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Patient Engagement Advisory Panel

January 13, 2015

Arlington, VA

Patient-Centered Outcomes Research Institute

Welcome, Introductions, and Review Agenda

Jean Slutsky, PA, MSPH

Chief Engagement and Dissemination Officer

Sue Sheridan, MIM, MBA, DHL

Director of Patient Engagement

Charlotte W. Collins, JD
Chair, Compensation Subcommittee

Darius Tandon, PhD
Chair, Evaluation Subcommittee

Patient-Centered Outcomes Research Institute

Patient Engagement Advisory Panel, January 13, 2015

Agenda for Jan. 13

9:30 – 10:00 a.m.	Welcome, Introductions and Review Agenda
10:00 a.m.– 12:00 p.m.	Perspectives on Meaningful Patient Representation in Research: A Discussion on Key Considerations and Recommendations
12:00 – 1:00 p.m.	LUNCH
1:00 – 2:00 p.m.	The Role of Other Stakeholders in PCORI Research – Discussion
2:00 – 3:00 p.m.	Compensation Framework - Finalization and Approval
3:00 – 3:30 p.m.	BREAK
3:30 – 4:45 p.m.	WE-ENACT Data and Rubric/Understanding Engagement Data – Update
4:45 – 5:00 p.m.	Wrap-up
5:00 – 6:00 p.m.	BREAK
6:00 – 6:30 p.m.	**Reception-** Crystal Ballroom Salon A
6:30 p.m.	**Dinner-** Crystal Ballroom Salon A

Advisory Panel on Patient Engagement

Charlotte Collins
Darius Tandon
Stephen Arcona
Paul Arthur
Steven Blum
Marc Boutin
Kristin Carman
Perry Cohen
Amy Gibson
Regina Greer-Smith
Bruce Hanson
Lorraine Johnson
Amy Kratchman
Julie Moretz
Kimberly McCleary
Melanie Nix
Sally Okun
Laurel Pracht
Sara van Geertruyden
Saul Weingart

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Perspectives on Meaningful Patient Representation in Research:

A Discussion on Key Considerations and Recommendations

Rebekah Angove
Engagement Director, LaCDRN
Perry Cohen
Patient Advocate
Kimberly McCleary
Director of Strategic Initiatives, FasterCures

Sue Sheridan, MIM, MBA, DHL
Director, Patient Engagement

Jaye Bea Smalley, MPA
Engagement Officer

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Overview

- Identify the different opportunities for patient engagement in our healthcare system
    - Reference Kristin Carman's framework
- Explore the various roles and characteristics of authentic patient representatives in patient engagement in research

  Perry Cohen, Rebekah Angove, Jaye Bea Smalley
- Identify the roles and characteristics of patient, caregiver and consumer advocacy organizations in research

  PEAP members
- Review models of patient engagement
    - NHC – Marc Boutin
    - Consumer and patient groups in the FDA setting – Kim McCleary
- Break into small groups to develop key considerations
- Report out

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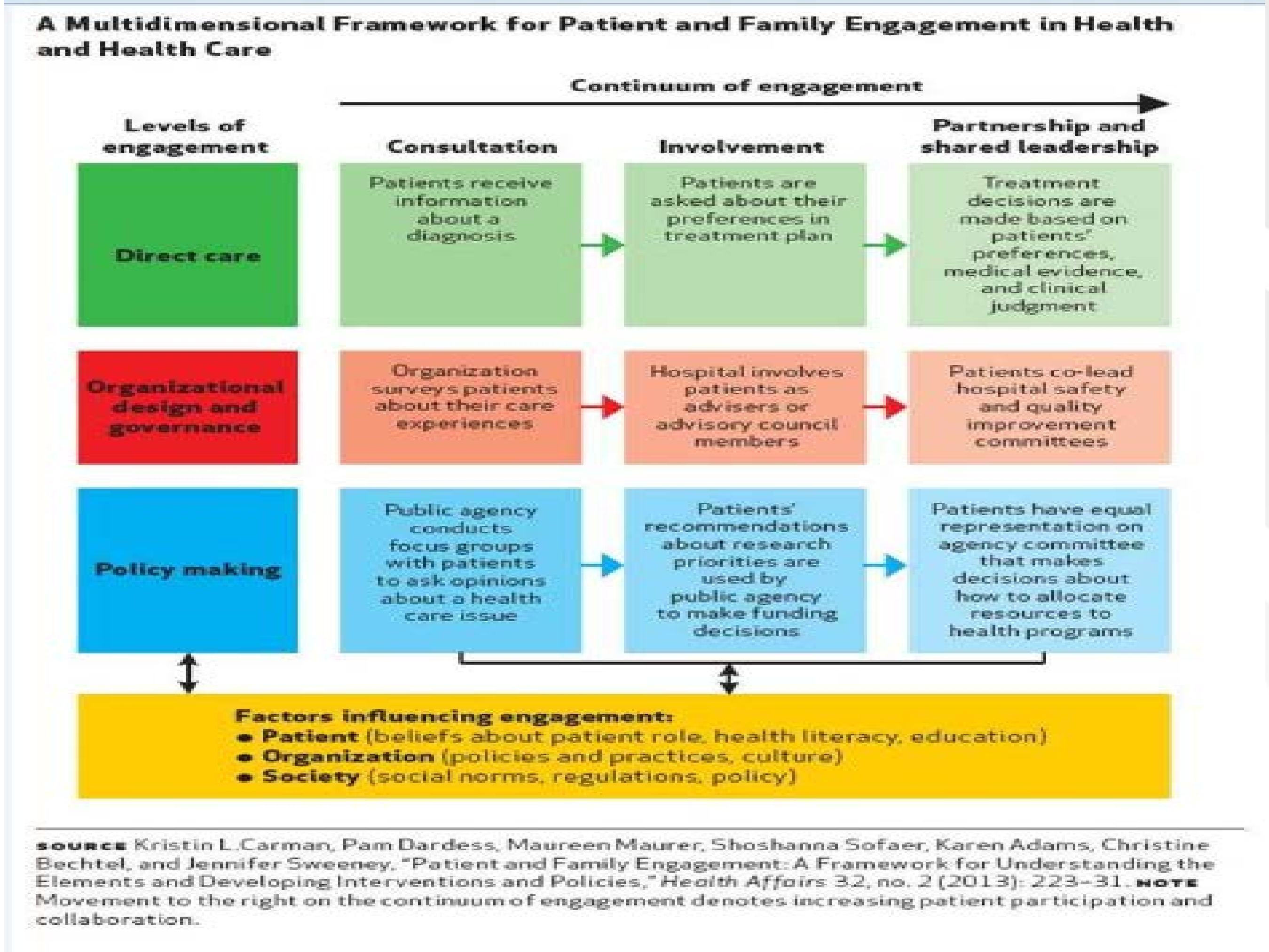

A Multidimensional Framework for Patient and Family Engagement in Health and Health Care

Continuum of engagement

Levels of engagement	Consultation	Involvement	Partnership and shared leadership
Direct care	Patients receive information about a diagnosis	Patients are asked about their preferences in treatment plan	Treatment decisions are made based on patients' preferences, medical evidence, and clinical judgment
Organizational design and governance	Organization surveys patients about their care experiences	Hospital involves patients as advisers or advisory council members	Patients co-lead hospital safety and quality improvement committees
Policy making	Public agency conducts focus groups with patients to ask opinions about a health care issue	Patients' recommendations about research priorities are used by public agency to make funding decisions	Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs

Factors influencing engagement:

- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)

SOURCE Kristin L. Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel, and Jennifer Sweeney, "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies," *Health Affairs* 32, no. 2 (2013): 223–31. NOTE Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.

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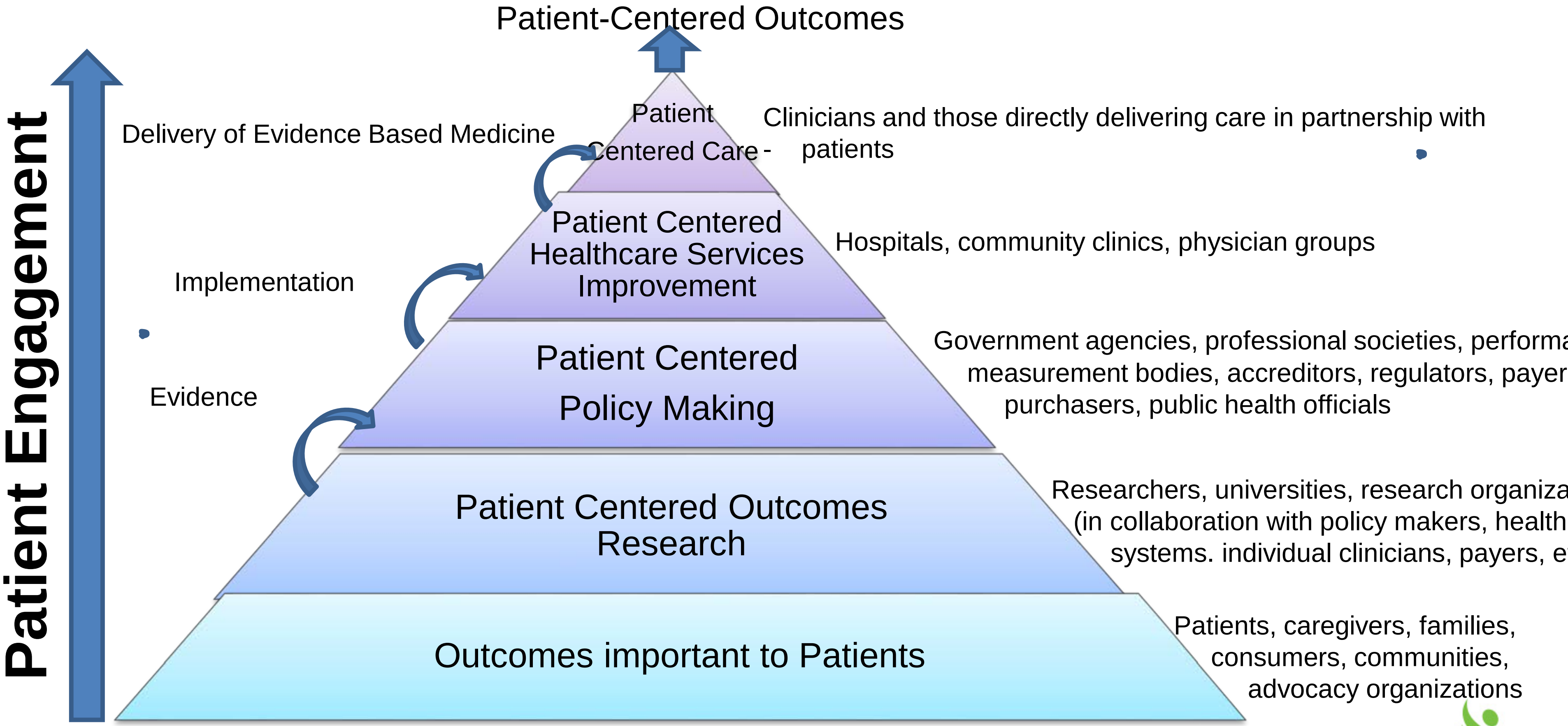
Patient Engagement in a Patient-Centered Healthcare System



Patient Engagement

Patient-Centered Outcomes

Delivery of Evidence Based Medicine

Patient Centered Care - Clinicians and those directly delivering care in partnership with patients

Patient Centered Healthcare Services Improvement

Hospitals, community clinics, physician groups

Implementation

Patient Centered Policy Making

Government agencies, professional societies, performa
measurement bodies, accreditors, regulators, payer
purchasers, public health officials

Evidence

Patient Centered Outcomes Research

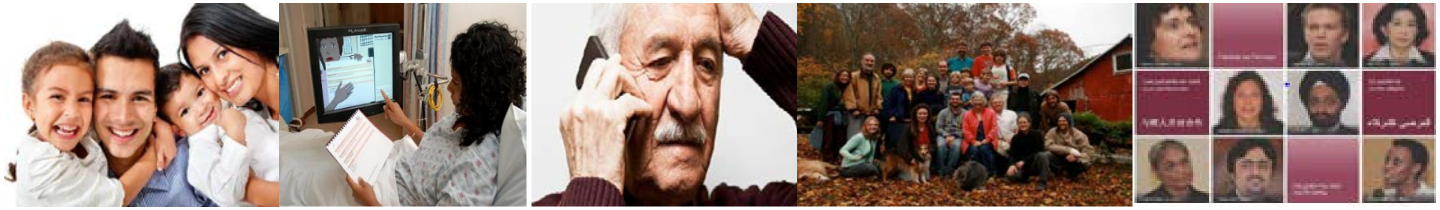
Researchers, universities, research organiza
(in collaboration with policy makers, health
systems. individual clinicians, payers, e

Outcomes important to Patients

Patients, caregivers, families,
consumers, communities,
advocacy organizations

Who Represents Patients in Patient 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. (PCORI)



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Authentic Patient Centered Roles and Capabilities

Advocating for Patients' Interests

Perry D Cohen, PhD

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Beyond traditional patient roles

- Research done differently means patient interests come first.
- Patients with a serious chronic illness have different perspectives and values (interests) than patients with less risky illnesses.
- Patients do not necessarily know the different interests of key stakeholder groups.
- Nurturing patient activation and expanding the role of patient advocates are necessary missing ingredients for improving medical care.

New Roles for Activated Patients

1. "e-patients”
2. Research partners
3. Stewardship activities
4. Patient representatives

Capabilities Needed for Patient Advocates

- Trained/ Informed-- up to date knowledge of scientific issues and patient views.
- Linked/ Reinforced -- connected with patient community
- Trusted -- History of interests, no conflict of interest
- Authorized/ Certified-- formal recognition of status

Recommendations

- Recruit and select qualified patient representatives
- Create “institutes” to define and maintain patients’ interests for different patient populations
- Include patient representatives in all policy decisions about research and treatment of illness

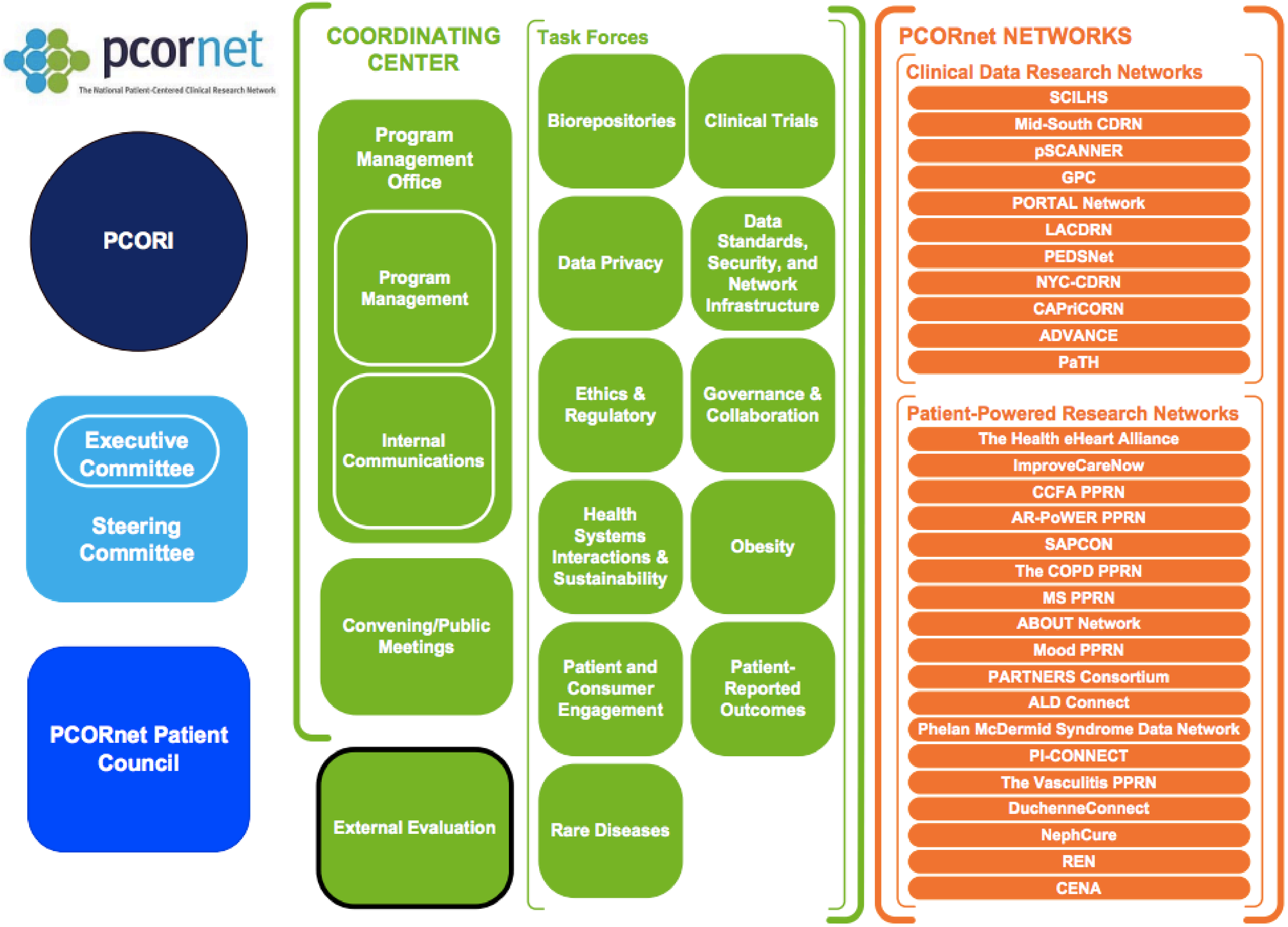
Who is the Authentic Patient in a Patient-Centered Research Network?

Jaye Bea Smalley, MPA
Engagement Officer, PCORI

Rebekah Angove, PhD
Engagement Director, LACDRN

pcornet
The National Patient-Centered Clinical Research Network

PCORnet Overview



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The National Patient-Centered Clinical Research Network

PCORI

Executive Committee

Steering Committee

PCORnet Patient Council

COORDINATING CENTER

- Program Management Office
  - Program Management
  - Internal Communications
- Convening/Public Meetings

External Evaluation

Task Forces

- Biorepositories
- Clinical Trials
- Data Privacy
- Data Standards, Security, and Network Infrastructure
- Ethics & Regulatory
- Governance & Collaboration
- Health Systems Interactions & Sustainability
- Obesity
- Patient and Consumer Engagement
- Patient-Reported Outcomes
- Rare Diseases

PCORnet NETWORKS

Clinical Data Research Networks

- SCILHS
- Mid-South CDRN
- pSCANNER
- GPC
- PORTAL Network
- LACDRN
- PEDSNet
- NYC-CDRN
- CAPriCORN
- ADVANCE
- PaTH

Patient-Powered Research Networks

- The Health eHeart Alliance
- ImproveCareNow
- CCFA PPRN
- AR-PoWER PPRN
- SAPCON
- The COPD PPRN
- MS PPRN
- ABOUT Network
- Mood PPRN
- PARTNERS Consortium
- ALD Connect
- Phelan McDermid Syndrome Data Network
- PI-CONNECT
- The Vasculitis PPRN
- DuchenneConnect
- NephCure
- REN
- CENA

Distinctions Unique to Engagement in a Network vs. a Particular Research Project

- Define Patient
  - “We are all patients” vs. meaningful patient experience

- Patient and other stakeholders are part of network governance
  - Determine research agenda
  - Data use and sharing agreements and policies
  - Co-developing privacy and consent policies
  - Involvement of advocacy organizations important
- Dual Roles
  - Given unique needs for particular expertise, many patients may play multiple roles in research networks.
  - Who is really looking through the lens of the patient when necessary?

