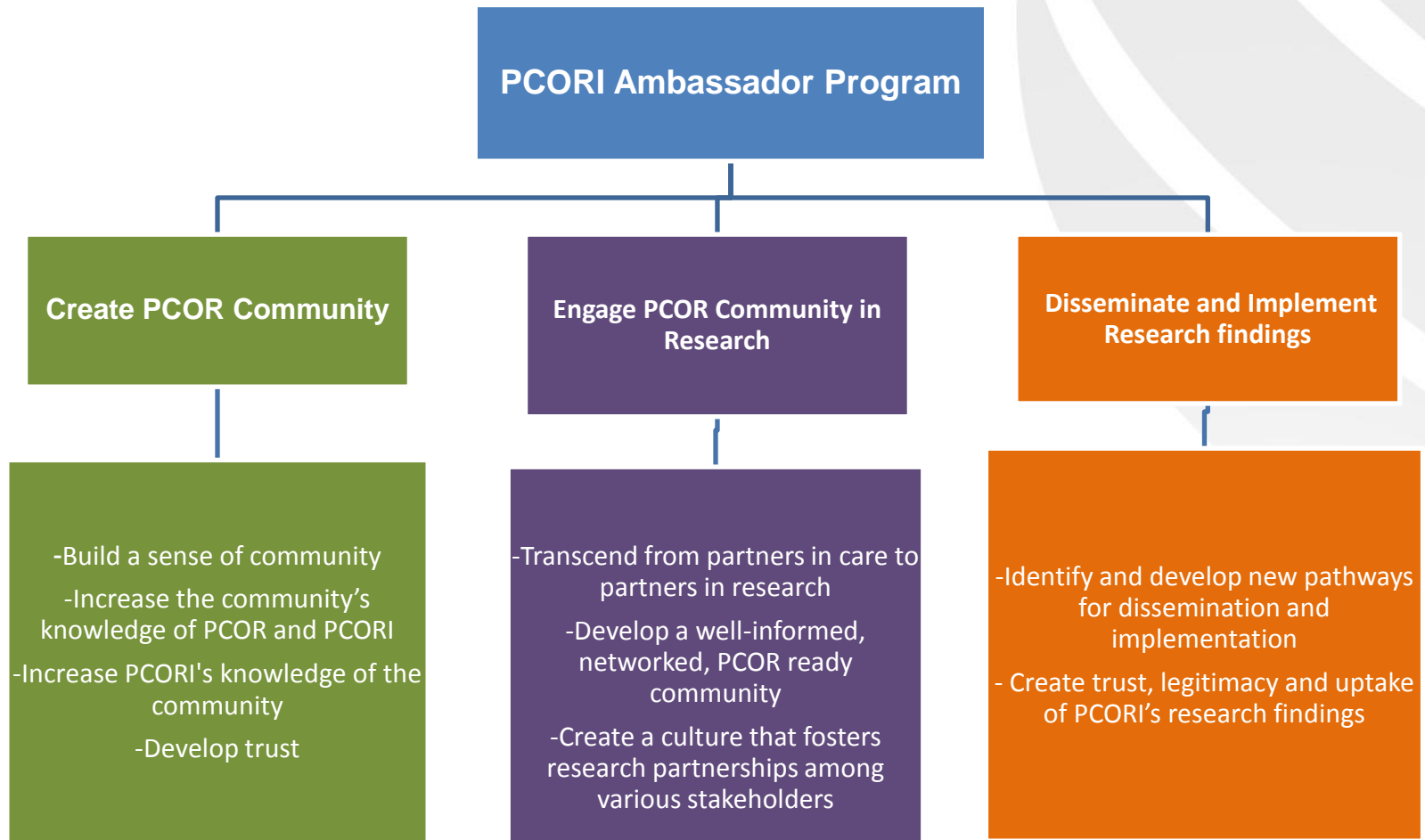
PCORI Ambassador Program

- *The PCORI Ambassador Program is a volunteer initiative that will unite individual and organizational Ambassadors around the promise of patient-centered outcomes research (PCOR)*
- *The initiative will equip, train and mobilize 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.*

Who Can Become an Ambassador?

