Patient Engagement Advisory Panel

April 28, 2014

Alexandria, VA

Patient-Centered Outcomes Research Institute

Welcome, Introductions, and Review Agenda

Jean Slutsky, PA, MSPH
Chief Engagement and Dissemination Officer
Sue Sheridan, MIM, MBA
Director of Patient Engagement

Charlotte W. Collins, JD
Co-Chair
Darius Tandon, PhD
Co-Chair

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Agenda for April 28

10:00 – 10:30 a.m.	Welcome, Introductions and Review Agenda
10:30 – 11:15 a.m.	Update on Pipeline to Proposal Awards
11:15 – 11:30 a.m.	Planned Member Presentation: A Roadmap to Patient and Family Engagement
11:30 – 11:45 a.m.	Discussion on Conflict of Interest forms
11:45 a.m. – 12:00 p.m.	Group Photo
12:00 – 1:00 p.m.	*LUNCH*
Joint Meeting with Advisory Panel on Addressing Disparities	
1:00 – 1:20 p.m.	Welcome and Introductions with Advisory Panel on Addressing Disparities
1:20 – 1:50 p.m.	Update on the Ambassador Program
1:50 – 2:50 p.m.	Addressing Disparities Program Portfolio
2:50 – 3:00 p.m.	*BREAK*
3:00 – 4:15 p.m.	Dissemination & Implementation Action
4:15 – 4:45 p.m.	Patient and Family Engagement Rubric
4:45 – 5:00 p.m.	Wrap-up
5:00 – 5:30 p.m.	*BREAK*
5:30 – 6:30 p.m.	Reception
6:30 – 8:00 p.m.	Dinner with the Addressing Disparities Panel

Update on Pipeline to Proposal Awards

Informational

Courtney Clyatt, MPH
Senior Program Associate on Patient Engagement

Kristen Konopka, MPH
Program Associate on Stakeholder Engagement

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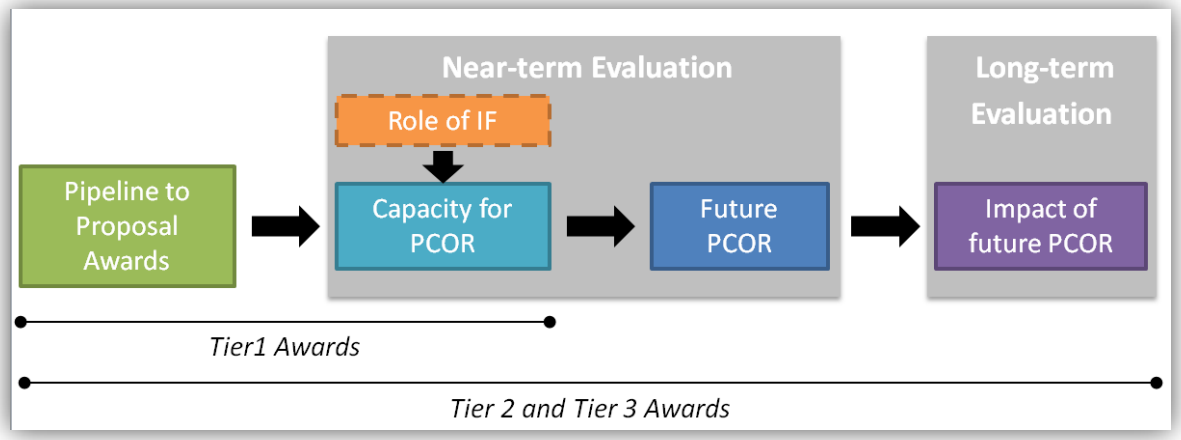
Pipeline to Proposal Initiative Update

- **Changes to the Pipeline to Proposal Initiative**
  - Removal from the Engagement Awards
  - Renaming Intermediate Funders
- **Awardee Management**
- **RFQ for the Midwest**
- **Pipeline to Proposal Evaluation**
- **Pipeline to Proposal Timeline through 2015**
- **Pipeline to Proposal Awardee Highlights**
  - Awardee activities
  - Awardee participation in other PCORI initiatives

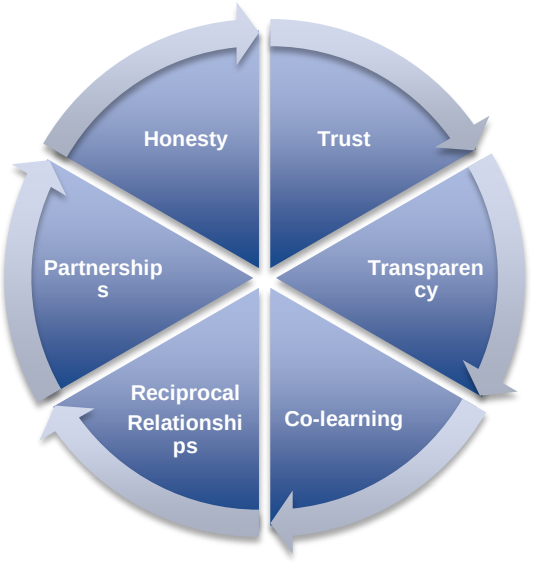
Evaluating the Pipeline to Proposals

*We hypothesize that **Pipeline to Proposal Awards** will promote capacity for PCOR (i.e., organizational structures, resources, collaborative relationships, policies, procedural protocols, and commitment to patient-centeredness needed to conduct PCOR). Moreover, we expect that this capacity will lead to future PCOR, which will ultimately have a scientific and clinical impact.*



What We Hope to Learn from the P2P

- What are some elements of successful partnership structures?
- Did these partnerships embody the PCORI Engagement Principles?
- To what extent did this project prepare awardees to pursue research funding from PCORI or another funder?



A Roadmap to Patient and Family Engagement

Gordon and Betty Moore Foundation
Summary of Convening and Ongoing Activities

Kristin L. Carman, PhD
Vice President, Health and Social Development Program

AIR®
American Institutes for Research®

PCORI Advisory Panel on Patient Engagement

Background

- Goals
  - Gather a multidisciplinary group of key stakeholders
  - Discuss and collaborate on a unified roadmap for the field
  - Advance research and practice
- Starting point
  - Carman et al. PFE Framework
- Timeline and Funding
  - Planning began July 2013, convening held February 2014
  - Funded by the Gordon and Betty Moore Foundation's Patient Care Program

Why hold a convening?

- Foster a high level of energy
- Recognize the value in participant interaction
- Build on the group's experience and expertise
- Create a collaborative vision
- Ask for a high level of commitment from participants
- Re-orient traditional thinking
- Generate strategies and tactics to *advance* the field

What made the convening unique?

- Pre-work
  - Micro-convenings
  - White papers
  - Participant website
- Participants
  - Diverse stakeholder mix
- Approach
  - Interdisciplinary groups
  - Appreciative Inquiry

What did we ask participants to do?

- Develop vision for the field – build physical roadmaps
  - Milestones and destinations
  - Strategies and tactics
  - Factors that affect progress
  - Timing: today, tomorrow, future

What did we learn: *process*?

- Seeking of common ground to unite perspectives
- Power of collaboration in eliciting new ideas
- Increasing energy over the convening
- Personal investment

What did we learn: *themes*?

- Current health care system offers numerous opportunities
  - Consumer demand
  - Health care professionals' capacity for change
  - Prioritization of transparency
  - Growing evidence base, innovation to support PFE
- The time for this work is **now**.

"The question is how we push past the barriers – how do we leap over those hurdles?"

Convening participant

Other themes

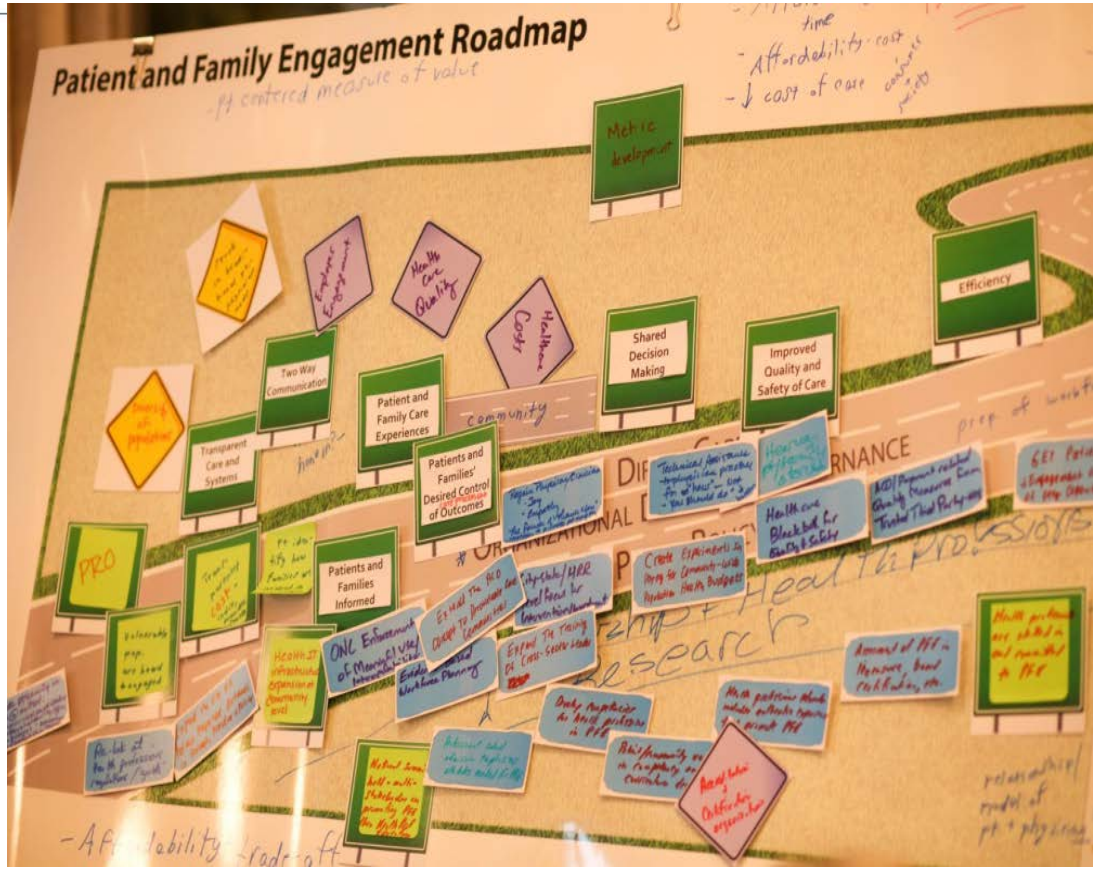
- Dominant model and paradigm need to shift: biomedical to patient-centered; sick care to health; revisit power
- Engagement: Means to an end *and* an end in itself