Our Goals

- Rich conversation with a group that has expertise diverse expertise in healthcare and research, including patient engagement
- Gain insights and considerations to inform Patient and Consumer Engagement Task Force Patient Engagement Policy Workgroup
- Case studies

Looking for Guidance and Considerations that help Preserve Authentic Patient Representation

- Patients often bring unique skill sets separate from being a patient /caregiver representative to a network.
  - When might they conflict and need to be discouraged?
  - How can we encourage patient representation from patient/caregiver representatives with complementary skills that are required by the network?
- When are there conflicts resulting from employment responsibilities?
- Can a patient/caregiver representative in a decision-making role on a governance committee make decisions that reflect the interests of patients given there expertise or professional affiliation?
- Who is eligible for patient compensation?
- How do we know patient representation decisions are aligned with the spirit of PCORnet (and not is just checking a box)?

Case Study #1

A CDRN’s patient representative on their governance committee happens to be the program manager for a participating institution’s community engaged research program

- Member of a minority community and has trusting relationship with that community
- Has lived experience for one of the CDRN’s 3 disease cohorts
- Works with investigator in charge of patient engagement for CDRN and executing network approach for engagement
- Dual role
- Professional implementing network patient engagement strategy
- Patient representative in decision-making role on governance committee

Case Study #2

A caregiver representative with expertise in technology and patient privacy serves on the governance committee for a PPRN. The network is using the technology developed by this individual.

- The representative has a long history of service to the participating disease advocacy organization-trusted member of the patient community.
- The technology was developed to address the unique concerns and needs as experienced by representative and community.
- The funding for the technology for the network comes from a variety of public/private organizations.

Case Study #3

A Clinical RN is employed by a large health system that is part of a CDRN. She serves on the patient advisory board as a patient representative for the CDRN operated by the health system that employs this person.

- The RN became aware of the opportunity through a public outreach initiative.
- The RN is not responsible for any administrative or research operations on behalf of the CDRN and participating health system.
- The RNs supervisor is not responsible for the day to day operations of the CDRN.

Small Group Discussion

- **What is an authentic patient when engaging patients in research?**
    - What are their roles when representing patients in research?
    - What are the key considerations and characteristics of patients engaged in research?

- **What is the profile of patient, caregiver and consumer advocacy organizations in research?**
    - What are their roles when representing patients in research?
    - What are the key considerations and characteristics of patient, caregiver and consumer advocacy organizations engaged in research?

- **Is it necessary to distinguish the difference? If not, what matters?**

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Lunch

Crystal Ballroom Salon A

We will reconvene at 1:00 p.m. in this room.

The Role of Other Stakeholders in PCORI Research Discussion

Susan Hildebrandt, MA
Director, Stakeholder Engagement
Greg Martin
Deputy Director, Stakeholder Engagement

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What We Will Cover

- Definition of stakeholder communities
- Engagement of stakeholders in PCORI activities
- Discussion

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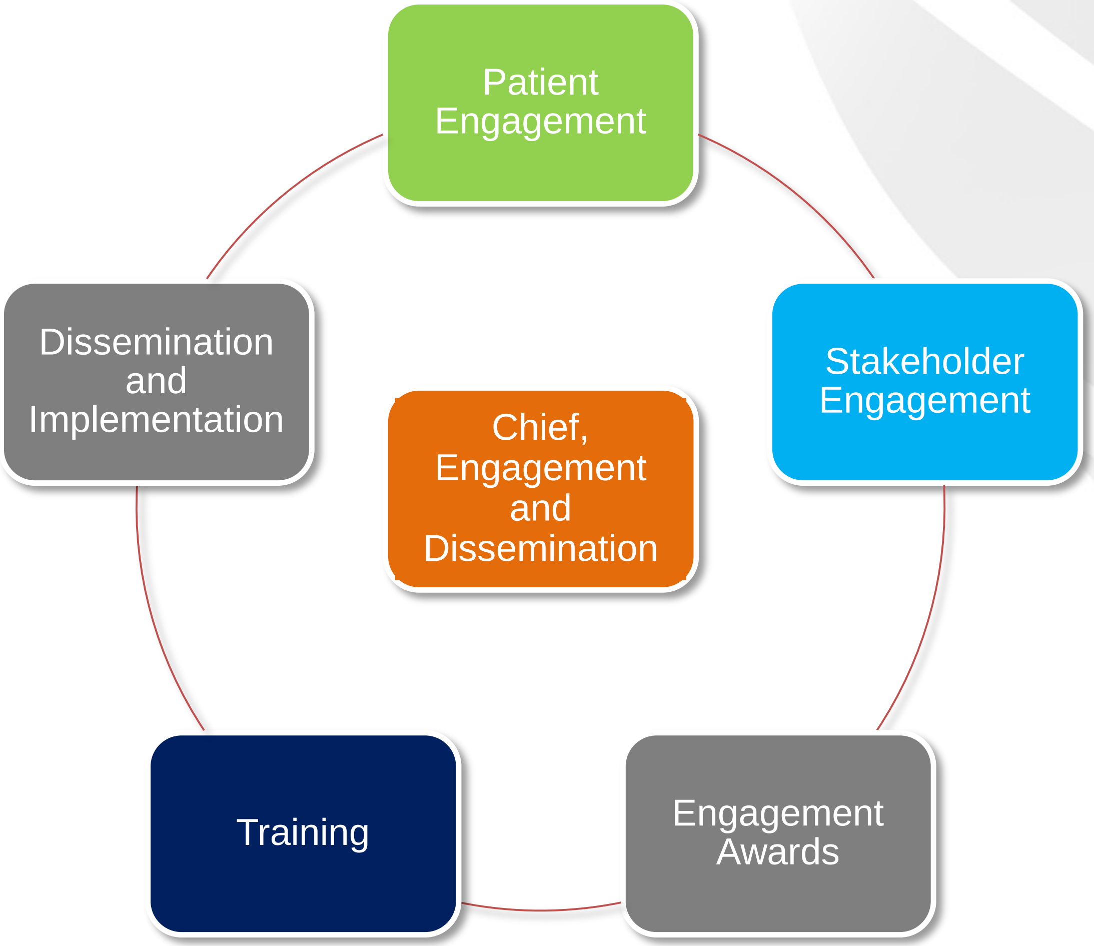
Engagement Division



Patient Engagement

Dissemination and Implementation

Chief, Engagement and Dissemination

Stakeholder Engagement

Training

Engagement Awards

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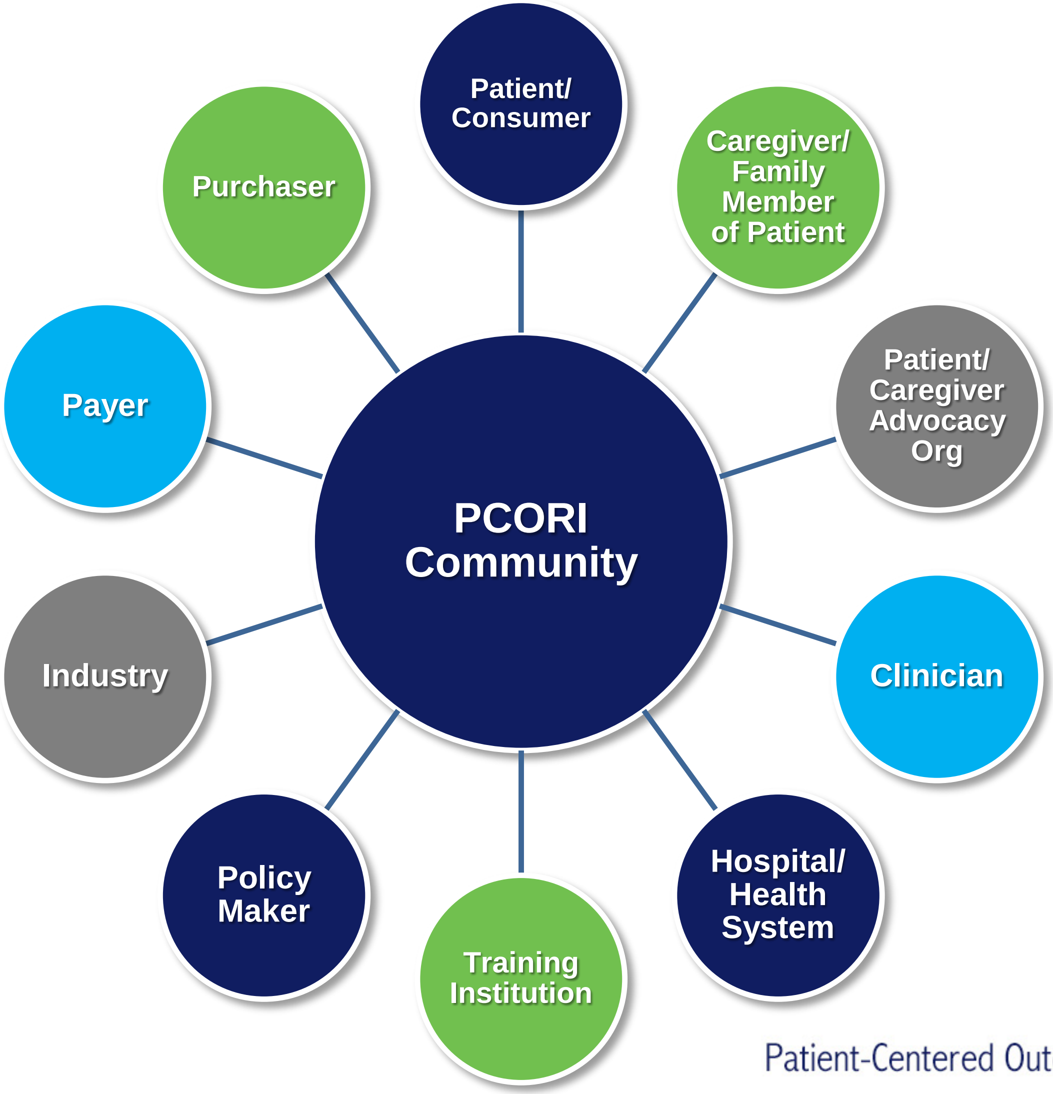
Who Are PCORI's Stakeholders?



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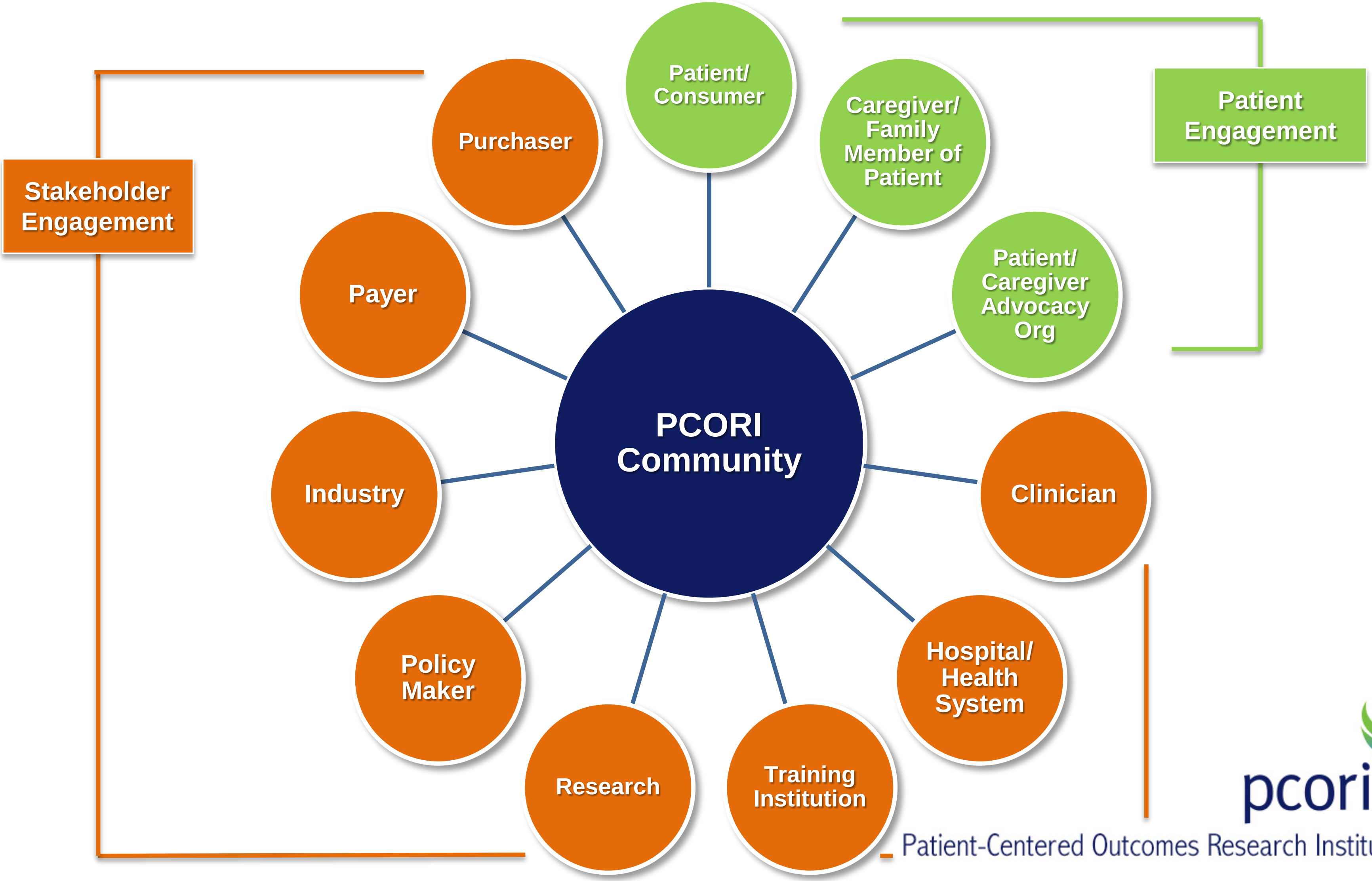
Who Are Our Stakeholders?



Stakeholder Engagement

Patient Engagement

PCORI Community

Patient/ Consumer

Caregiver/ Family Member of Patient

Patient/ Caregiver Advocacy Org

Clinician

Hospital/ Health System

Training Institution

Research

Policy Maker

Industry

Payer

Purchaser

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Engagement of Stakeholders

- Evaluation
- Government Relations
- State Engagement
- Regional Workshops
- Roundtables
- Webinars
- Advisory Panels
- Work Groups
- Merit Review
- 1:1 Meetings
- Topic Generation
- Speakers' Bureau
- Award Notification

Stakeholder Engagement Activities

- How did we determine these options?
  - We systematically engaged representative organizations from each community
  - They indicated that these ways would be most the meaningful and substantive ways to engage
    - their organization and
    - their members.
  - Strong interest in helping PCORI craft its portfolio
  - Less interest in being involved in the conduct of research
    - Particularly so with payers and purchasers

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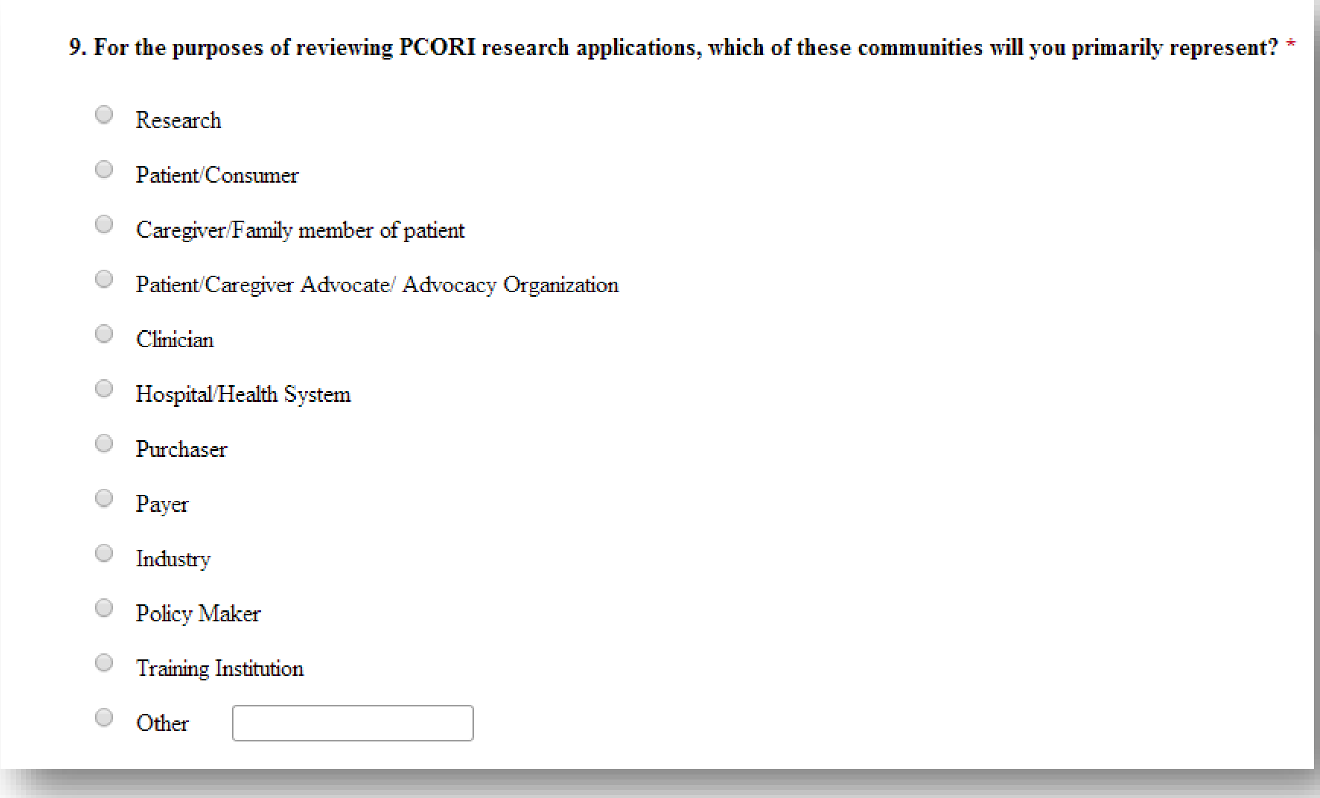
Stakeholder Mapping

- Capturing engagement with each of our stakeholder communities
  - Classify past interactions
  - Identify gaps
  - Determine new activities to continue meaningful engagement of stakeholders

Defining Stakeholder Categories

- PCORI program participants are always invited to self-identify with a primary stakeholder community