- ✓ Organizations, consumers, patients, caregivers, clinicians, researchers and other healthcare professionals, who:
 - have participated in a PCORI workshop, roundtable, working group or other designated PCORI convening;
 - are members of PCORI advisory panels (inaugural Ambassadors will be from the Patient Engagement Advisory Panel)
 - have served as PCORI merit reviewers and reviewer mentors
 - are currently serving as a patient/stakeholder partner or researcher in funded PCORI projects, or
 - have hosted a PCORI presentation, panel, breakout session or initiative.
- ✓ Completed PCOR Science Certification (By end of 2013).
- ✓ Completed intake form agreeing to our principles, roles and expectations.

Ambassador Program Goals and Objectives



Ambassador Activities

Create PCOR Community:

- Informing others about PCORI via presentations, sharing of information, distributing materials, op-eds and letters to the editor.
- Forwarding PCORI announcements, alerts and surveys to their membership, community and related organizations.
- Participating in Ambassador social network forum to share lessons learned and pursuing collaborations.
- Organizing and fostering “affinity groups” aligned with PCORI’s current and future research agenda.
- Contributing as a guest blogger, co-author, webinar presenter, and Engagement e- newsletter contributor.

Ambassador Activities

Engaging PCOR community in research:

- Participating in PCOR science training to cultivate skills for future participation as patient/stakeholder partner in PCORI research projects.
- Helping frame, collect and propose potential CER questions from communities, affiliates, disease groups, etc.
- Participating in or recruit applicants for funding opportunities, including the Pipeline Awards.
- Participating in and recruiting networks and affiliates for survey panels.
- Contributing to targeted funding announcement working group discussions.

Ambassador Activities

Disseminating and Implementing Research Findings

- Sharing PCORI results and announcements with their networks
- Participating in forums and conferences to help share the PCORI story and the results of research

PCORI Ambassador Benefits

- Receiving PCORI Ambassador communications tools and PCOR science training;
- Being recognized as a “PCOR Science Certified Ambassador” on the PCORI Ambassador webpage offering visibility to potential researchers seeking trained patient/stakeholder partners for PCORI proposals or patients and stakeholders seeking PCOR researcher partners;
- Connecting with and building relationships and affinity groups with other PCORI Ambassadors and PCORI staff;
- Being identified on our webpage as having co-authored publications, submitted guest blogs and participated in other media opportunities;
- Being highlighted for exemplary work in patient-centered research in PCORI e-newsletters
- Access to and/or participation in PCORI informational webinars;
- Learning of opportunities to serve as PCORI reviewers, working groups and on survey panels; or
- Serving as a panelist or co-presenter at PCORI sponsored events such as workshops, roundtables, launches, etc.

Roles and Expectations

To develop and preserve the credibility, sustainability and the integrity of the Ambassadors and the Ambassador Program the following are addressed in the overview document:

- Vision and Goals
 - Role of PCORI Engagement Team
 - Role of PCORI Ambassadors
- Who Can Participate
- Expectations
 - Program Integrity
 - Conflict of Interest
- Ambassador Activities
 - Creating PCOR Community
 - Engaging PCOR Community in Research
 - Disseminating and Implementing Research Findings
- Ambassador Benefits
- Program Evaluation