Opportunities

- Areas for focused action
  - Education and preparation
  - System and process redesign
  - Integration of patient and family perspective and governance at all levels
  - Measurement and data that reflects patient priorities
- Immediate strategies for small but powerful changes
- Longer-term strategies

Next steps

- Deeper data analysis
- A roadmap to guide progress in research and practice
- Community of action



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Fellow, Patient Care Program
Gordon and Betty Moore Foundation
Dominick.Frosch@moore.org

AIR's Center for Patient & Consumer Engagement
www.aircpce.org

Discussion on Conflict of Interest Forms

Informational

Emma Djabali

Research and Project Assistant

Jayne Jordan

Special Assistant to the General Counsel

Kara Odom Walker, MD, MPH, MSHS

Deputy Chief Science Officer, Office of the Chief Science Officer

Patient-Centered Outcomes Research Institute

Group Photo

In the convention level foyer followed by a

1 Hour Break

Lunch is served in the
Upper lobby foyer.
We reconvene at 1:00 pm in Magnolia C.

Welcome and Introductions

Advisory Panel on Patient Engagement

Charlotte W. Collins, JD *Co-Chair*

Darius Tandon, PhD *Co-Chair*

Advisory Panel on Addressing Disparities

Doriane Miller, MD *Co-Chair*

Grant Jones *Co-Chair*

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Advisory Panel on Patient Engagement

Charlotte	Collins
Stephen	Arcona
Paul	Arthur
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

Advisory Panel on Addressing Disparities

Alfie Breland-Noble
Tammy Burns
Monique Carter
Alyna Chien
Echezona Ezeanolue
Kevin Fiscella
Martina Gallagher
Venus Gines
Martin Gould
Jacqueline Grant
Chien-Chi Huang
Elizabeth Jacobs
Grant Jones
Patrick Kitzman
Doriane Miller
Alan Morse
Carmen Reyes
Russell Rothman
Mary Ann Sander
Deborah Stewart

Update on the PCORI Ambassador Program

Informational

Aingyea Kellom, MPA

Program Associate, Patient Engagement

Patient-Centered Outcomes Research Institute

Objectives for Update

- To provide an update on program status
- To share the planned agenda and meeting objective for annual meeting
- To share implementation of evaluation plan and the opening of the program to the public

Program Status

- 67 individual and 14 organizational ambassadors
- Geographic region: 7 West, 12 Midwest, 26 Northeast, 25 Southeast, and 11 Southwest
- Training: 24 completed
- First quarterly newsletter distributed

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Annual Meeting

- Theme: “Building a National Community for PCOR”
  June 2014
  Minneapolis, MN

  Key components: ambassador presentations, social media training, Pipeline to Proposals opportunity, panel on consumer health and health care research

- First planning committee call held April 21st

Evaluation Plan and Public Invitation

- First six month program evaluation will be released in August 2014
  - Engagement Priorities Measured: Develop Community, Engagement Community in Research, and the Dissemination and Implementation of Research Findings
  - Targeted interviews with Ambassadors and PCORI staff
- Evaluation Tools: Web Intake Form, Program Surveys, Training Course Survey, Yammer Analytics, and Twitter Tracking
- Public initiation pending review of first annual evaluation

Q&A

Addressing Disparities Program Portfolio

Discussion Item

Romana Hasnain-Wynia, PhD

Program Director, Addressing Disparities

Patient-Centered Outcomes Research Institute

Agenda

- **Addressing Disparities Program Background**
  - Program mission and goals
  - Program progress to date
- **Conceptual Framework & Driver Model**
  - Addressing Disparities program portfolio
  - Disparities projects across all PCORI programs
- **Next Steps**
- **Discussion**

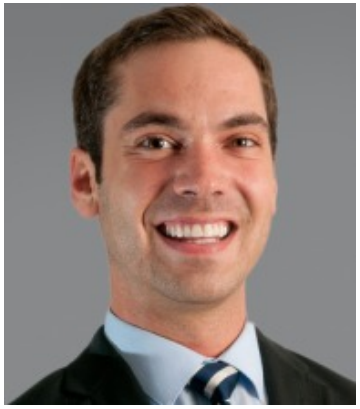
Addressing Disparities Program Staff

Romana Hasnain-Wynia, MS, PhD
Program Director

Cathy Gurgol, MS
Program Officer

Ayodola Anise, MHS
Program Officer

Katie Lewis, MPH
Program Associate



Mychal Weinert
Program Associate

Tomica Singleton
Senior Administrative Assistant

Addressing Health Disparities Advisory Panel

Addressing Disparities Mission Statement

PCORI's
Vision, Mission, Strategic Plan

Program's Mission Statement

To **reduce disparities** in healthcare outcomes and **advance equity** in health and health care

Program's Guiding Principle

To support comparative effectiveness research that will identify best options for **eliminating disparities.**

Addressing Disparities: Program Goals

Identify Research Questions	• **Identify** high-priority **research questions** relevant to reducing and eliminating long-standing disparities in health care outcomes
Fund Research	• **Fund** comparative effectiveness **research** with the highest potential to reduce and eliminate health care disparities
Disseminate Promising/Best Practices	• **Disseminate** and facilitate the adoption of **promising/best practices** to reduce and eliminate health care disparities

Progress toward Goal (2012—15)

Broad PFAs
4 cycles

- **31** projects totaling **$52.8M**

Targeted PFAs

1 cycle

- Treatment Options for Uncontrolled Asthma: **8** projects totaling **$23.2M**

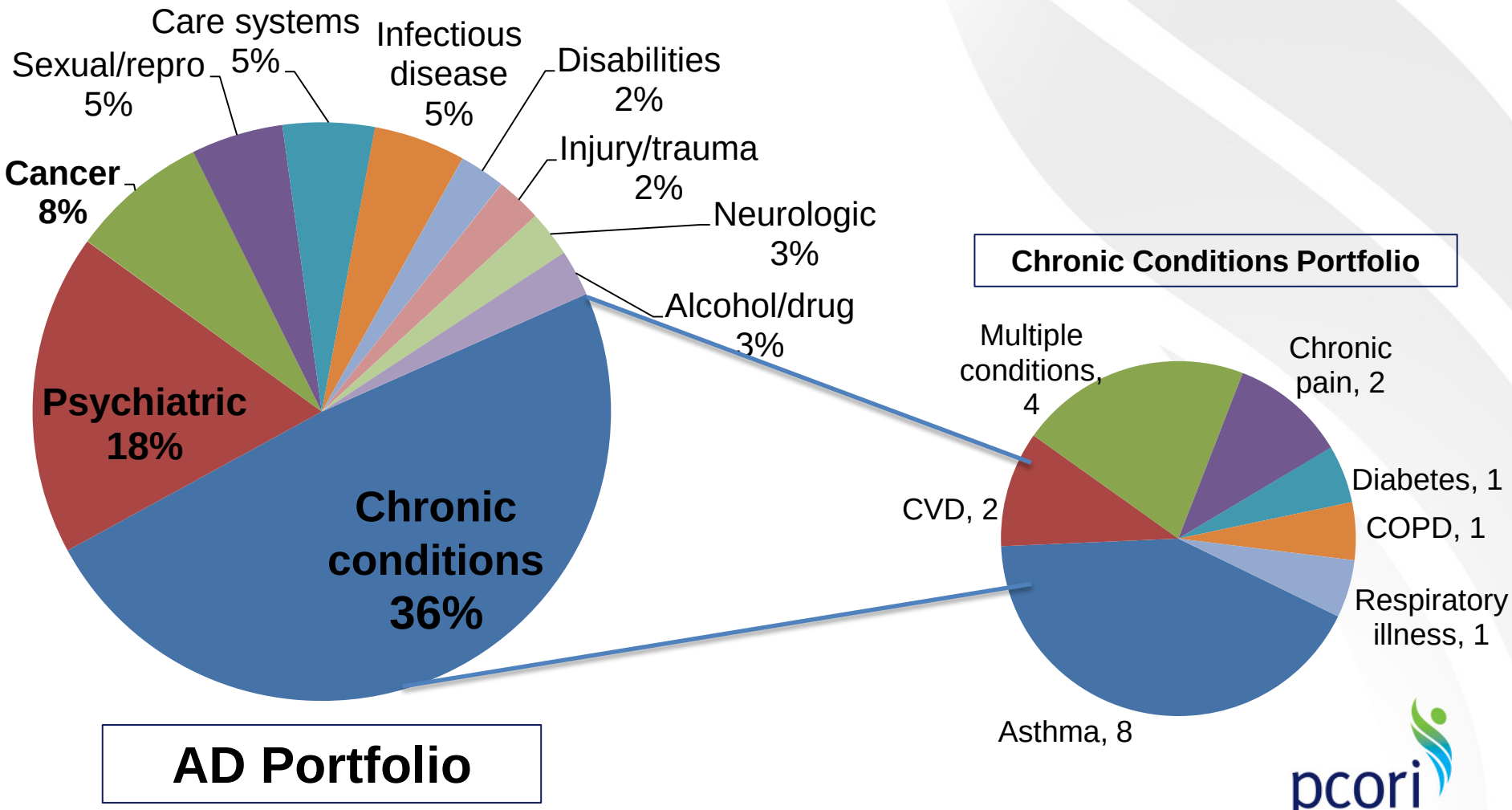
Pipeline for Targeted PFAs

- Obesity treatment options in primary care, awards in August 2014
- Pragmatic clinical trials, awards in January 2015
- In Development Stage **(**Hypertension ,Perinatal, Lower Limb Amputations)