9. For the purposes of reviewing PCORI research applications, which of these communities will you primarily represent? *

○ Research

○ Patient/Consumer

○ Caregiver/Family member of patient

○ Patient/Caregiver Advocate/ Advocacy Organization

○ Clinician

○ Hospital/Health System

○ Purchaser

○ Payer

○ Industry

○ Policy Maker

○ Training Institution

○ Other ☐

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Stakeholder Mapping

Evaluation

Government Relations

State Engagement

Regional Workshops

Roundtables

Webinars

Advisory Panels

Work Groups

Merit Review

1:1 Meetings

Topic Generation

Speakers' Bureau

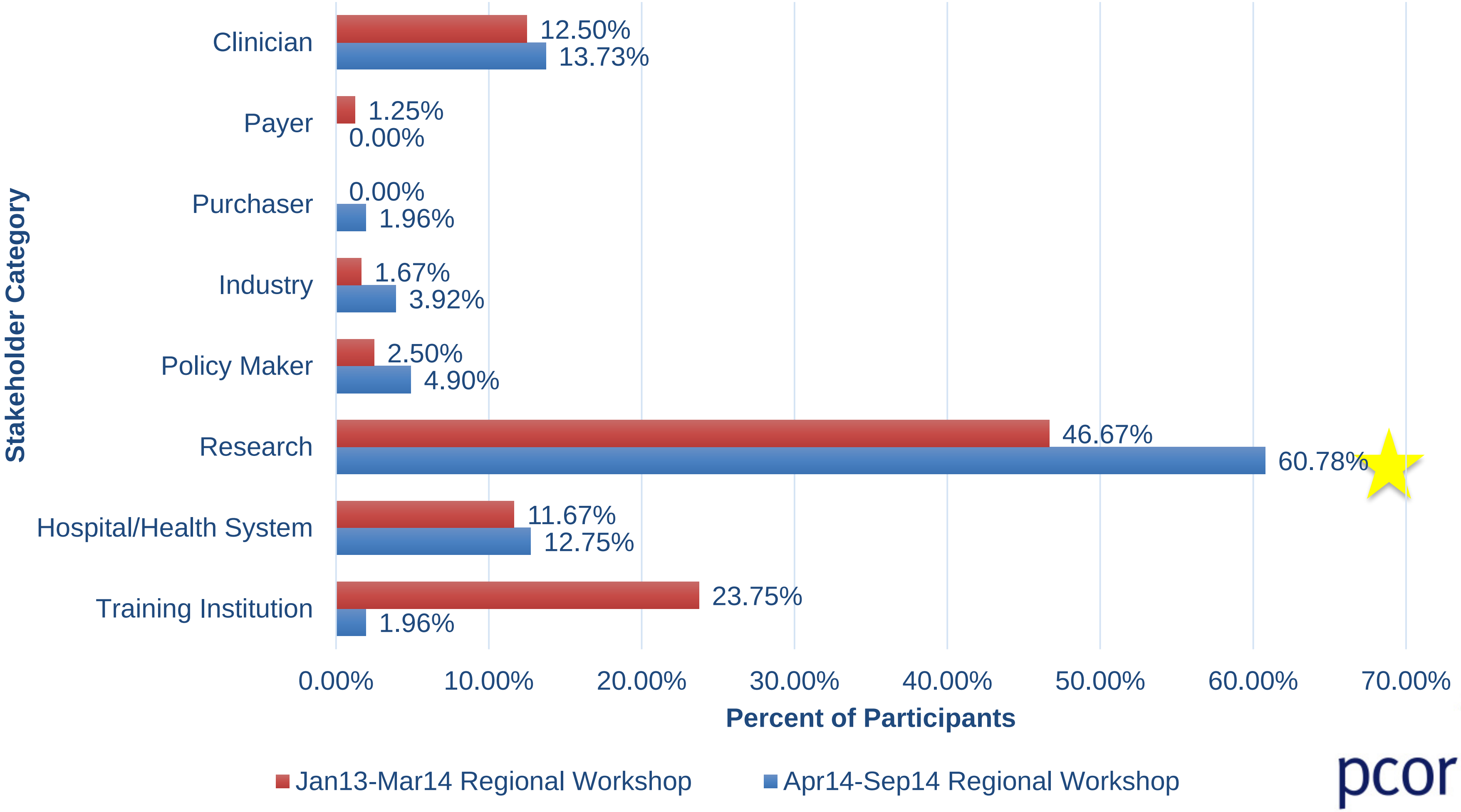
Award Notification

Community Building

Community Building

Regional Workshop Participants by Stakeholder Category

(Jan13-Mar14 N=240, Apr14-Sep14 N=102)



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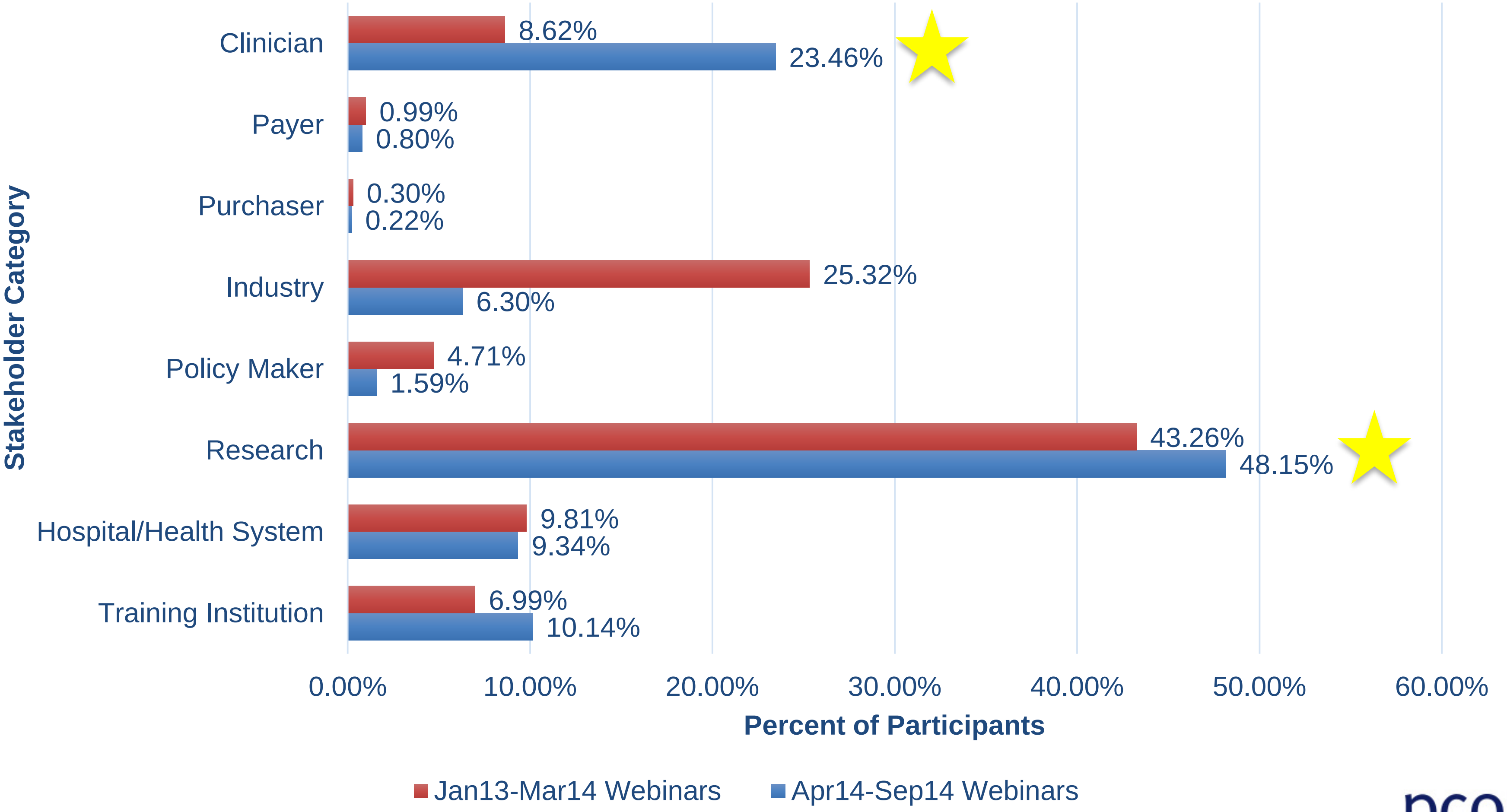
Community Building

Webinar Participants by Stakeholder Category

(Jan13-Mar14 N=2,018, Apr14-Sep14 N=1,381)



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Community-building Activities

- Current Activities
  - Webinars
    - Hosted and co-hosted webinars with professional groups to target key stakeholder communities, including medical specialists, industry, medical device manufacturers, and nurses
  - Regional Workshops
    - Hosted a multi-stakeholder event in Minneapolis, Minnesota to provide interaction among PCORI, patients and stakeholders
- Future Activities
  - Increase education and outreach efforts to still underrepresented communities: payers, purchasers and industry
  - Continue personalized webinars
  - Plan and implement research specific workshops

Stakeholder Mapping

- Evaluation
- Government Relations
- State Engagement
- Regional Workshops
- Roundtables
- Webinars
- Advisory Panels
- Work Groups
- Merit Review
- 1:1 Meetings
- Topic Generation
- Speakers' Bureau
- Award Notification

Research Prioritization

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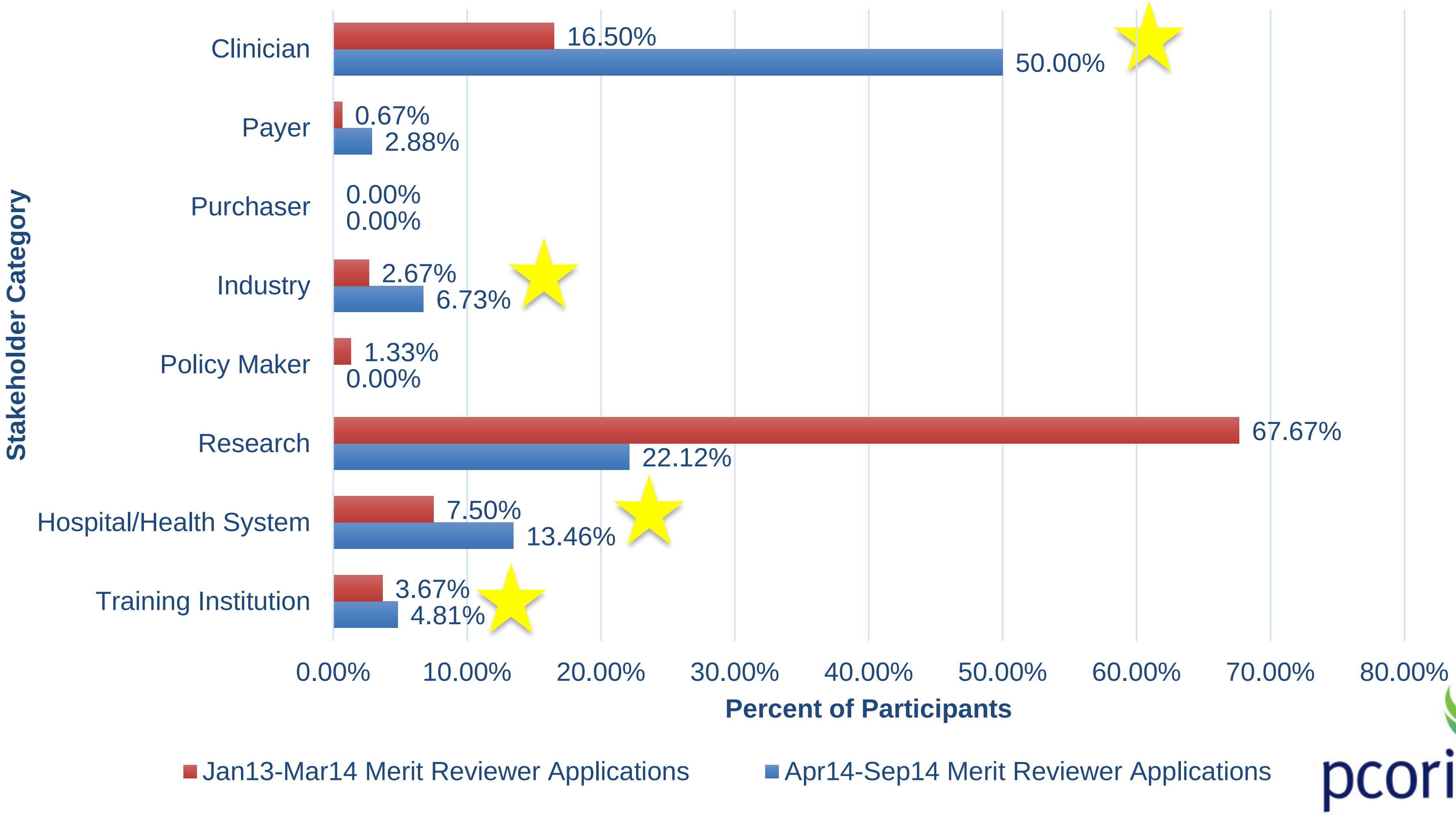
Research Prioritization

Merit Reviewer Applications by Stakeholder Category

(Jan13-Mar14 N=600, Apr14-Sep14 N=104,)



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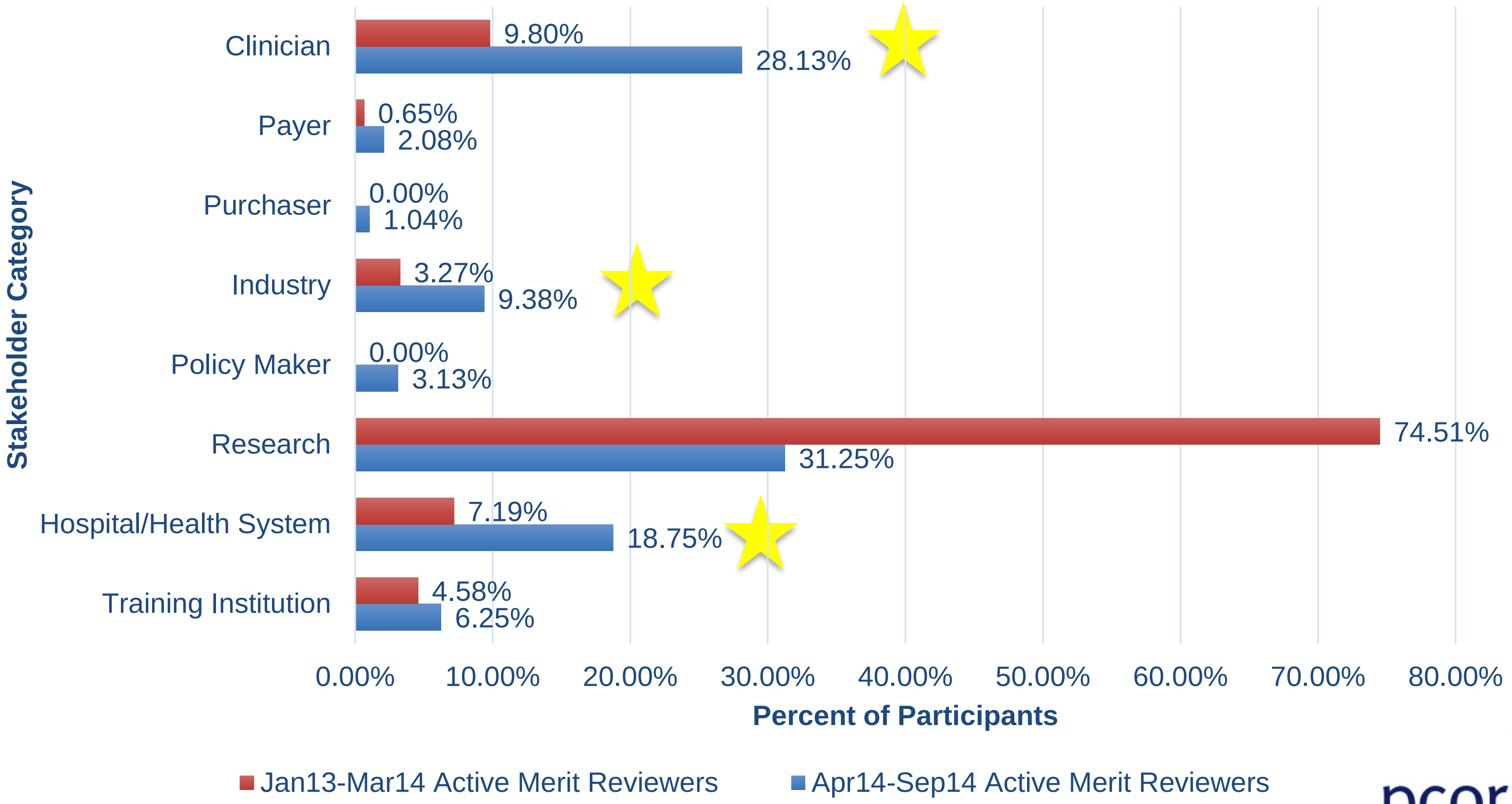
Research Prioritization

Active Merit Reviewers by Stakeholder Category

(Jan13-Mar14 N=153, Apr14-Sep14 N=96)



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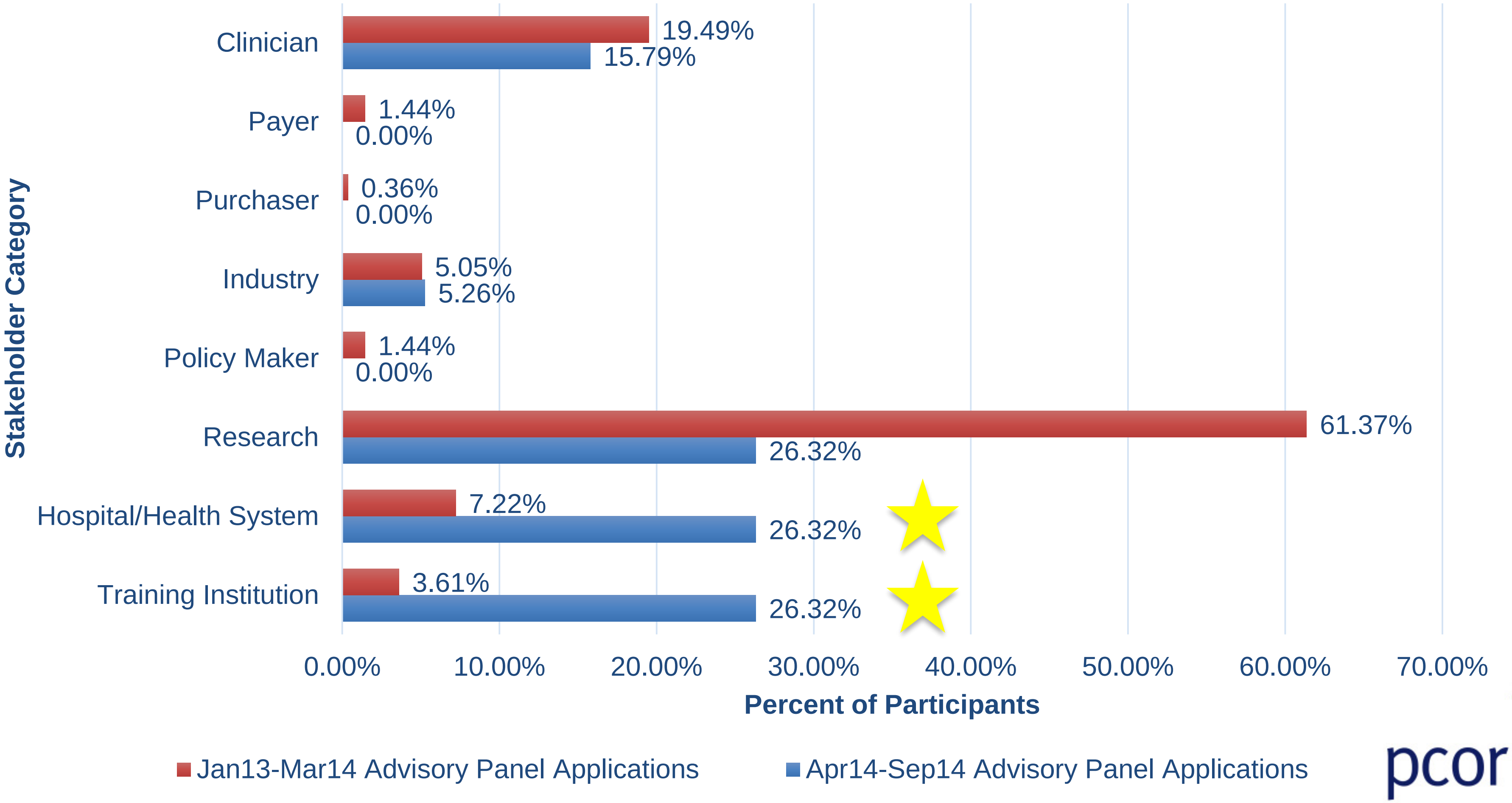
Research Prioritization