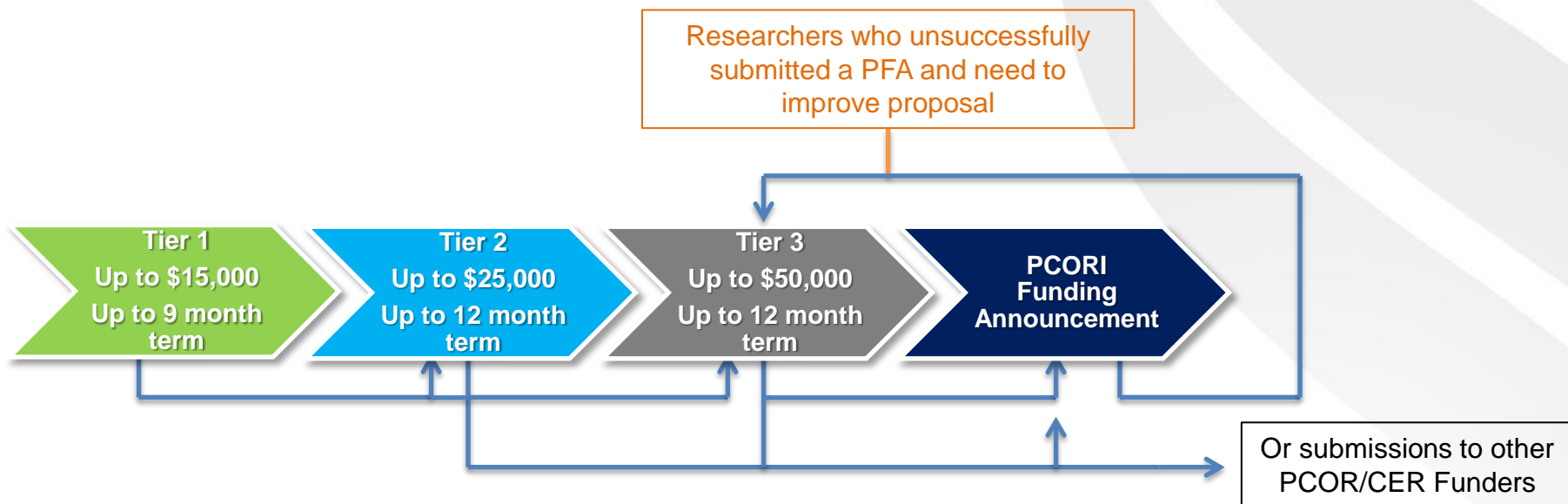
Pipeline to Proposal Awards Update and Discussion

Suzanne Schrandt, JD

Deputy Director of Patient Engagement

Patient-Centered Outcomes Research Institute

Example of Training and Development Awards Pipeline to Proposals



Tier I Pipeline Awards

(Up to \$15,000 for up to 9 months)

Available to individuals, consumer/patient organizations, clinician(s), researcher(s) or a combination of the above to support:

- Community building around an area of research interest to improve outcomes for patients
- Creation of structure and communication strategies
- Develop an understanding of PCORI, and “research done differently”



Tier II Pipeline Awards

(Up to \$25,000 for up to 1 year)

Available to emerging research/non-research partnerships to support:

- Data network and registry development
- Development of infrastructure
- Generation and refinement of research question through community events, town hall meetings, etc.



Tier III Pipeline Awards

(Up to \$50,000 for up to one year)