Targeted Funding Announcement: Treatment Options for African Americans and Hispanics/Latinos with Uncontrolled Asthma

- 8 Awards, $24 million
- Projects focus on
  - Comparing interventions to improve clinician and patient adherence to NHLBI guidelines by
    - Enhancing provider and patient communication (e.g., use of mobile technology);
    - Improving systems of care (e.g., evaluate models that look at data integration); and/or
    - Improving integration of care (e.g., team-based care).
  - Include patient-centered outcomes
  - Strong stakeholder engagement

Addressing Disparities Portfolio Snapshot
Research Areas



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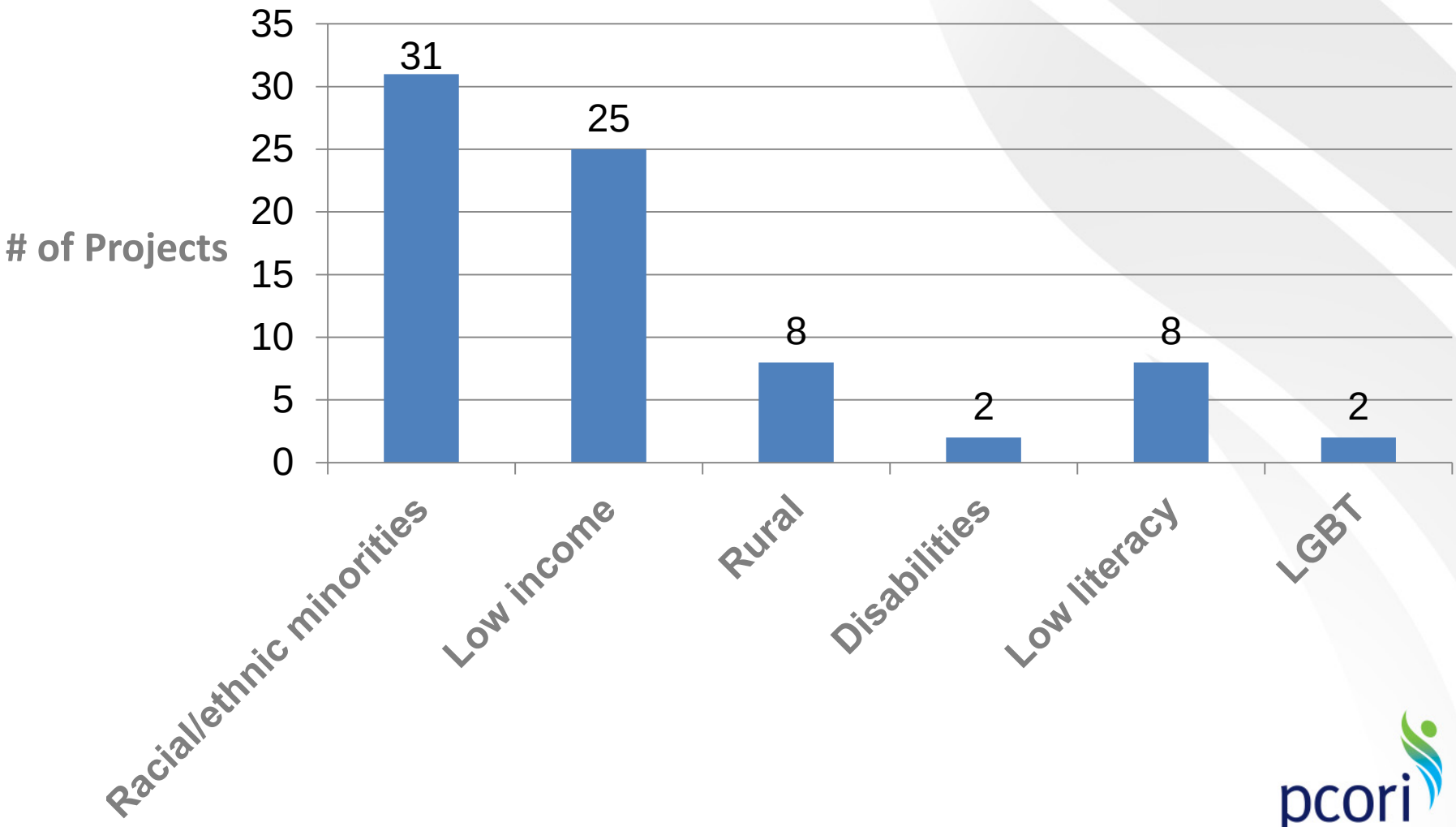
Addressing Disparities Portfolio Snapshot

Disparities Population (not mutually exclusive)



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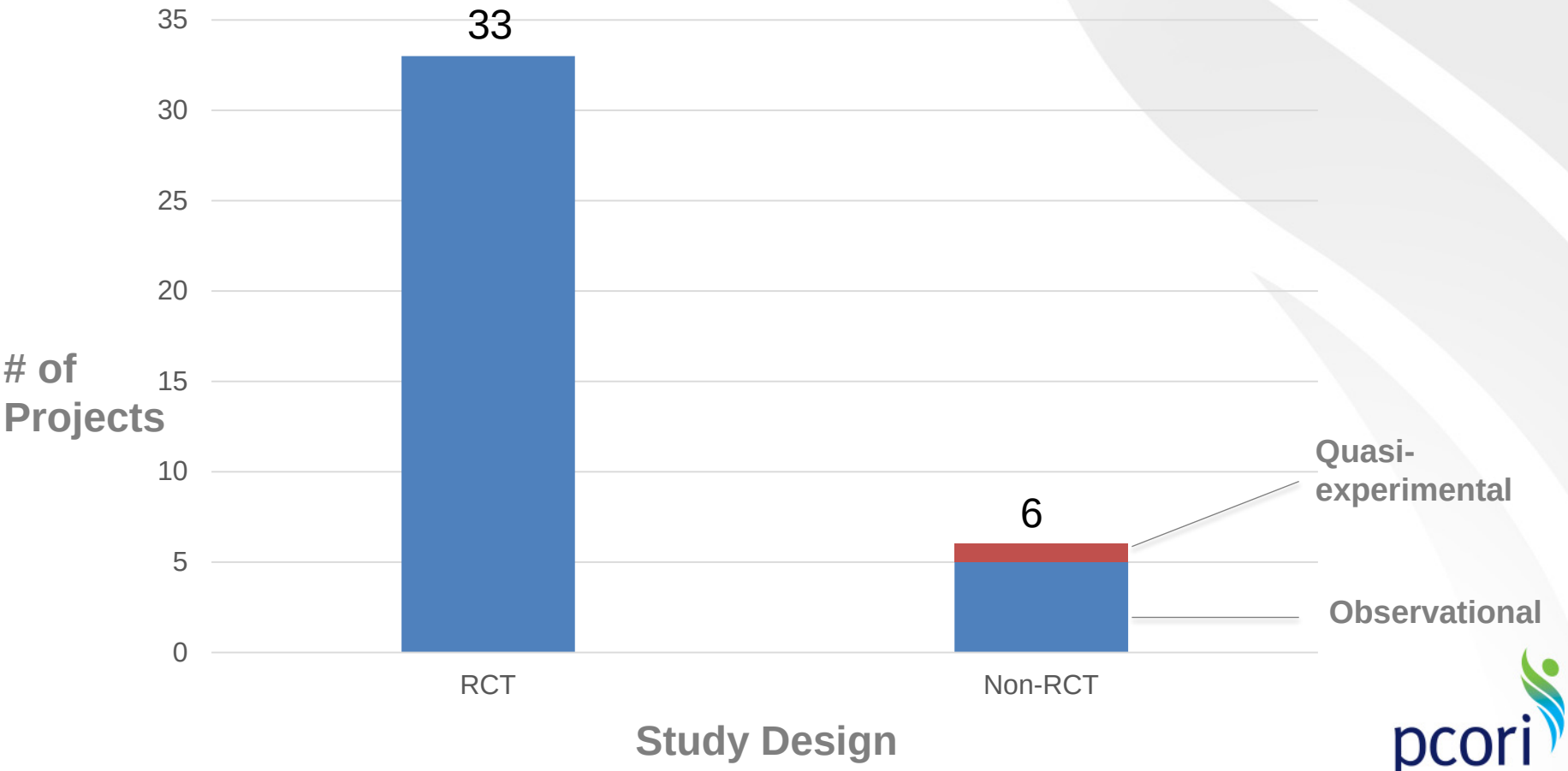
Addressing Disparities Portfolio Snapshot
Research Methods: Study Design



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Long-Term Outcomes of Community Engagement to Address Depression Outcomes Disparities

Engagement

- Community agencies collaborate to tailor depression toolkits to the needs and strengths of community

Potential Impact

- Could change practice by providing information about how depressed patients prioritize outcomes and make decisions, and could affect practice by showing how clinicians respond to patients' preferences

Methods

- Mixed methods approach and a randomized controlled trial

Looks at long-term patient outcomes of community engagement intervention vs. a technical assistance model, identifies patient preferences and priorities for outcomes, and assesses community capacity to respond to these priorities.