Advisory Panel Applications by Stakeholder Category

(Jan13-Mar14 N=277, Apr14-Sep14 N=19)



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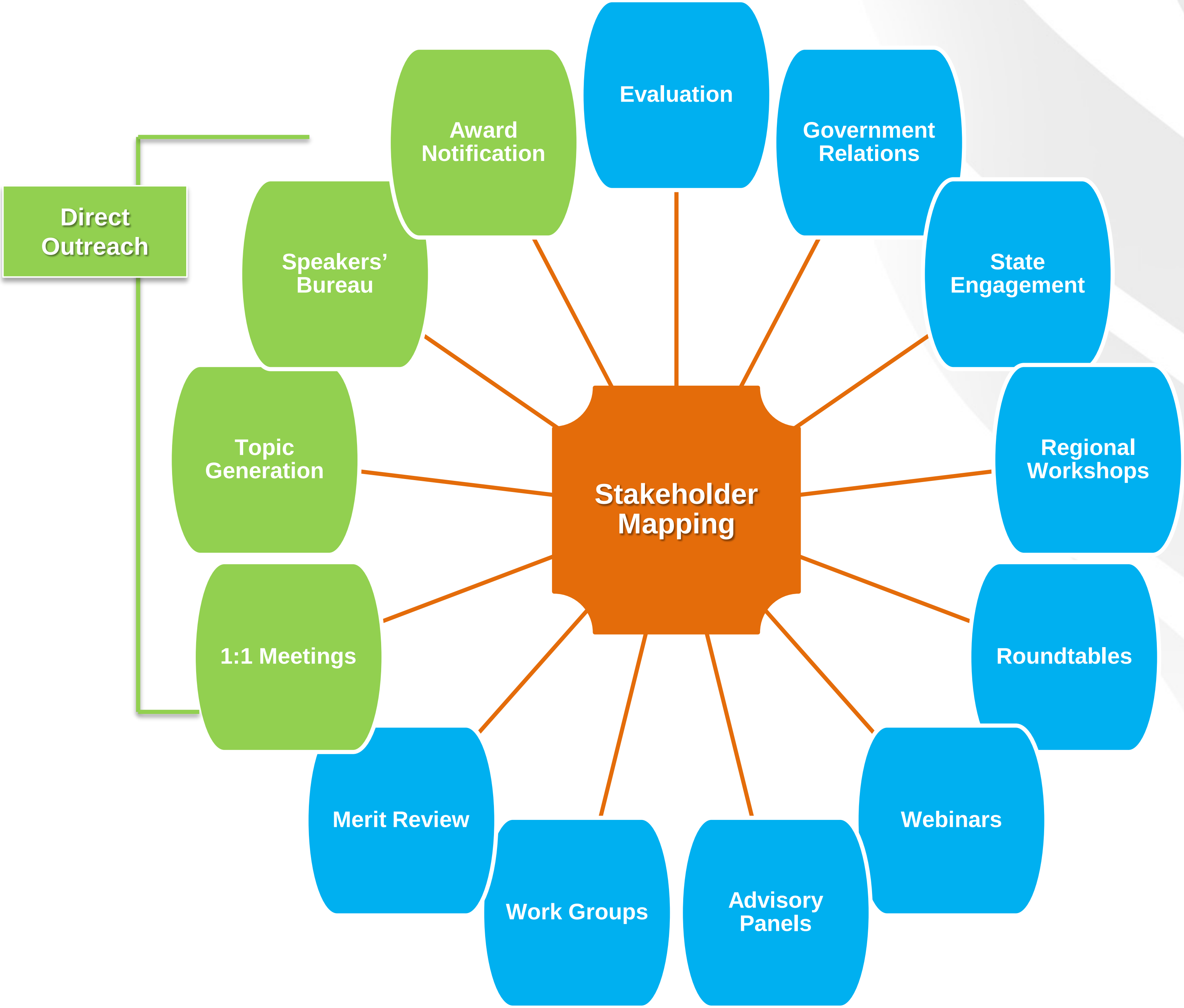
Research Prioritization

- Current Activities
  - Advisory Panels
    - Solicit applications and nominations, review applications, and provide strategic advice on final nomination slate
  - Manage the Patient and Stakeholder (P/S) Reviewer Program
    - Invite stakeholders to join the PCORI P/S Reviewer pool
    - Vet applications
    - Evaluate of P/S Reviewers
    - Recruit, train and manage mentor reviewers

- Future Activities
  - Continued focus on increasing the diversity of our merit reviewers
  - Revamp training



Direct Outreach

Award Notification

Evaluation

Government Relations

State Engagement

Speakers' Bureau

Topic Generation

Stakeholder Mapping

Regional Workshops

1:1 Meetings

Roundtables

Merit Review

Webinars

Work Groups

Advisory Panels

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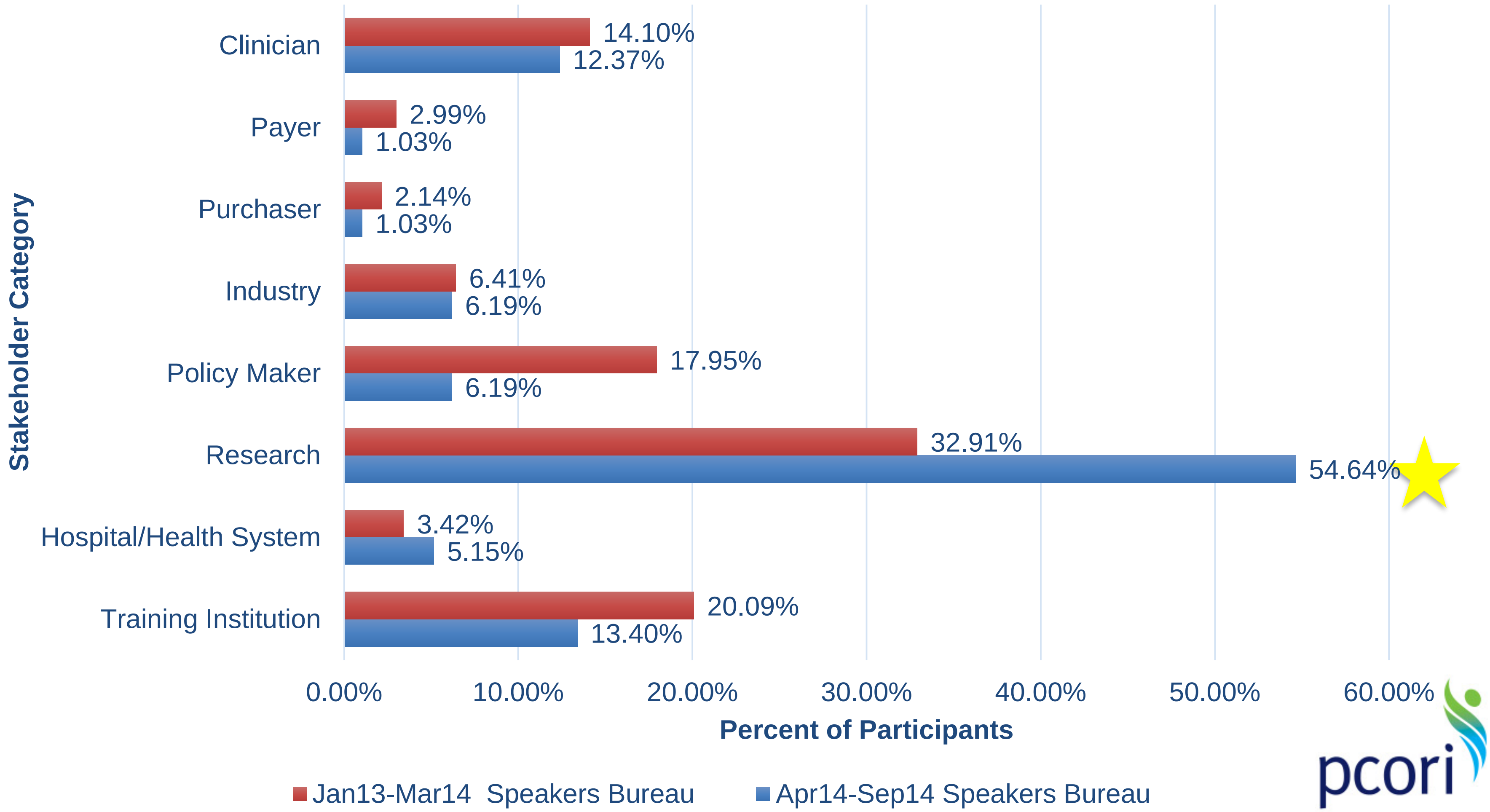
Direct Outreach

Speakers' Bureau by Stakeholder Category

(Jan13-Mar14 N=234, Apr14-Sep14 N=97)



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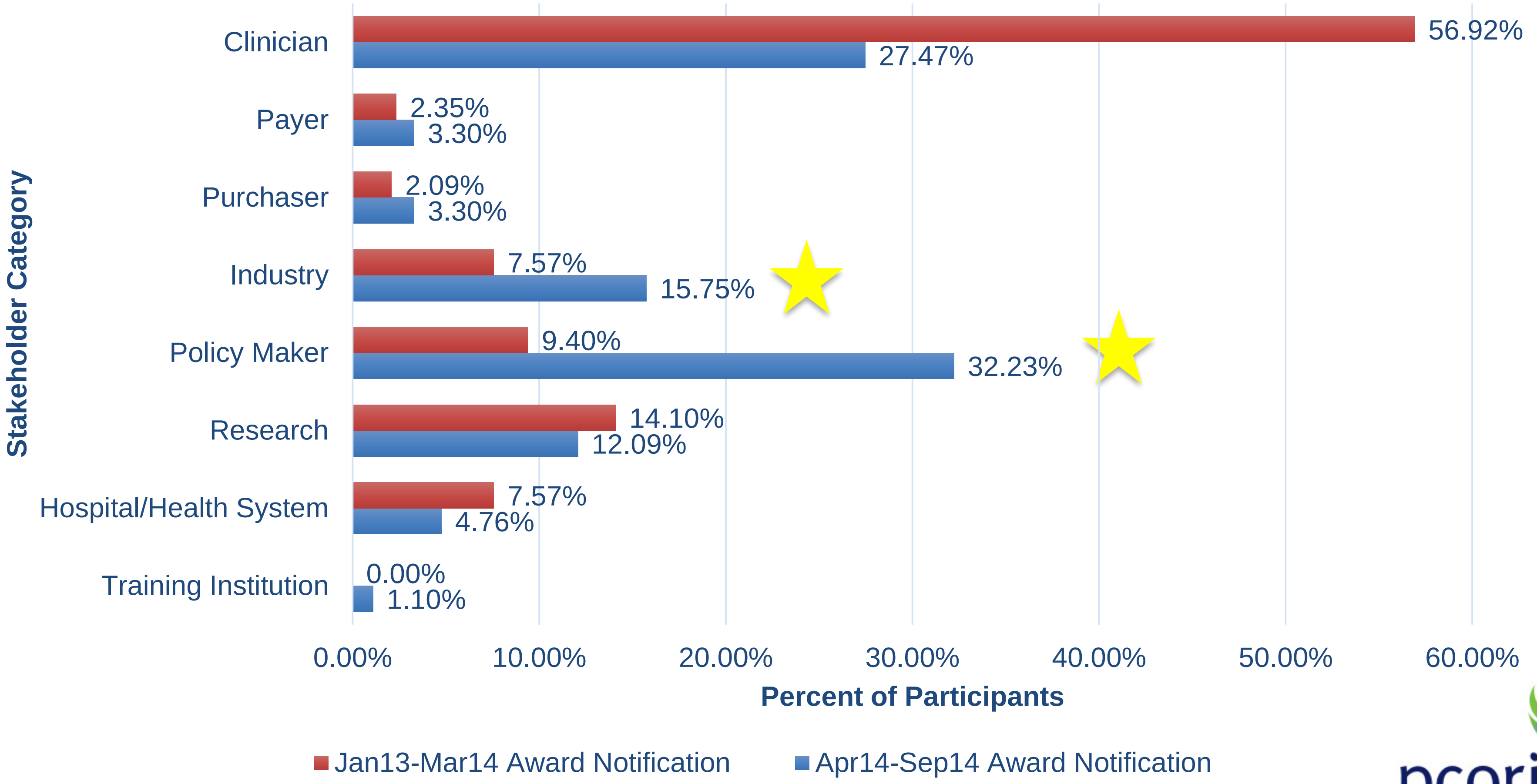
Direct Outreach

Award Notification by Stakeholder Category

(Jan13-Mar14 N=383, Apr14-Sep14 N=273)



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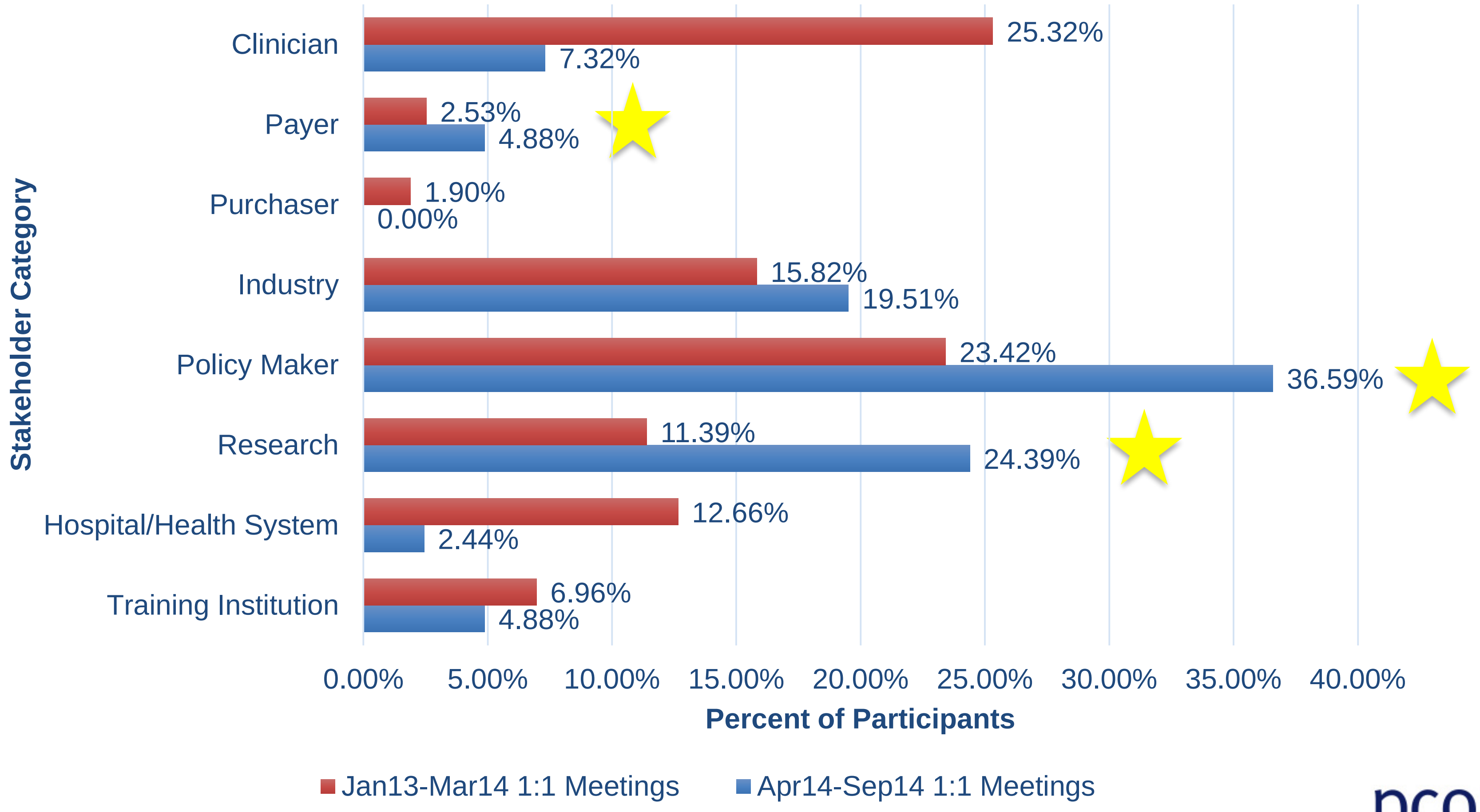
Direct Outreach

1:1 Meetings by Stakeholder Category

(Jan13-Mar14 N=158, Apr14-Sep14 N=41)



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Direct Outreach

- Current Activities
  - Speakers' Bureau
    - Vet and respond to incoming requests for PCORI speakers at outside events
    - Proactively engage targeted stakeholder organizations to secure a PCORI presence at their meetings
  - Award Notification
    - Notify senators and representative each time a constituent receives a PCORI award
    - Targeted notification of PCORI funding opportunities
    - Targeted notification of new PCORI awardees
  - 1:1 Meetings

- Future Activities
  - Significantly expand outgoing requests to targeted stakeholder organizations to have a PCORI presence on their meeting agendas
  - Continue targeted award notification
  - Continue to reach out to organizations for key research topics

Topic Generation

- Topic Generation
  - Have proactively collected priority topics of key stakeholder organizations
  - Analyze topics against present PCORI portfolio
  - Create targeted activities for stakeholders to continue to provide advice and input around priority topics

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Stakeholder Mapping

Evaluation

Government Relations

State Engagement

Regional Workshops

Roundtables

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Advisory Panels

Work Groups

Merit Review

1:1 Meetings

Topic Generation

Speakers' Bureau

Award Notification

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Government Relations

- Increased Focus on Educating Congress
  - Meet with and provide personalized materials to all staff on authorizing committees to educate them on PCORI activities; respond to regular requests for information; and, update PCORI leadership on congressional affairs
  - Evaluate composition of 114th Congress
  - Engage consultants
  - Plan education strategy