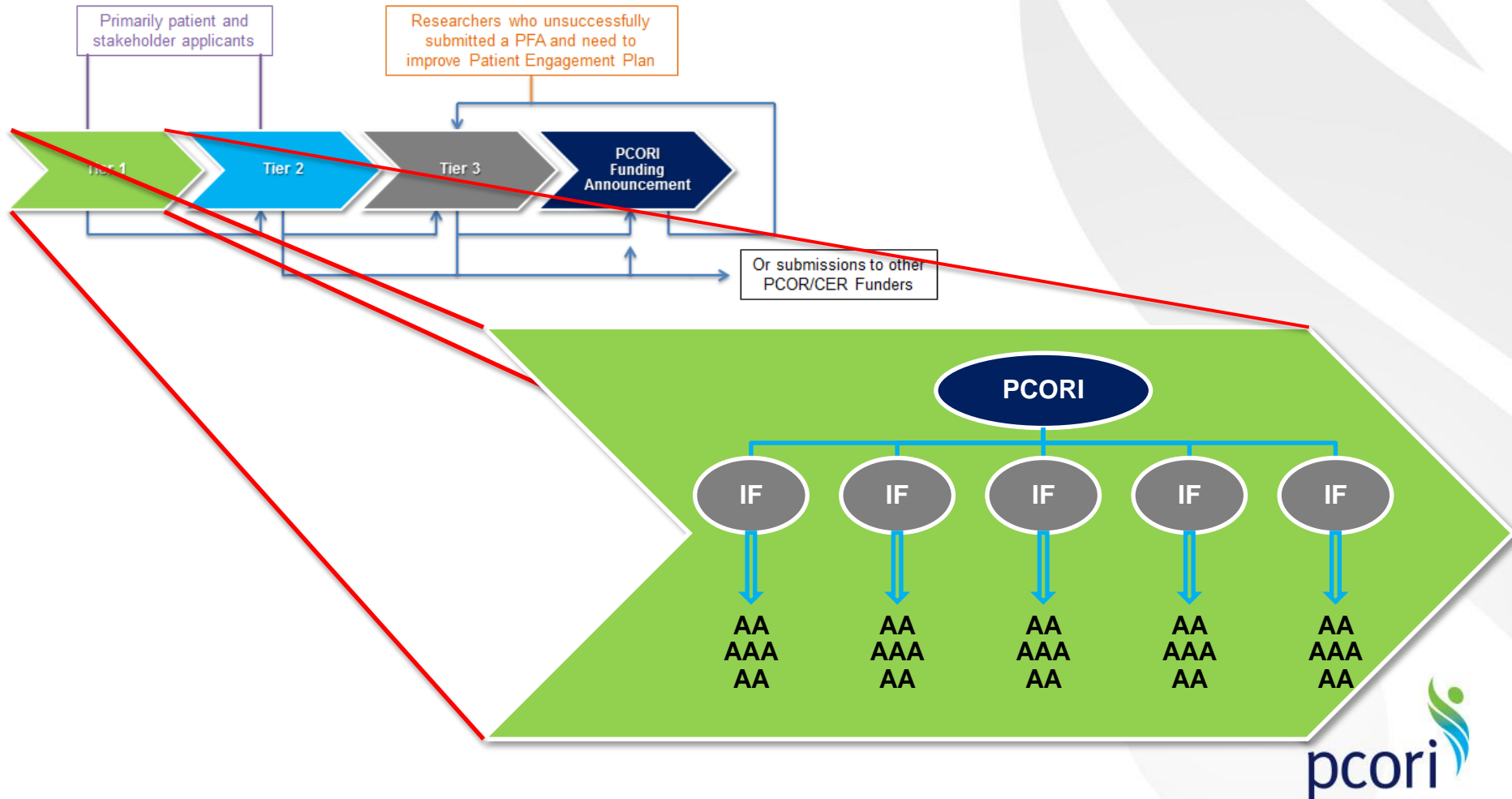


Available to advanced research/non-research partnerships, including those who submitted PCORI proposals and were not funded, to support:

- PCORI research proposal (re)submission focusing on development of engagement plan
- Research partnership skill development

Tier I Awards:


Role of Intermediate Funder



Timeline

Pipeline to Proposal

Pilot Program

- Pilot intermediate funder awarded
- Tier I pipeline award RFP opens October 15
- Tier I pipeline award RFP closes November 15
- Tier I pipeline awardees announced December 15
-  Additional intermediate funder RFQ announced before 2014
-  Tier II pipeline award RFP announced before 2014
-  Tier III pipeline award RFP announced early 2014

Discussion



Wrap-Up

Sue Sheridan, MIM, MBA
Director of Patient Engagement

Patient-Centered Outcomes Research Institute

Looking to Day 2

- Discuss Framework for Engagement in Dissemination
- PCORI Topics for Discussion

1 Hour Break

*Dinner will be at 6:30 pm
in the Dumbarton Room*