Kenneth Wells, MD, MPH,
University of California, Los Angeles
Los Angeles, CA

Addressing Disparities Research Project, awarded December 2012

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Mrs. A and Mr. B (People with Disabilities, Primary Care Provider Quality, and Disparities)

Investigates why it is more difficult for people with disabilities to get care, with the main goal of developing the Patient-Inspired Surveillance Tool to provide guidance on addressing disparities in care.

Margaret Stineman, MD,
University of Pennsylvania
Philadelphia, PA

Engagement

- Patient participation informs the design and specific aims of the study, and qualitative data collection from families and clinicians examines access to care from additional perspectives

Potential Impact

- Could change practice by providing information to patients with disabilities on how they can best access care and stay healthier

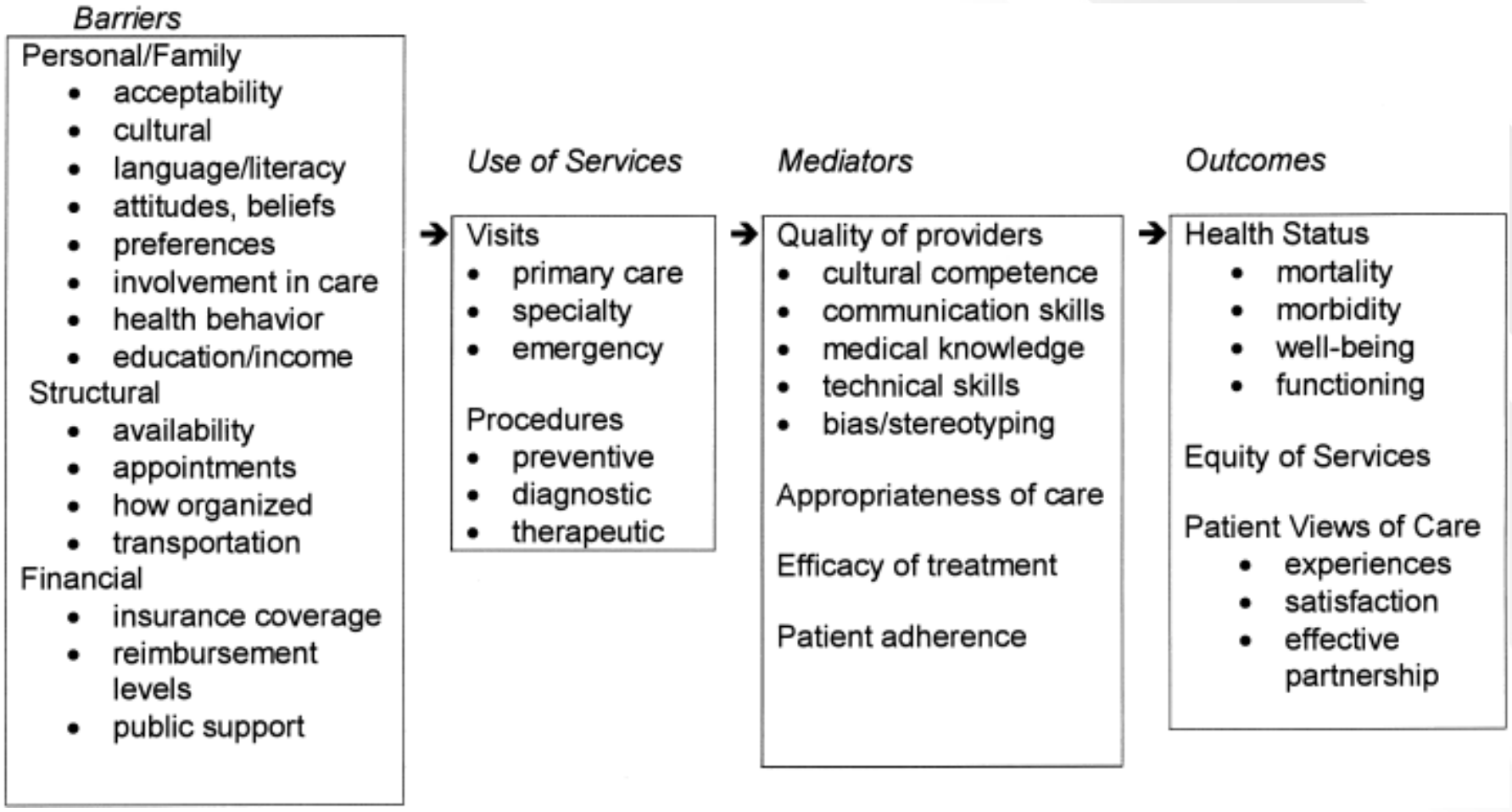
Methods

- Secondary data analysis complemented by mixed methods

Addressing Disparities Research Project, awarded May 2013

Conceptual Framework & Driver Model

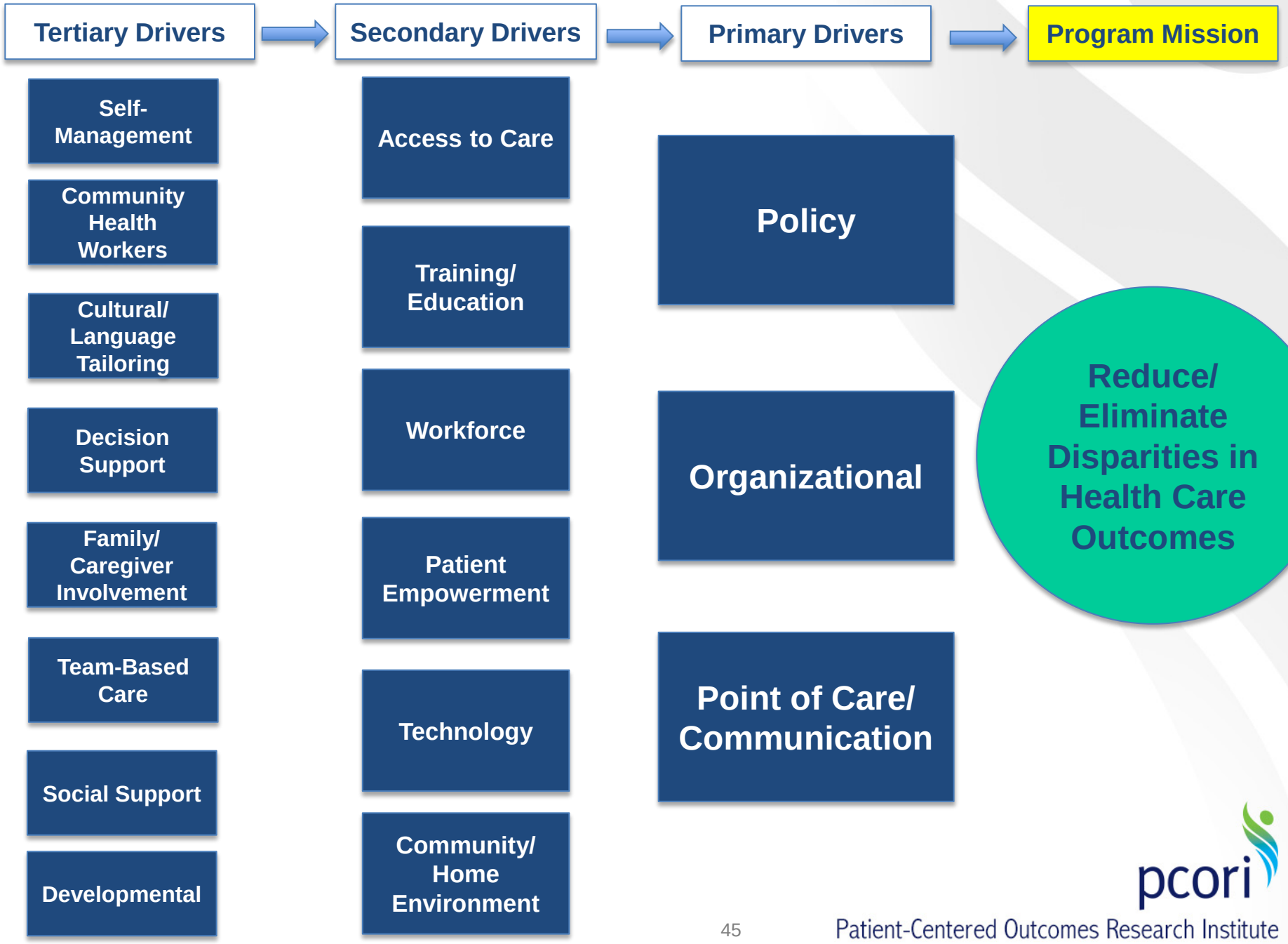
Conceptual Framework: Designing and Evaluating Interventions to Eliminate Disparities in Health Care



Cooper et al.