State Engagement

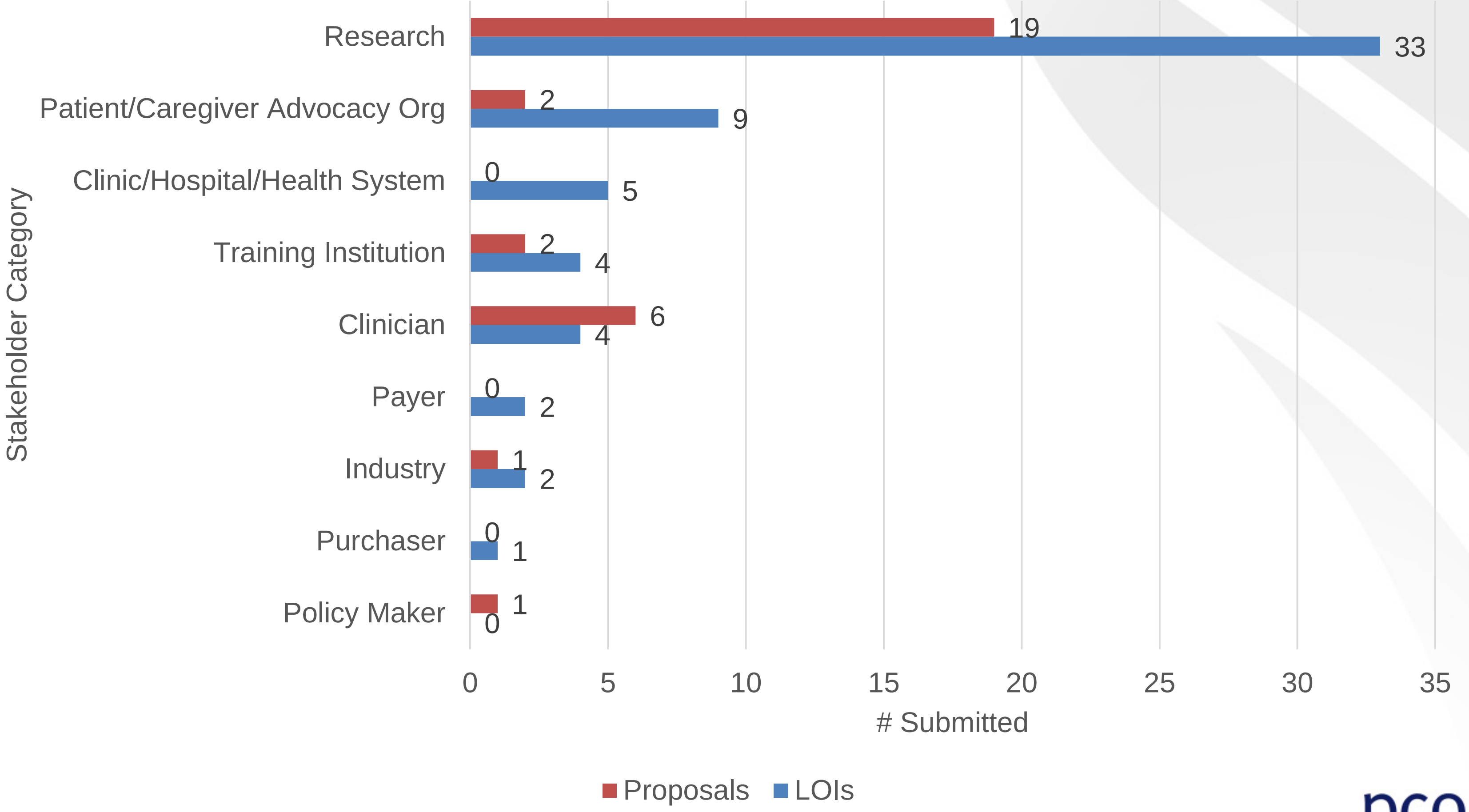
- Medicaid Medical Directors Network
  - Developing closer ties with the Medicaid Medical Directors Network
    - Now under the National Association of Medicaid Directors
  - Received an Engagement Award to support convening the Network (6/2014 – 5/2015)

- State Policy Makers
  - Maintaining relationships with key organizations
    - National Academy for State Health Policy
    - National Conference of State Legislatures
    - Public Sector Healthcare Roundtable
    - National Association of Insurance Commissioners

Evaluation

- Work closely with PCORI Evaluation Group to evaluate engagement programs and projects, along with PCORI activities
  - Evaluate all engagement activities
  - Align with organizational standards all engagement-led data collection tools and domains
  - Feed appropriate metrics into organizational evaluation framework and dashboard
  - Use program and project evaluations to inform future decisions

Stakeholder Involvement with Engagement Awards



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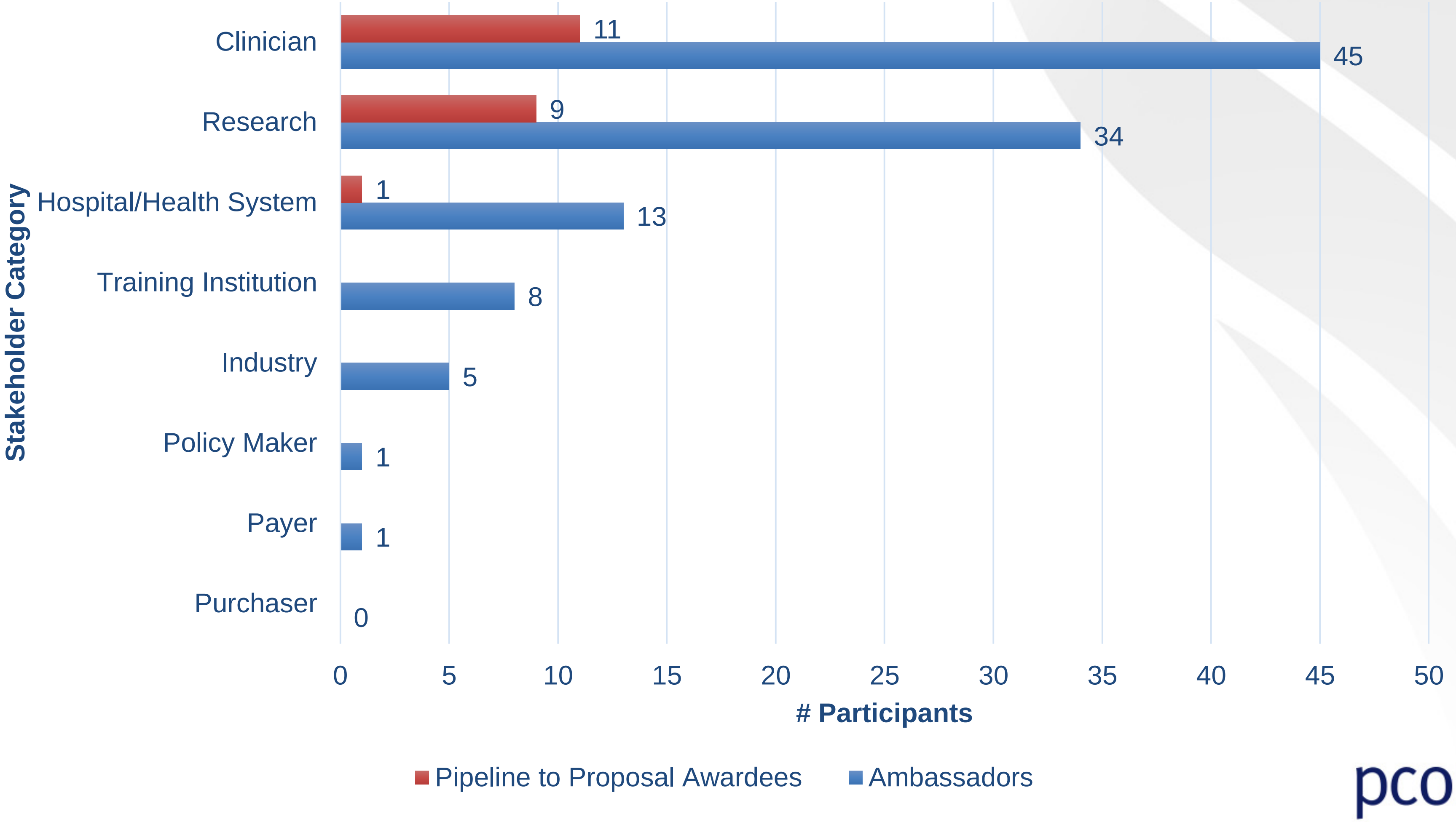
Stakeholder Involvement with the Ambassador Program & Pipeline to Proposals



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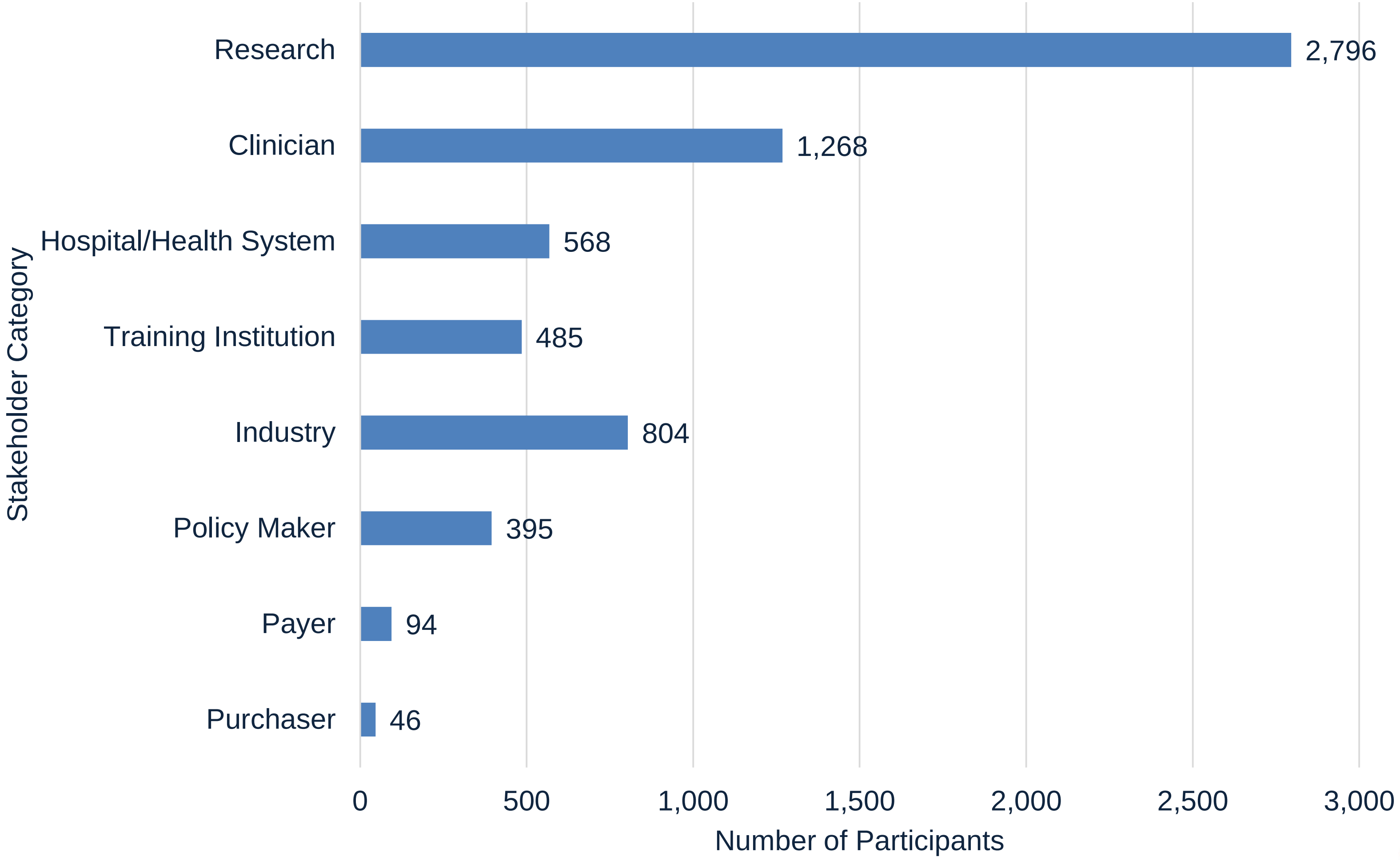
Total Stakeholder Participation

January 1, 2013-September 31, 2014 ***(N=6,456)***



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Compensation Framework - Finalization and Approval

Charlotte W. Collins, JD
Chair, Compensation Subcommittee
Suzanne Schrandt, JD
Deputy Director of Patient Engagement

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30 Minute Break

Refreshments outside

Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT): Preliminary Results

Laura Forsythe, PhD, MPH
Senior Program Officer for Research Integration and Evaluation
Kristen Konopka, MPH
Senior Program Associate for Stakeholder Engagement

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Agenda

- Review background on collection of information about engagement in funded projects
- Present preliminary results
- Discuss:
  - implications of findings
  - opportunities for improvement

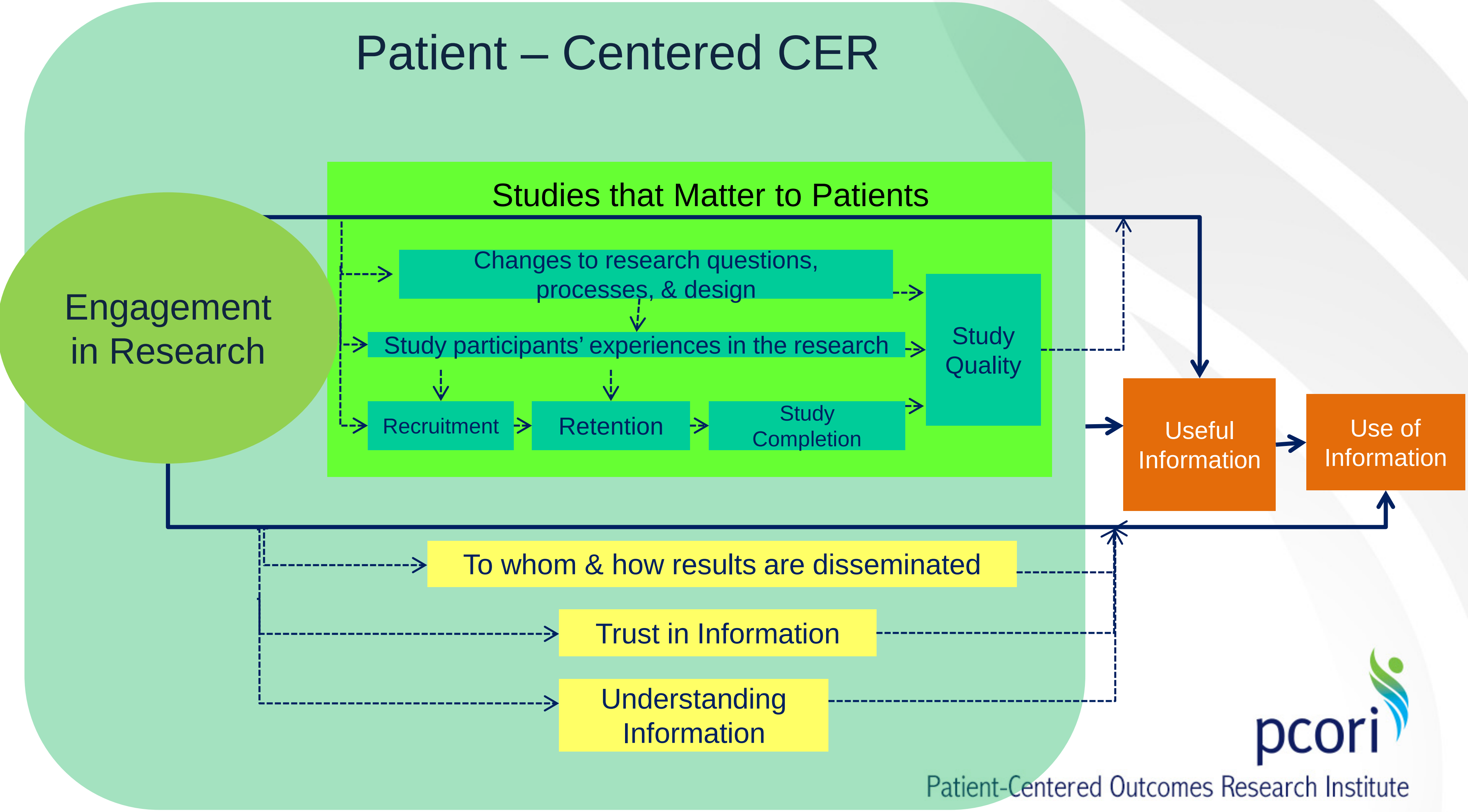
Multiple Objectives for Measuring Engagement

- **Describe** engagement in PCORI-funded projects
- **Support** project progress
- **Evaluate** impact on PCORI strategic goals
- **Inform** PCORI funding requirements
- **Guide** current awardees, future applicants, and others interested in patient-centered outcomes research

Domains for Describing Engagement in Research

- Who is engaged?
- When are they engaged?
- Partnership characteristics
- Level of research engagement
- Effects of engagement on research questions, processes, study design, and implementation
- Perceived level of partners' influence
- Challenges and facilitators
- Lessons learned
- Evidence for PCOR principles

Evaluating Engagement in Research



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Engagement in Research

Studies that Matter to Patients

Changes to research questions, processes, & design

Study participants' experiences in the research

Recruitment

Retention

Study Completion

Study Quality

Useful Information

Use of Information

To whom & how results are disseminated

Trust in Information

Understanding Information

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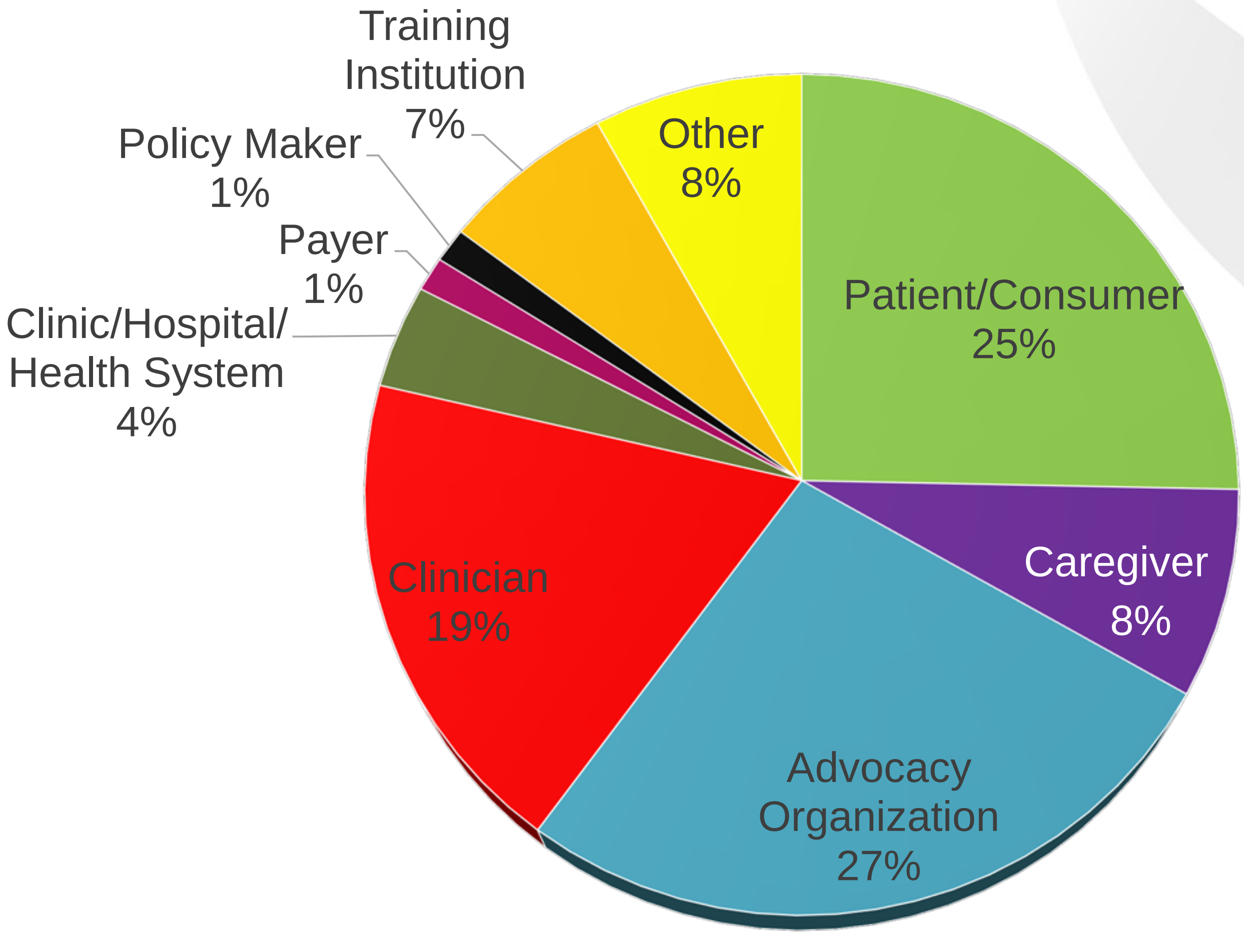
Ways of Engaging - ENgagement ACtivity Tool: WE-ENACT

- Self-report
  - Principal investigators
  - Patient and stakeholder partners
- Completed at baseline and annually
- Versions developed for
  - PCORI pilot projects
  - PCORnet projects
  - PCORI broad and targeted portfolio

WE-ENACT: Preliminary Results

- PIs and patient and stakeholder partners from Cycles I, II, III, and Inaugural Methods Cycle have been invited to respond to the one- year inventory.
- Today’s sample
    - 58 PIs or their designees *(data shown in blue)*
    - 75 patient or stakeholder partners, representing 29 projects *(data shown in red)*

Stakeholder Sample (n=75)



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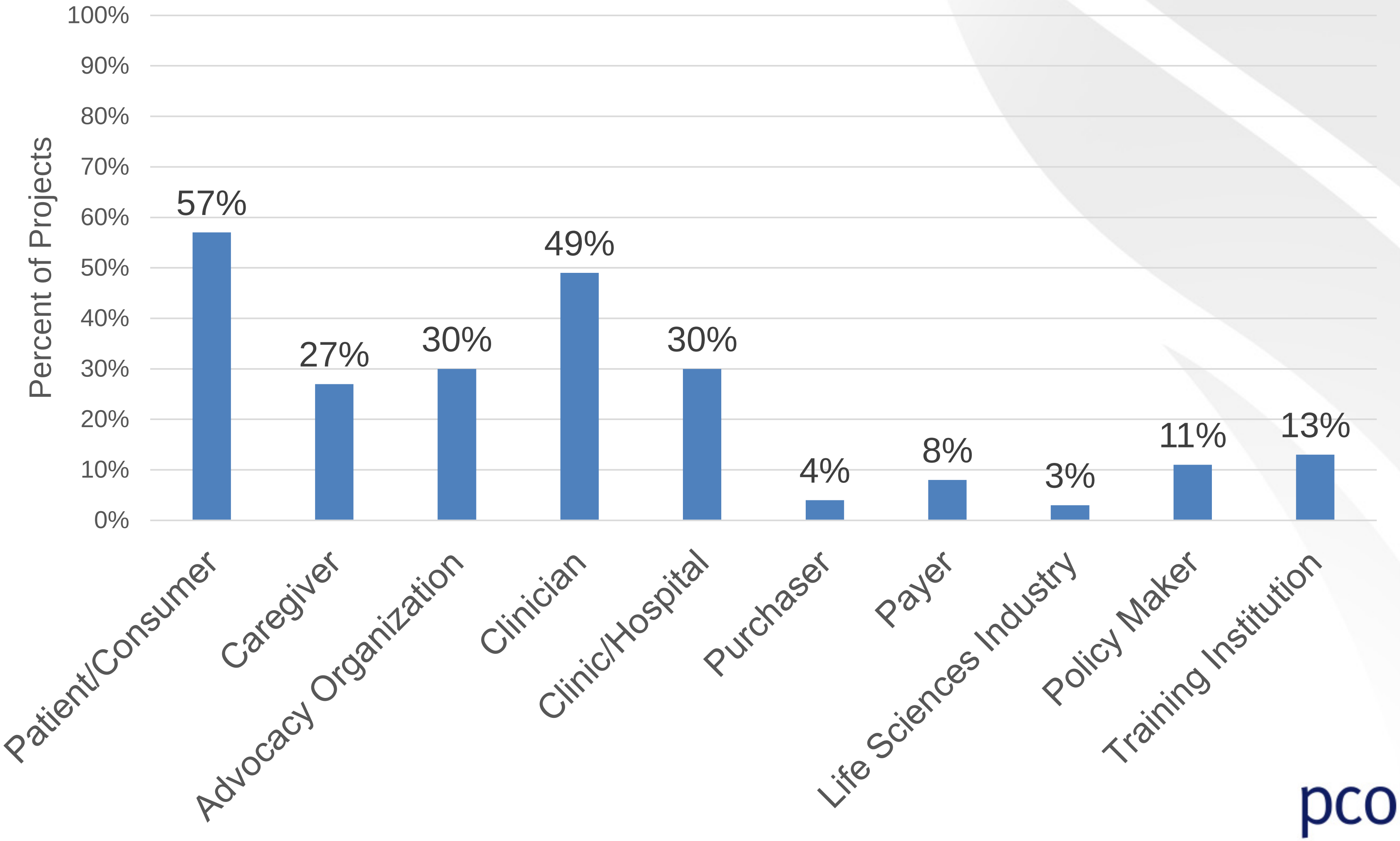
Types of Stakeholders Engaged

Researcher Report



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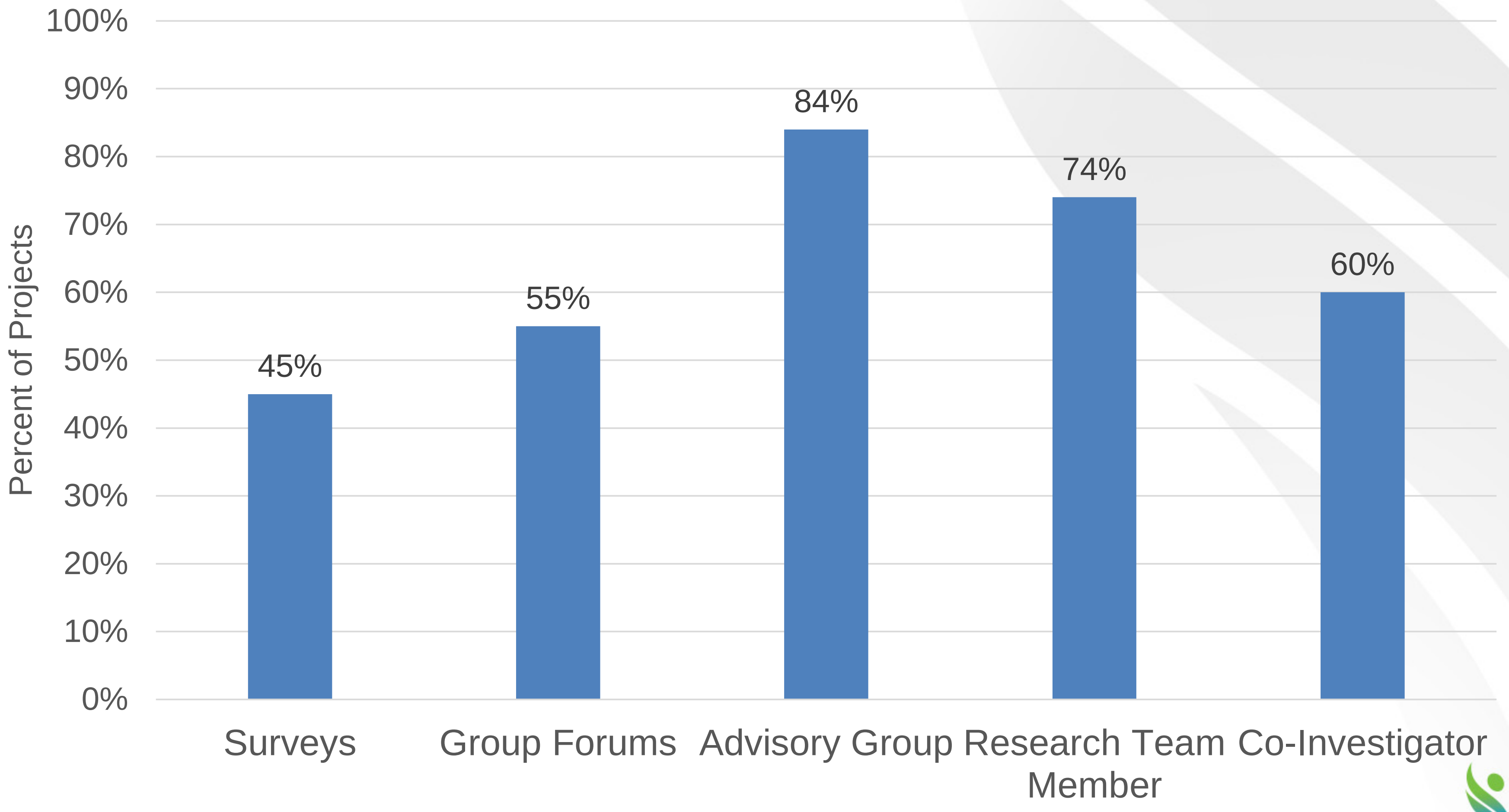
Approaches to Engagement

Researcher report



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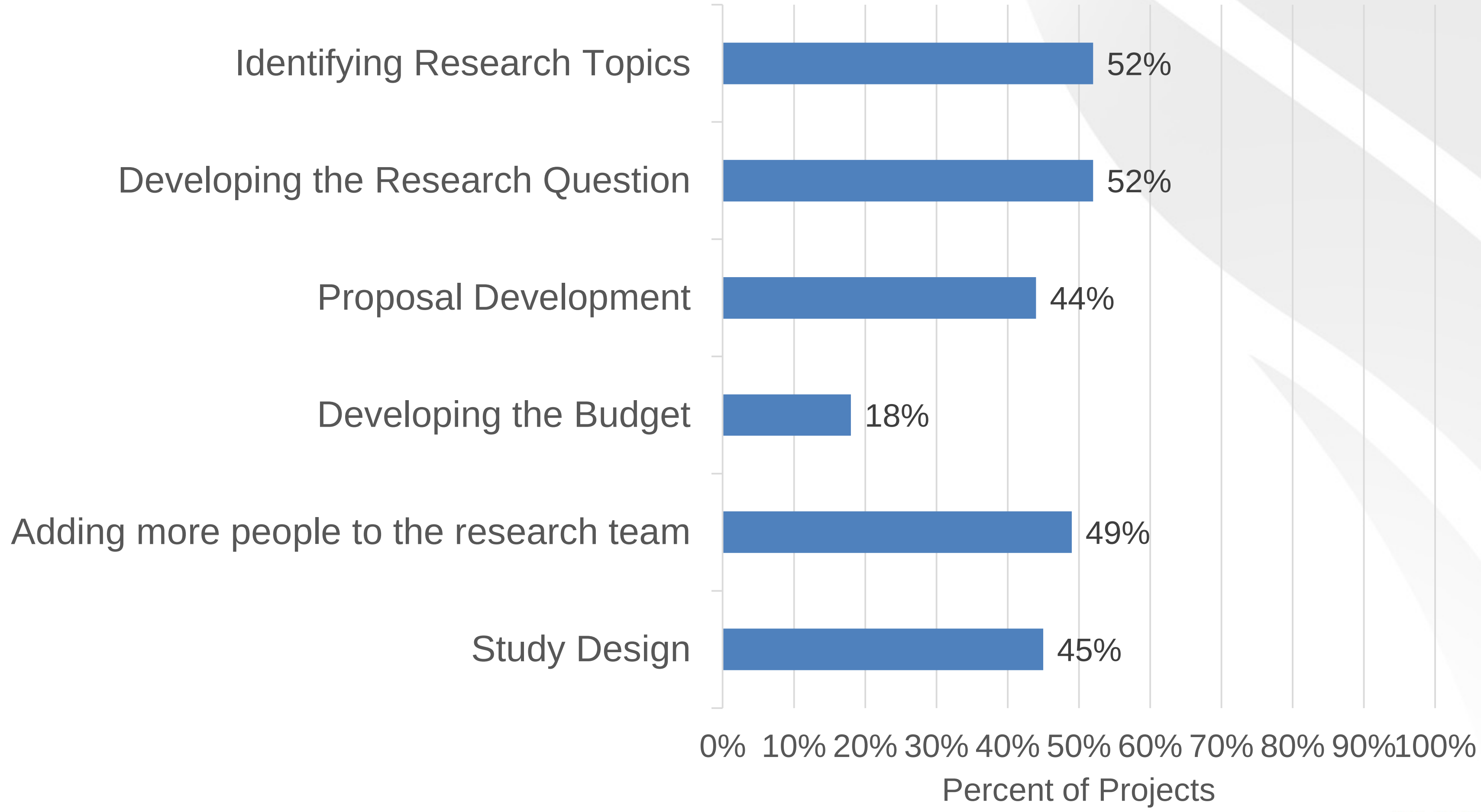
Engagement in Planning the Study
Researcher Report



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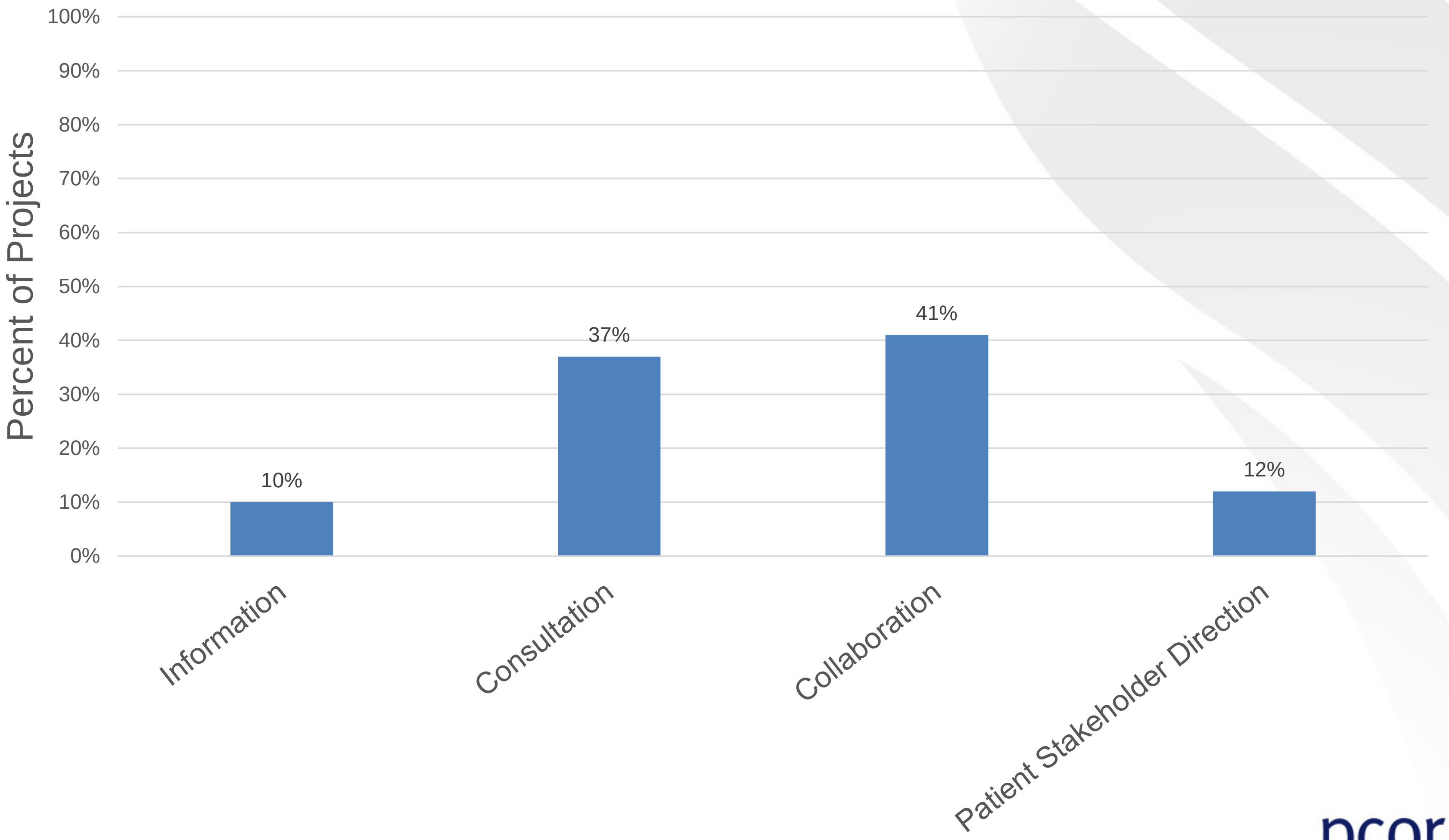
Identifying Research Questions: Level of Engagement Researcher Report



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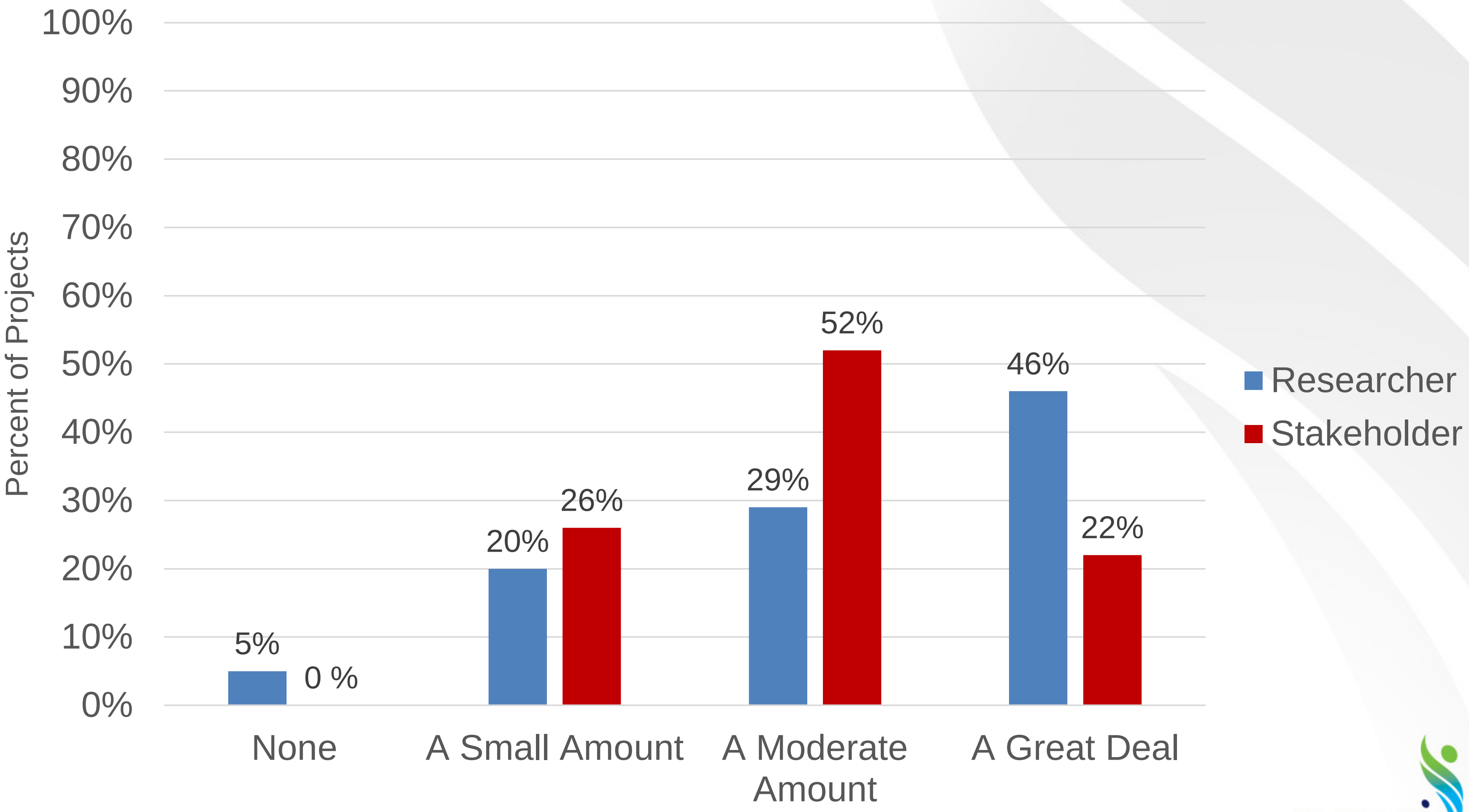
Identifying Research Questions: Perceived Influence