Journal of General Internal Medicine
Volume 17, Issue 6, pages 477-486, 24 JUL 2002 DOI: 10.1046/j.1525-1497.2002.10633.x
http://onlinelibrary.wiley.com/doi/10.1046/j.1525-1497.2002.10633.x/full#f1

Addressing Disparities Driver Model



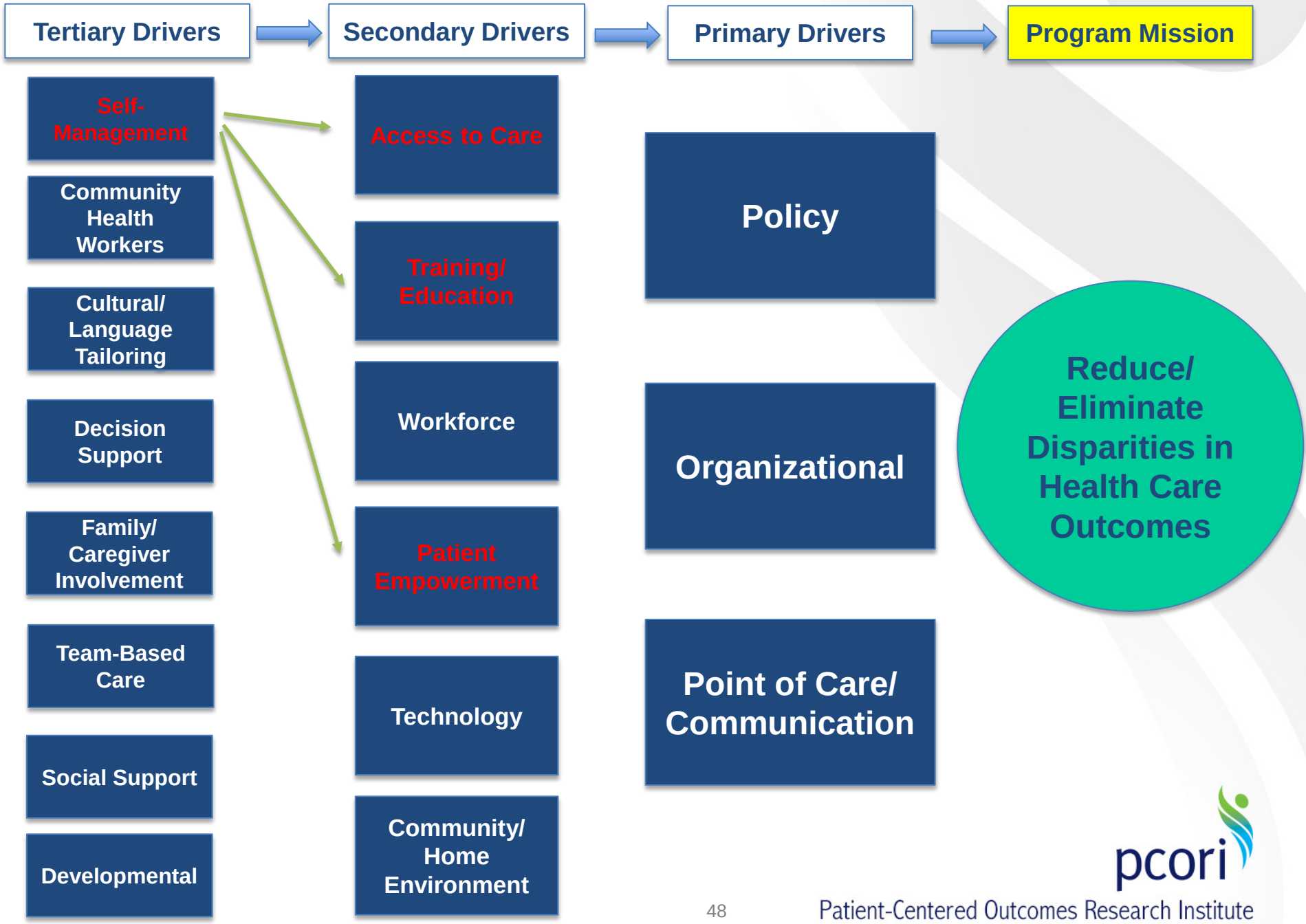
Addressing Disparities Driver Model

- The model is an *evolving* tool used to
  - Evaluate where we are
  - Identify where we need to go

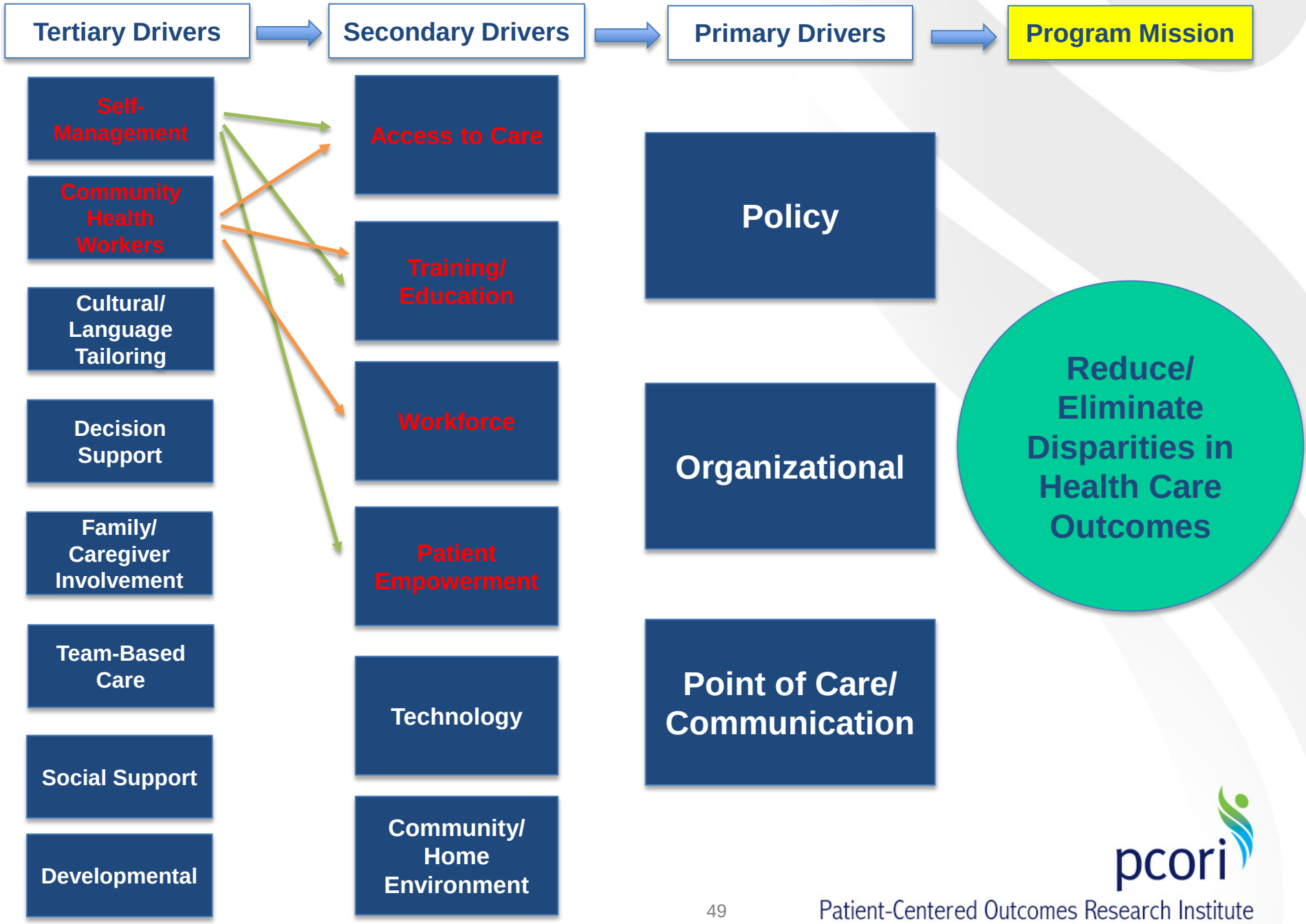
Addressing Disparities Project: *Mapping Example 1*

Project Title	A Helping Hand to Activate Patient-Centered Depression Care among Low-Income Patients
PI	Kathleen Ell
Organization	University of Southern California
State	California
Project Description	Study compares two safety-net clinic depression care models among patients with major depression and comorbid conditions. Patients are randomized to usual PCMH care OR PCMH + self-management training with a community health worker

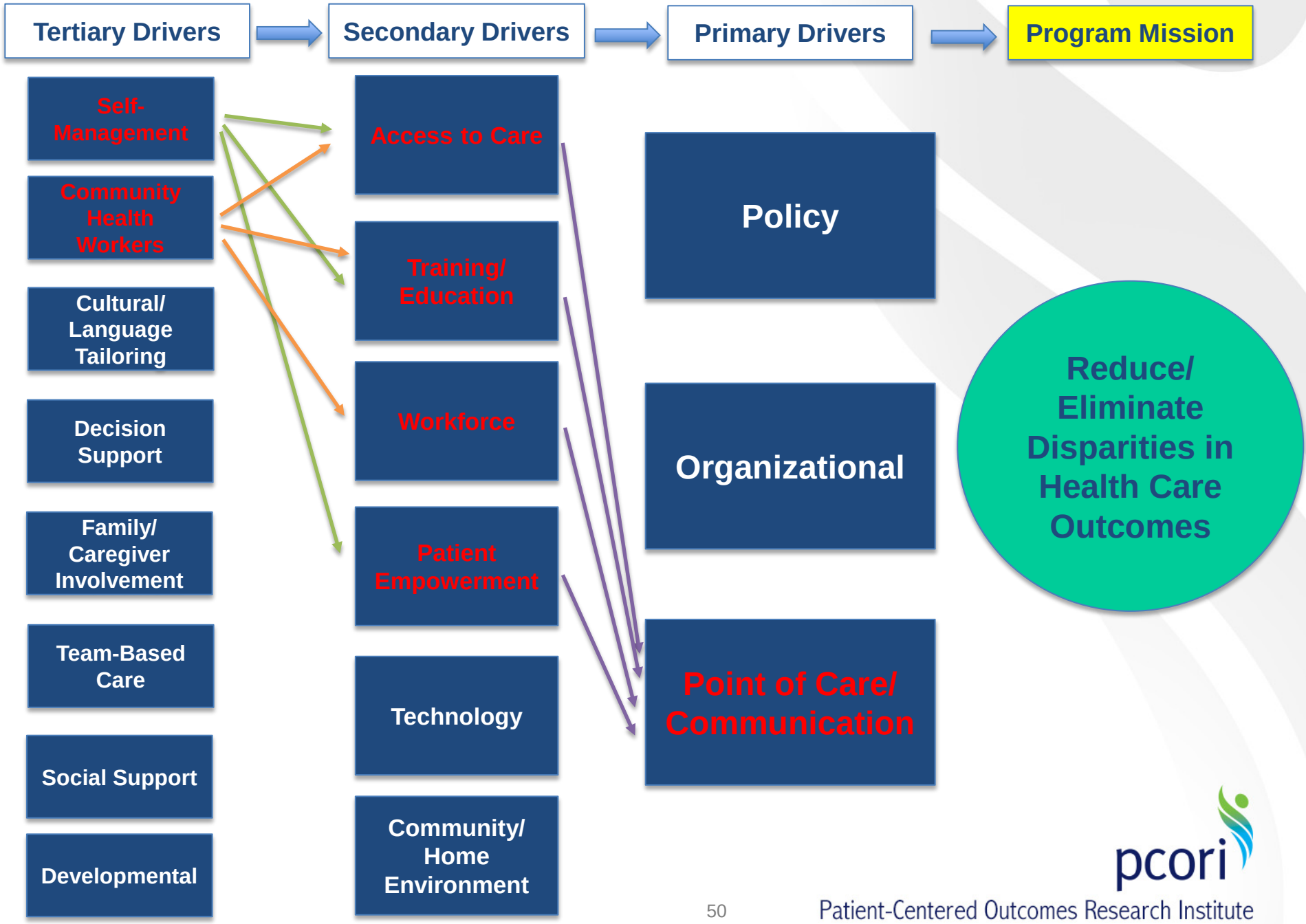
Addressing Disparities Driver Model: Mapping Example 1



Addressing Disparities Driver Model: Mapping Example 1



Addressing Disparities Driver Model: Mapping Example 1



All Addressing Disparities Projects Mapped to Driver Model

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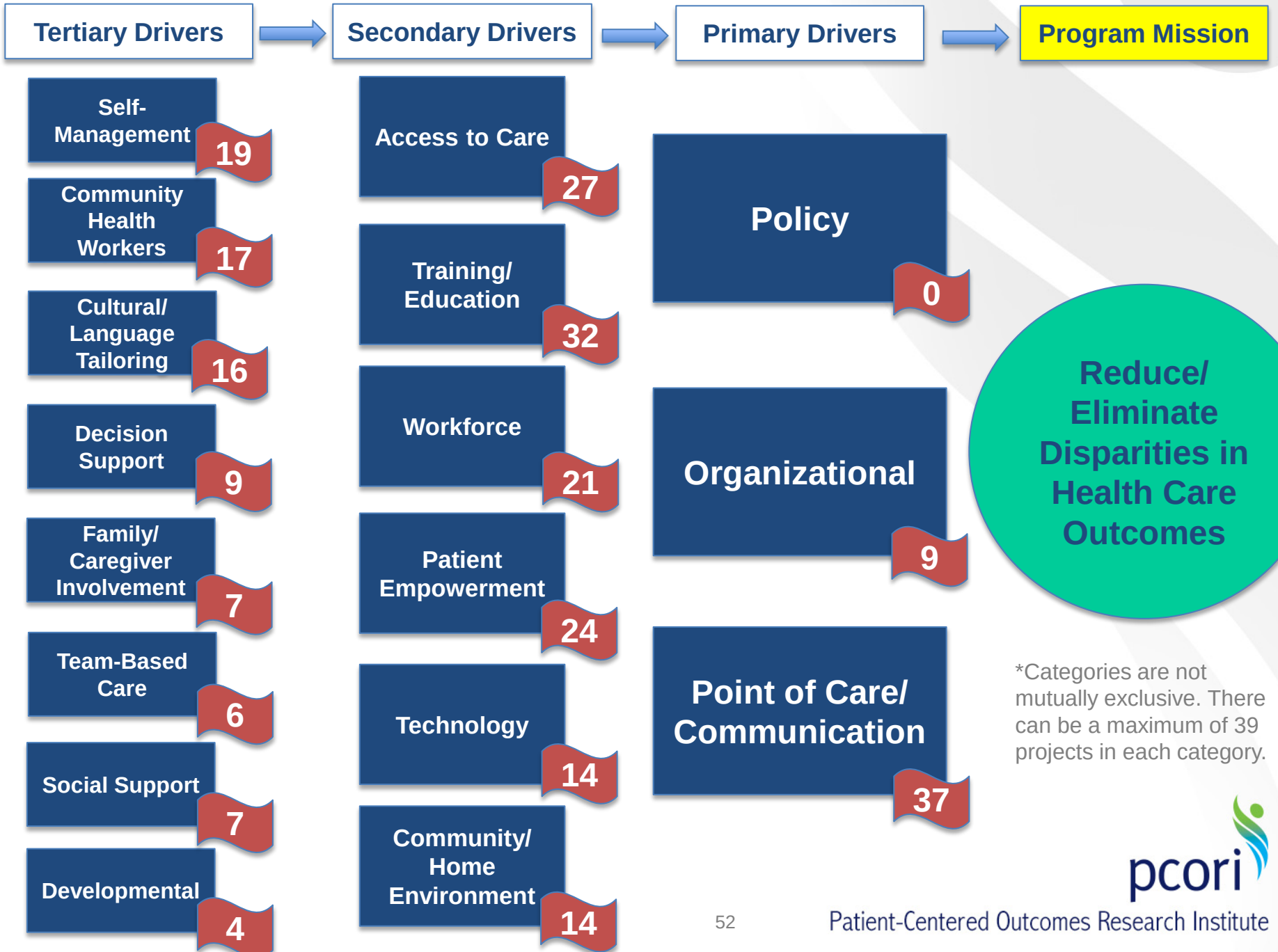
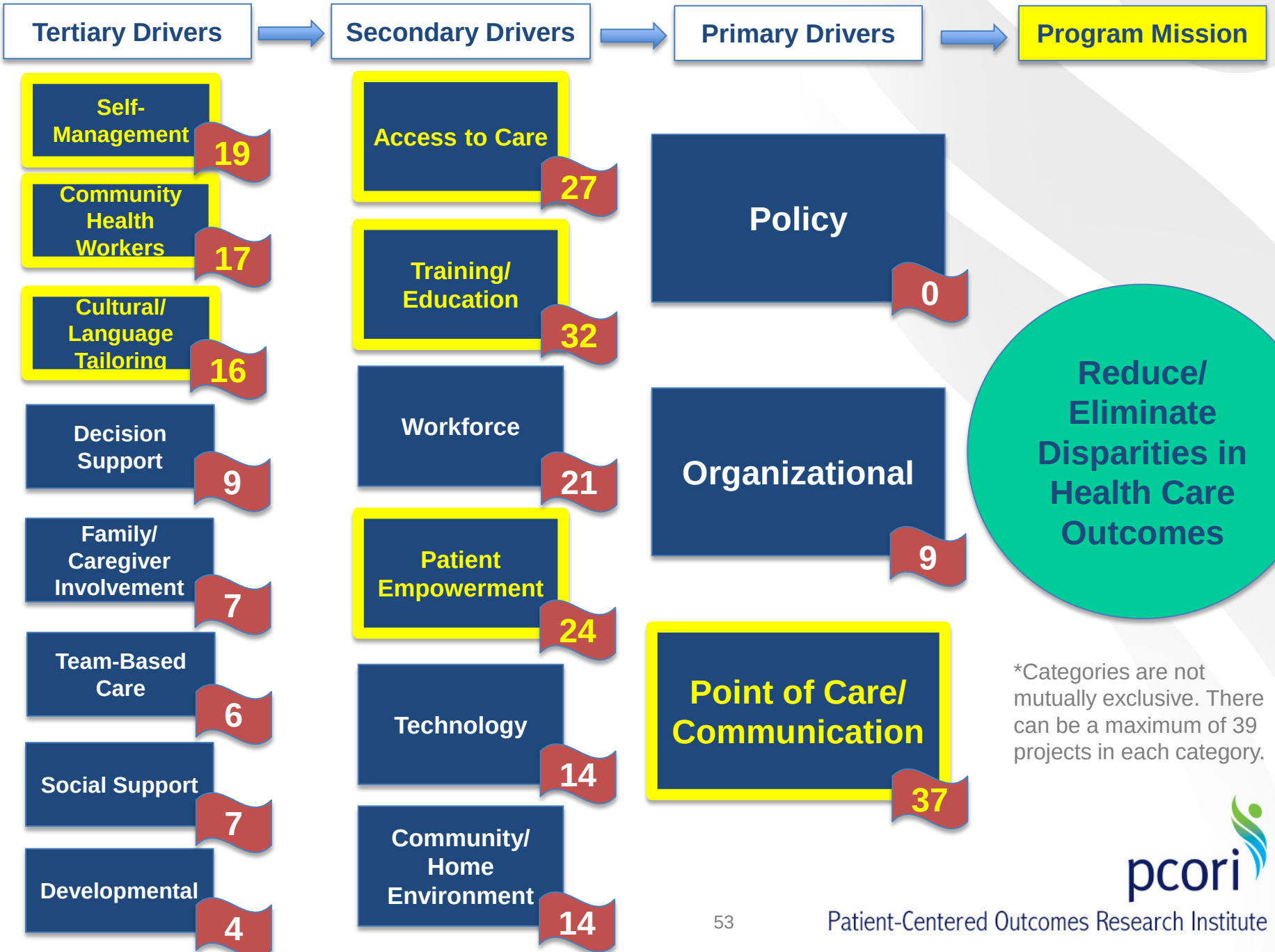
Addressing Disparities Driver Model (n=39*)