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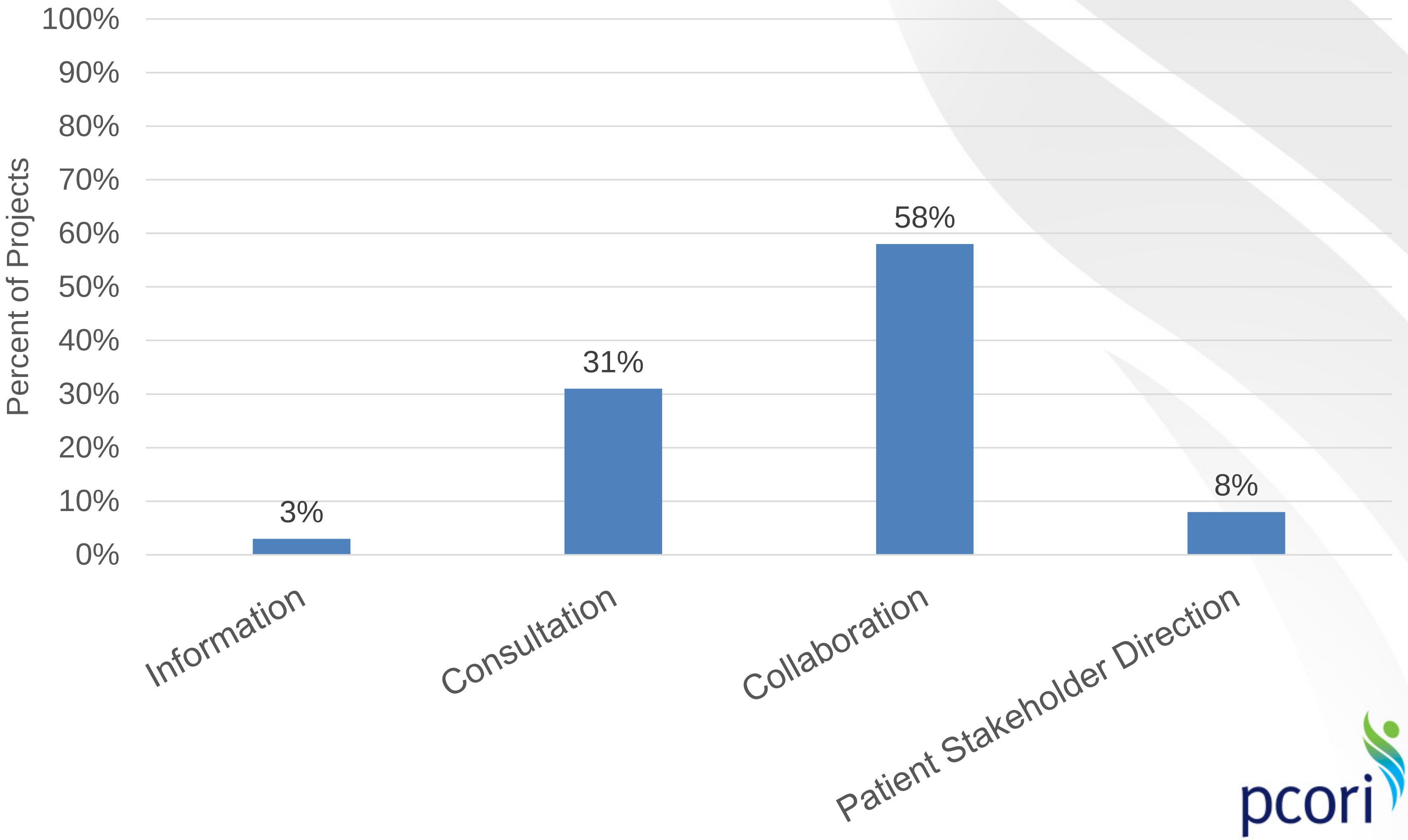
Identifying Research Questions: Impact of Research Engagement

“Their insight into the problem among patients in their community helped focus the research project.”

“Topics were more tailored to parent and family concerns.”

“We ended up with different research questions and framing than I would have initially thought, and this was specifically because of input from stakeholders concerning the research question.”

Study Design: Level of Engagement
Researcher Report



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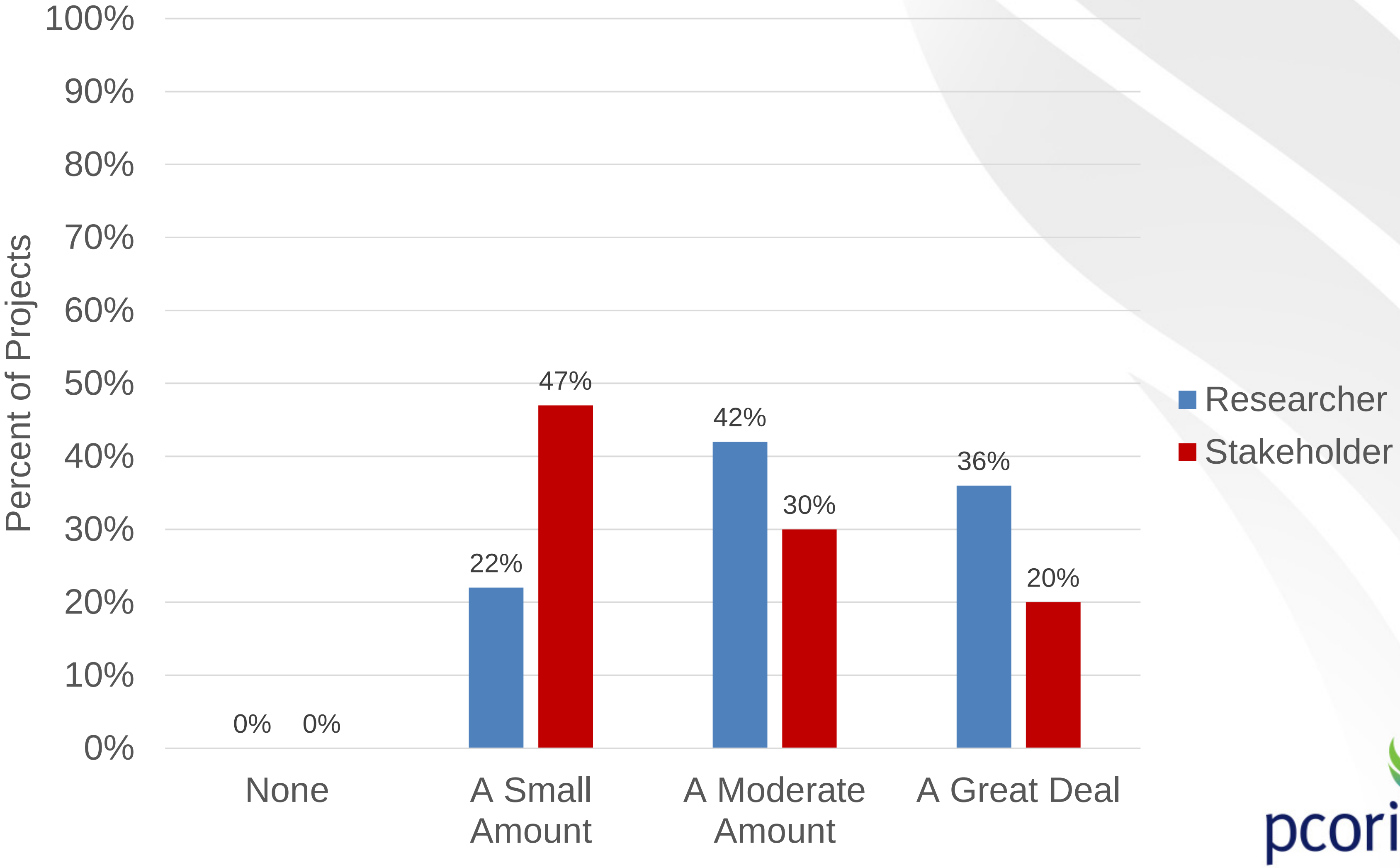
Study Design: Perceived Influence



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Study Design: Impact
Researcher Feedback

"Patients and stakeholders helped form the content of interventions… to better meet the needs of [patients]."

"Our community discussions… led to several modifications of our study design…This led us to include a third group in our research design: community-based group exercise. We also decided to use…[a specific] outcome measure, based upon input from… patients who told us that their biggest concern was the ability to walk and stay active."

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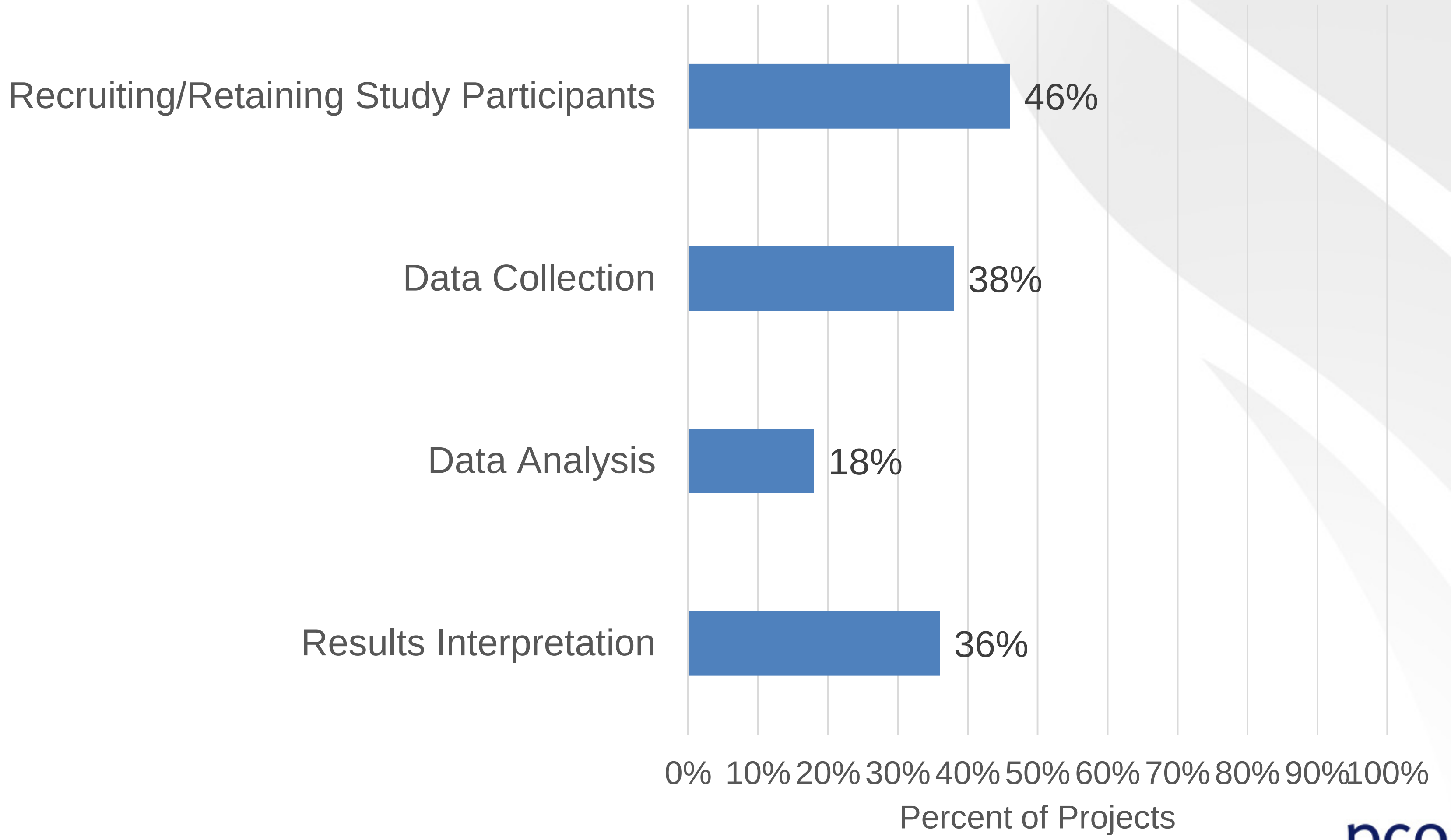
For Discussion

- What information is most notable or surprising?

Engagement in Conducting the Study

Researcher Report



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Engagement in Disseminating Study Results

Researcher Report

- 34% of researchers reported engagement in dissemination.

> *“When draft reports and publications are distributed we all use the review function in Microsoft Word to offer our thoughts. Everyone on the team chimes in, and after a few iterations we have a solid product.”*

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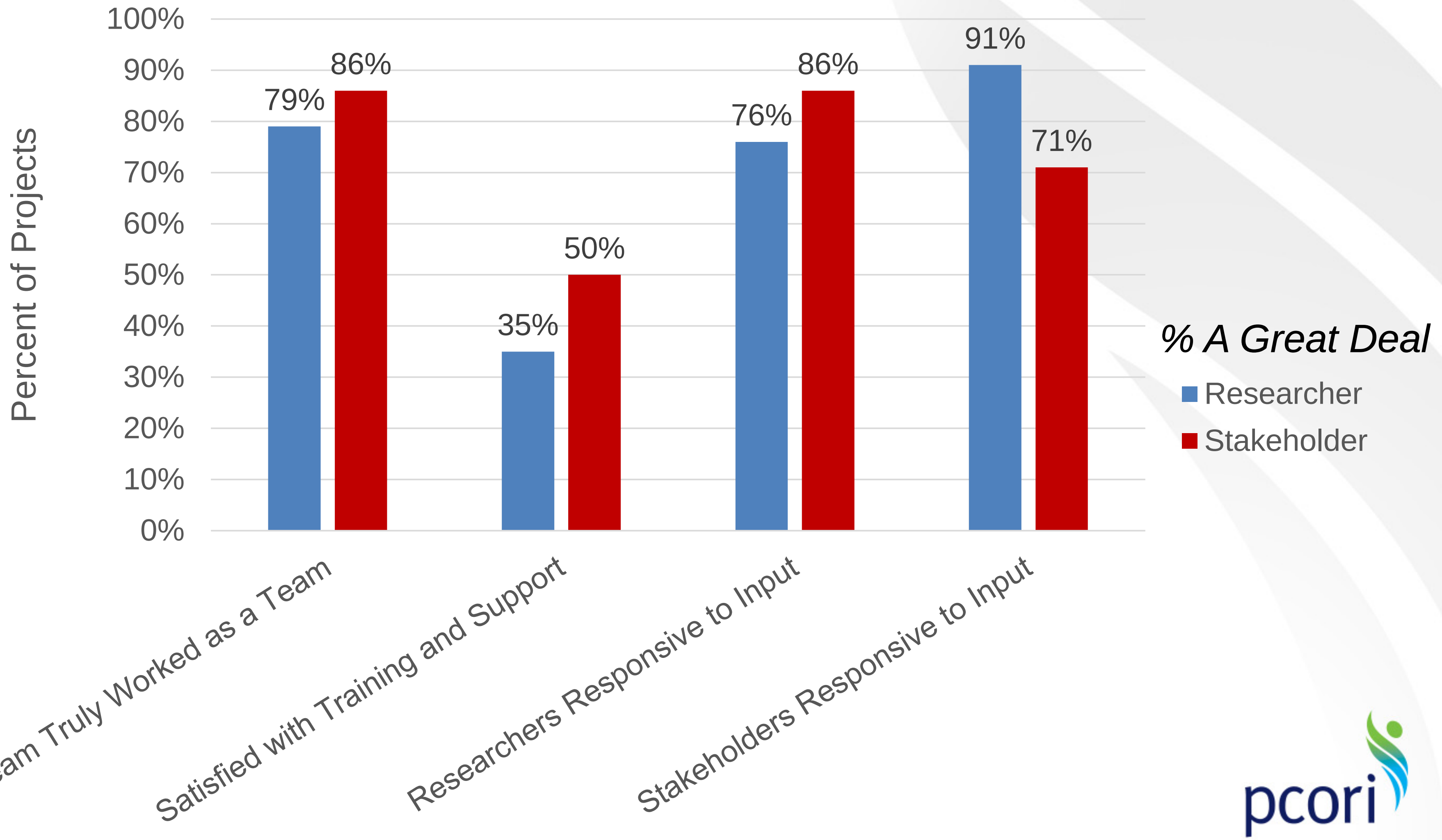
For Discussion

- What information is most notable or surprising?

Summary

- PCORI awardees engage in research with a wide range of stakeholders, most often via advisory groups or as research team partners.
- Engagement is occurring across all stages of research.
- Perceived level of influence on research should be examined further to understand differences between research partners and Principal Investigators.

PCOR Principles



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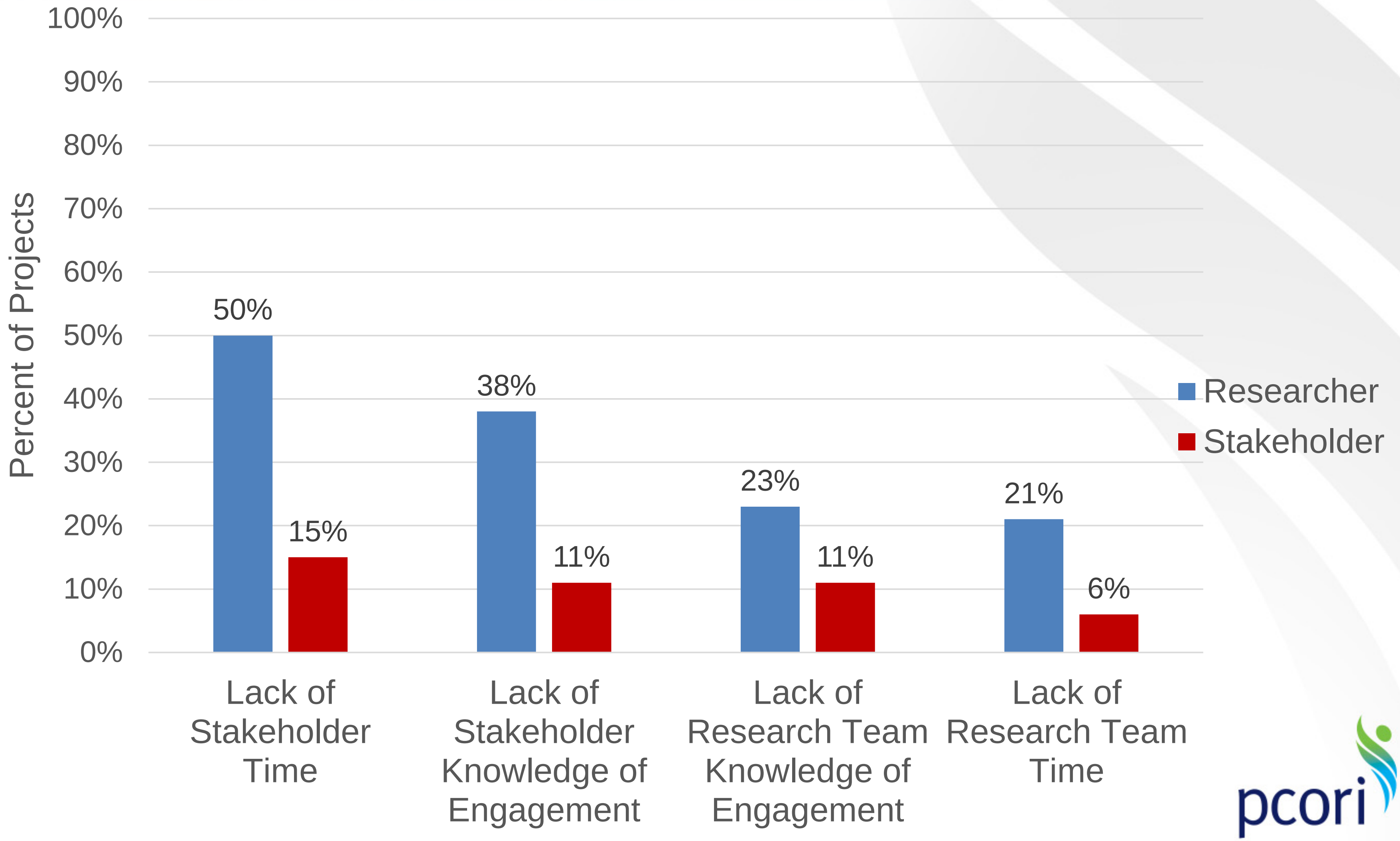
Engagement Challenges



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Engagement Challenges

“Much more ‘face time’ is required to build trust and learn about the culture you are going to. But the face time pays off.”