*Categories are not mutually exclusive. There can be a maximum of 39 projects in each category.

Addressing Disparities Driver Model (n=39*)



*Categories are not mutually exclusive. There can be a maximum of 39 projects in each category.

Disparities Projects across All PCORI Program Areas

Addressing Disparities: *Mapping Disparities Projects Across All Programs*

PCORI Disparities Projects - All Funding Cycles			
Program	**# of Disparities Projects**	**Total # of Projects in Program**	**% of Portfolio Looking at Disparities**
Addressing Disparities	39	39	100%
Improving Healthcare Systems	31	41	76%
Assessment of Prevention, Diagnosis and Treatment Options	31	65	48%
Communication and Dissemination Research	12	25	48%
TOTAL	**113**	**170**	**66%**

Addressing Disparities Driver Model:
Mapping All Disparities Projects

	AD Projects	Non-AD Disparities Projects
Tertiary Driver	1. Self-Management 2. CHWs 3. Cultural/language Tailoring	1. Decision Support 2. Self-management 3. Family/caregiver Involvement
Secondary Driver	1. Training/education 2. Access to Care 3. Patient Empowerment	1. Training/education 2. Community/home environment 3. Workforce

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Where Do We Go From Here?
Learning, Disseminating, and Implementing

- Engage patients and other end-users from start to finish (i.e., research topic generation → dissemination)

- Learning Communities

  - Mechanism to foster cross-learning among project teams

  - Bring together the research community and end-users including patients, payers (e.g., AHIP), employers and purchasers (e.g., National Business Group on Health), clinicians, professional societies, policy makers, and training institutions.

Where Do We Go From Here?
Funding Opportunities

1. "Broad" Funding Announcements
2. Targeted Funding Announcements
3. Pragmatic Clinical Studies
4. Engagement Awards

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Where Do We Go From Here?
Learning, Disseminating, and Implementing

Working with the Addressing Disparities Advisory Panel:

- Continue to develop a more sophisticated understanding of the practices that are effective in reducing disparities in care at the policy, community, organizational, practice, and individual levels.

- Produce a strong evidence base of promising/best practices for disparities reduction strategies

- Disseminate promising/best practices in partnership with key stakeholders

Addressing Disparities Program

Questions and Discussion

15 Minute Break

Refreshments in the upper lobby foyer.

The PCORI Dissemination and Implementation Action Plan

Presentation to Patient Engagement Advisory Panel and Advisory Panel on Addressing Disparities

Mathematica Policy Research, AcademyHealth, Palladian Partners, and WebMD Team

April 28, 2014

Agenda

- **Introduction to the Project**
  - **Team introductions**
  - **Project overview**
- **Breakout Discussion Groups**
  - **Dissemination**
  - **Implementation**
- **Note: Discussion highlights to be shared via email**

Goals for Today's Discussion

- **Share plans for developing a dissemination and implementation (D&I) action plan for PCORI**
- **Hear your thoughts on D&I of health and health care evidence, focusing on:**
  - **Engagement of stakeholders and priority populations**
  - **Identification of D&I best practices**
  - **Facilitators and barriers to effective D&I**
  - **Evaluation strategies for D&I efforts**

Introduction to Project

Project Team

Mathematica Policy Research

- **Dominick Esposito**, Jennifer de Vallance, **Sarah Forrestal, Jessica Heeringa**, Laura Kimmey, Betsy Santos, Amanda Lechner, Heather Gordon

AcademyHealth

- **Alison Rein**, Kristin Rosengren, Kelsi Feltz, Lisa Simpson

Palladian Partners

- **Donna Messersmith**, Heather Pierce, Susan Keown

WebMD

- **Jane Lowers**, Matthew Holland

Stakeholder Council

- 25 members with representation of clinicians, health systems, consumers, public and private payers, employers, pharmaceuticals industry, health technology organizations, and journalists/media

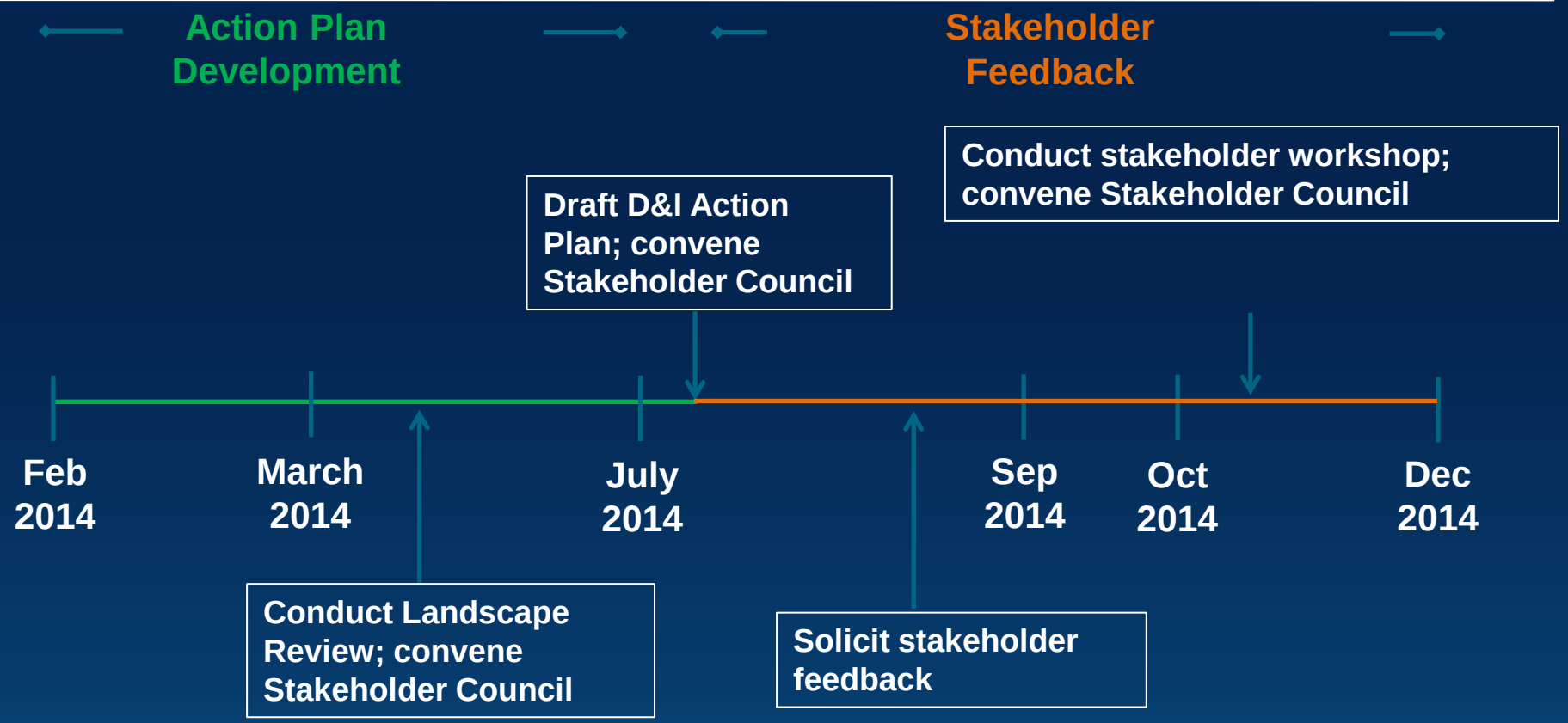
D&I Action Plan

- **A strategic plan to guide D&I activities for PCORI-funded research**
- **Core principles**
  - **Inclusiveness of stakeholder groups**
  - **Multimodal engagement and dissemination tactics**
  - **Informed and innovative approaches**
- **Key components**
  - **D&I definitions and multilevel D&I framework**
  - **Identification of needs for various stakeholder audiences**
  - **Identification of tactics that work best for target audiences**
  - **Partnership and engagement strategies**
  - **Recommendations for testing and evaluating D&I efforts**

PCORI D&I Action Plan Goals

- **Guide PCORI in the dissemination of its funded research**
- **Speed implementation by facilitating the use of research findings by health care decision makers**
- **Assess the effectiveness of D&I efforts in reducing practice variation and disparities**
- **Address the dissemination needs of a diverse array of stakeholder groups**

Project Activities and Time Line



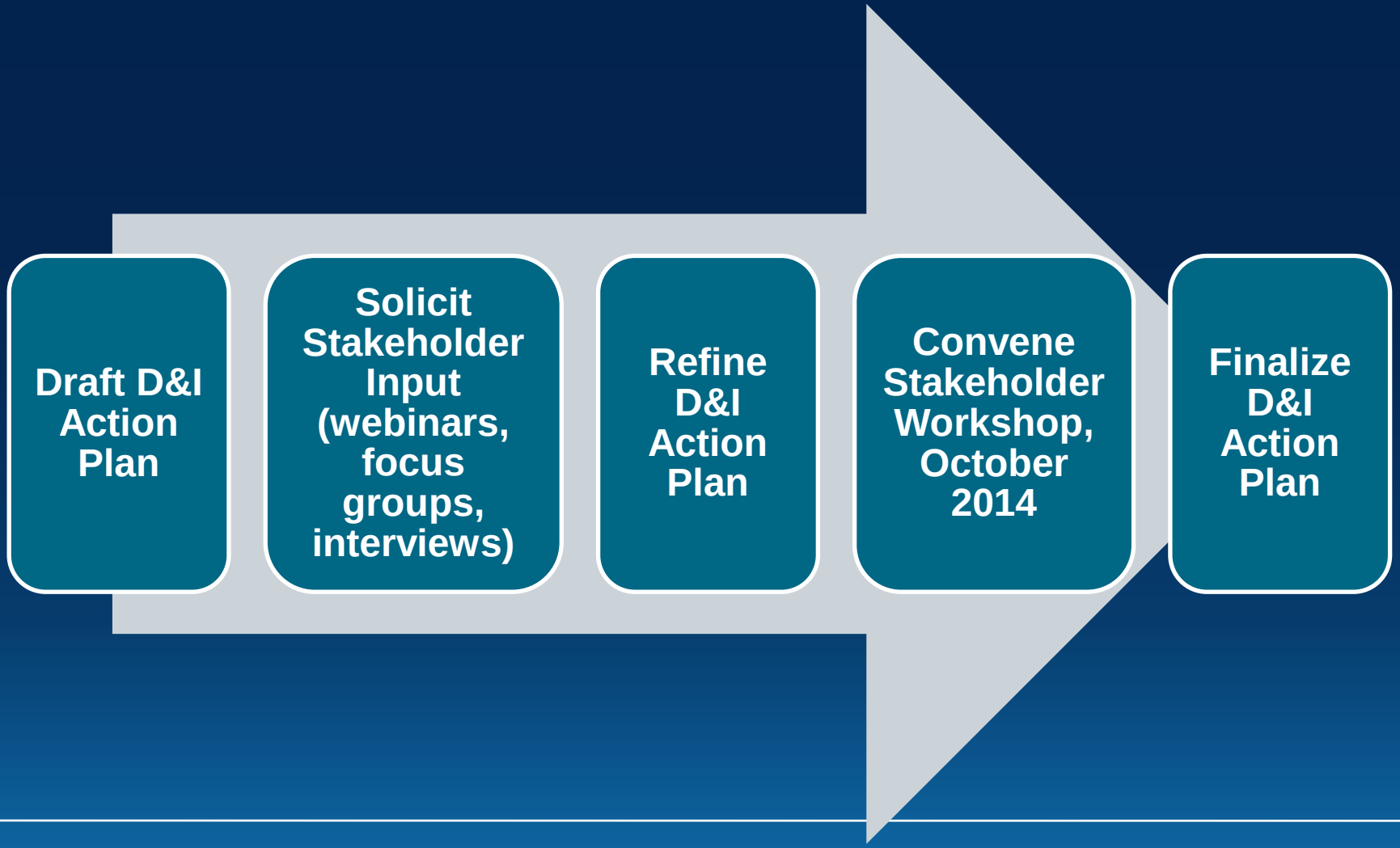
Action Plan Development

- **Development activities – in process**
  - **Literature Scan**
  - **Interviews (stakeholder and exemplar)**
    - **Topic guide and database of notes**
    - **Collaborative validation via Codigital**
  - **Gap analysis**
  - **Case studies**
  - **Summary landscape report**

Stakeholder Feedback on Action Plan – Target Groups

- Patients (unaffiliated and organizations)
- Consumer organizations
- Clinicians
- Hospitals/health systems
- Purchasers
- Health care journalists
- Community organizations and public health professionals
- Payers (public and private)
- Philanthropic groups
- Peer-reviewed journals
- Industry: Life sciences
- Industry: Tech companies, EHR vendors
- Researchers
- Policymakers

Stakeholder Feedback on Action Plan – Process



Action Plan Format

- **Strategic Framework: Connecting D&I Goals with Evidence and Best Practices**
  - **Definitions of dissemination and implementation**
  - **Research usefulness assessment**
  - **Engagement vehicles and approaches**
  - **Audience identification and segmentation**
  - **Measurement and evaluation**
- **Operational Toolkit**
  - **Tools for Action Plan users considering D&I of research findings**
  - **Illustrative examples of the D&I process**

Project Next Steps

- **Complete landscape review – June 2014**
- **Draft D&I Action Plan – July 2014**
- **Solicit Stakeholder Feedback – July to September 2014**
- **Refine D&I Action Plan – October 2014**
- **Stakeholder Workshop – October 2014**
- **Develop Recommendations for Evaluating and Measuring the Impact of D&I Efforts – April to October 2014**
- **Finalize D&I Action Plan – November 2014**

Ways to Provide Further Input

- **Consider participating in working group to provide input as project progresses**
- **Email us:**
  - **Dominick Esposito, desposito@mathematica-mpr.com**
  - **Jennifer de Vallance, jdevallance@mathematica-mpr.com**

Breakout Discussion Groups

Working Definitions of D&I

- ***Dissemination*** **refers to the intentional, active communication and distribution of information to increase awareness, often targeting and tailoring the communication to specific audiences. Dissemination aims to "help it happen."**

- ***Implementation*** **refers to the intentional, active communication of information and additional actions to overcome barriers to achieve use of the information. Implementation aims to "make it happen."**

Dissemination Discussion Questions

- **In your experience, what are some best practices in the dissemination of health and health care evidence?**
  - **How do you know these are best practices?**
- **What facilitates or makes dissemination easier?**
- **What are the challenges to successful dissemination?**
  - **How can these be addressed?**
- **How can disseminators effectively identify and take into account the needs of various audiences?**
  - **In what ways can dissemination strategies be more effective in reaching underserved groups?**

Implementation Discussion Questions

- **In your experience, what are some best practices in the implementation of health and health care evidence?**
  - **How do you know these are best practices?**
- **What facilitates or makes implementation easier?**
- **What are the challenges to successful implementation?**
  - **How can these be addressed?**
- **How can implementers effectively identify and take into account the needs of various stakeholders?**
  - **In what ways can implementation strategies be more effective in including underserved groups?**

Patient and Family Engagement Rubric

Informational

Sue Sheridan, MIM, MBA

Director of Patient Engagement

Patient-Centered Outcomes Research Institute

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 20th , 2013)

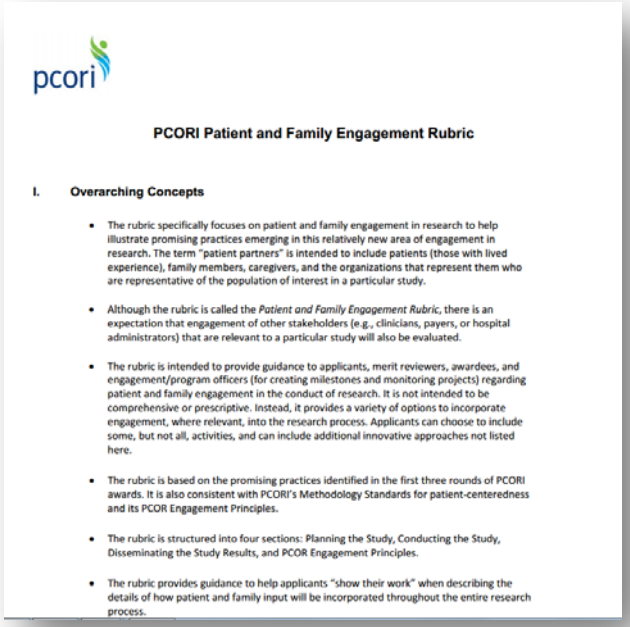
PCORI Engagement staff to review and refine with Scientific Program Directors and Executive Committee (November 2013)

PCORI Engagement to review refined 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 re-defined by the community of researchers, patients, caregiver and advocacy organizations

Rubric Launch



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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

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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.

Patient Partnerships

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

See More »

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.

Rubric Launched in February 2014 PFAs

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 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)
- 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 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

Next Steps

- Identify opportunities for presentations and publications to patient, researcher, and other stakeholder audiences
- Seek feedback from applicants and merit reviewers and make revisions to the rubric as necessary
- Explore mechanisms for outlining stakeholder engagement in a similar tool
- Revise and expand rubric via multiple sources of input
- Evaluation:
  - Evaluate the effectiveness of the rubric
  - Evaluate the role and function of the EOs

30 Minute Break

The reception will begin at 5:30 p.m., followed by dinner at 6:30 p.m. in the Upper lobby foyer.