“Some patients were very cautious to really contribute, because some of their doctors were in the room...but got a very different picture about their experience when [we] met with them separately. This is a challenge in engaging patients – how authentic that engagement is, and the way they would answer questions with another survivor vs. people who take care of them.”

Overcoming Challenges to Engagement

Researchers' Recommendations 1

"One research team member is primarily tasked with maintaining contact with patients and advisers engaged on the project to ensure that there is a point of contact for engagement at all times."

"We have paid stakeholders for their time. We have tried to schedule meetings at their convenience. We have solicited information from stakeholders individually (as opposed to being in a group) whenever the stakeholder could not make a meeting."

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Overcoming Challenges to Engagement

Researchers' Recommendations 2

"More experience and learning over the course of the research project; developed capacity-building materials. We still believe there is a role of a short research curriculum…that could be completed by stakeholders."

"We learn as we go by immersing ourselves in each others' cultures and explicitly valuing what each does."

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Patient and Stakeholder Feedback

“The researchers kept in very good contact with me, always answered my emails and always sent prompt updates on the project. I never wondered what was being worked on or what was needed from me. All data was shared with me. I felt very included in the team at all times.”

“Was very impressed that this research team is open to discussion and took a lot of time and consideration in how the community wants to see some of the things they're doing. Very different than what has happened in the past. Institutions are opening up and valuing what the community has to say.”

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Group Discussion

- What questions do you have that PCORI can answer with these data?
- What are the opportunities for PCORI and the PEAP to leverage these learnings?
- Improving the definition of engagement for respondents
- Are there other opportunities for improvement?

For Discussion: Defining Engagement for Patients and Stakeholder Respondents

PCORI research helps patients and healthcare stakeholders make decisions about their health.

Stakeholders are people who care about health. Some examples include family caregivers, doctors, hospital leaders, and insurance companies. This survey is about the role of patients and stakeholders in PCORI projects.

****

We want to learn about your experiences with this PCORI project. Research engagement means people are involved in research in ways other than as research subjects. This includes things like:

- Choosing the study questions;
- Deciding the study characteristics, like whom to study;
- Choosing study outcomes;
- Tracking study progress; or
- Sharing study findings.

Have you engaged in this PCORI research project in ways other than as a research subject?

Thank You!

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Learning from Applicants and Reviewers about Engagement Resources

Sana N. Vieux, MPH

Program Associate, Research Integration and Evaluation

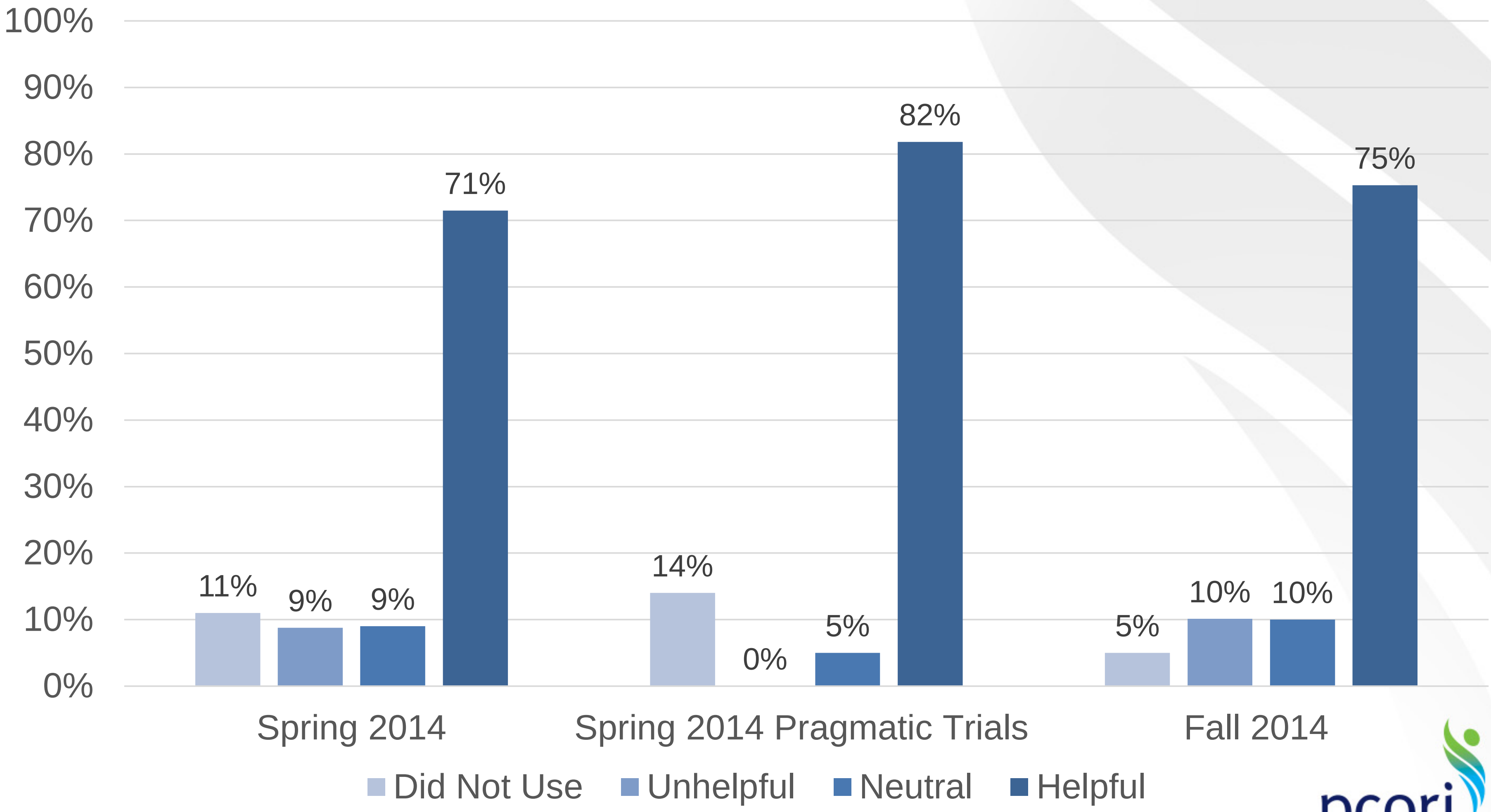
Patient-Centered Outcomes Research Institute

Applicant and Reviewer Surveys

	Spring 2014 ***(May 2014)***	**Spring 2014 Pragmatic Trials** ***(August 2014)***	**Fall 2014** ***(November 2014)***
Applicant Surveys	Total N = 791 Response rates = 44 – 74%		
Reviewer Surveys	Total N = 363 Response rates = 86 – 88%		---

Applicant Survey Results

Helpfulness of Sample Engagement Plans



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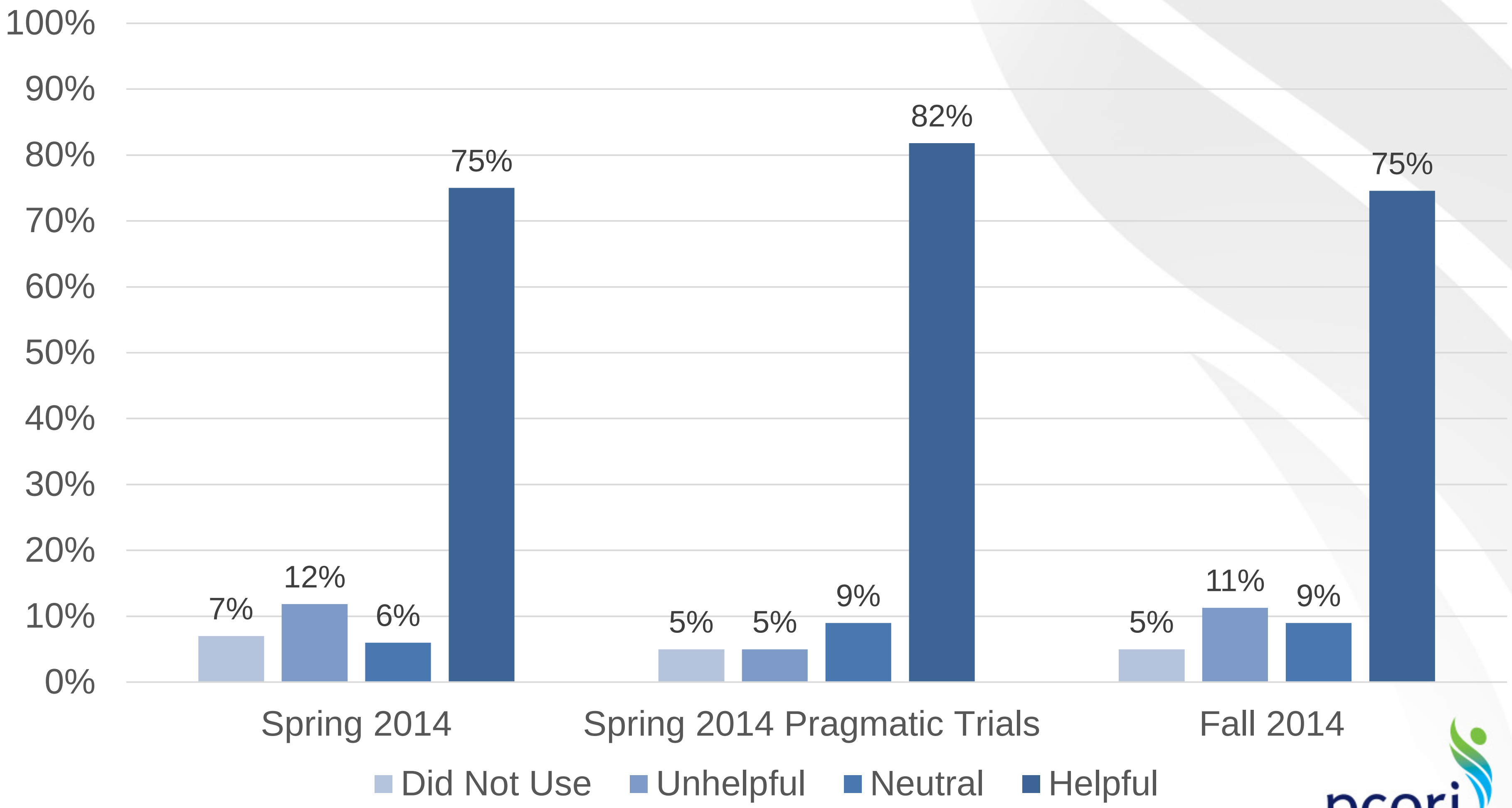
Helpfulness of Engagement Rubric



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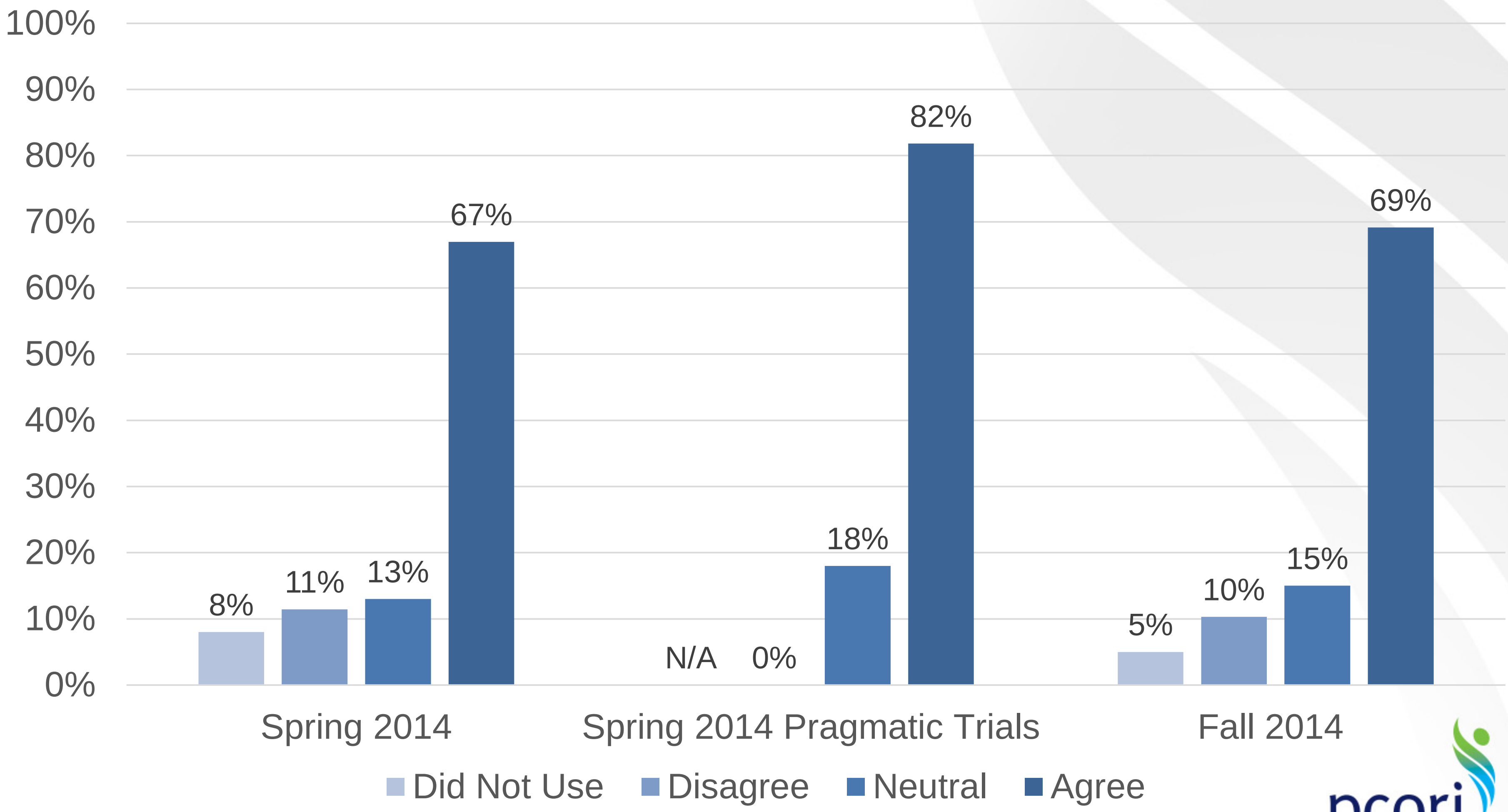
Engagement Rubric Helped Identify and Fill Gaps in the Engagement Plan



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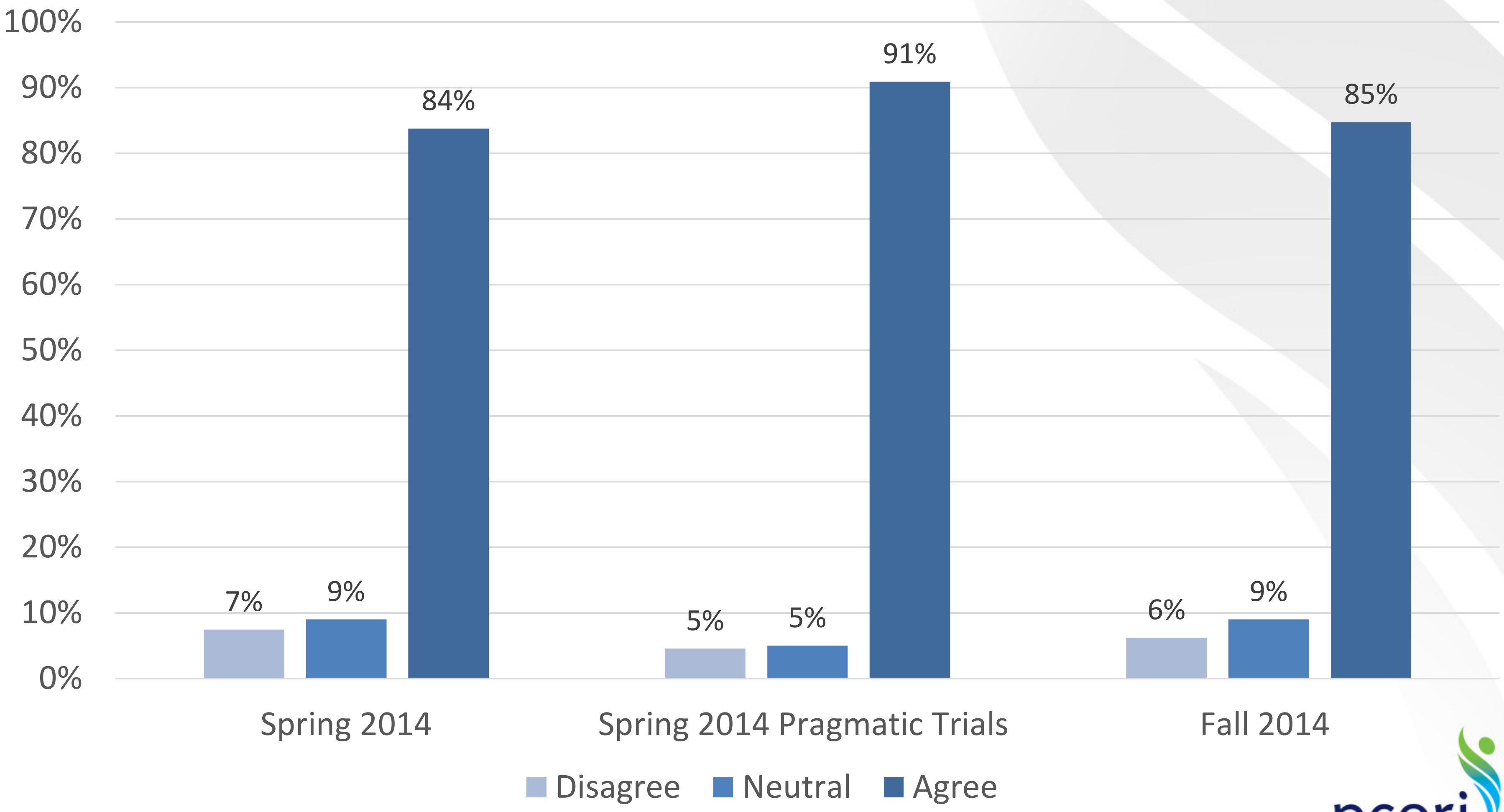
“I Understand PCORI’s Requirements for Patient and Other Stakeholder Engagement.”



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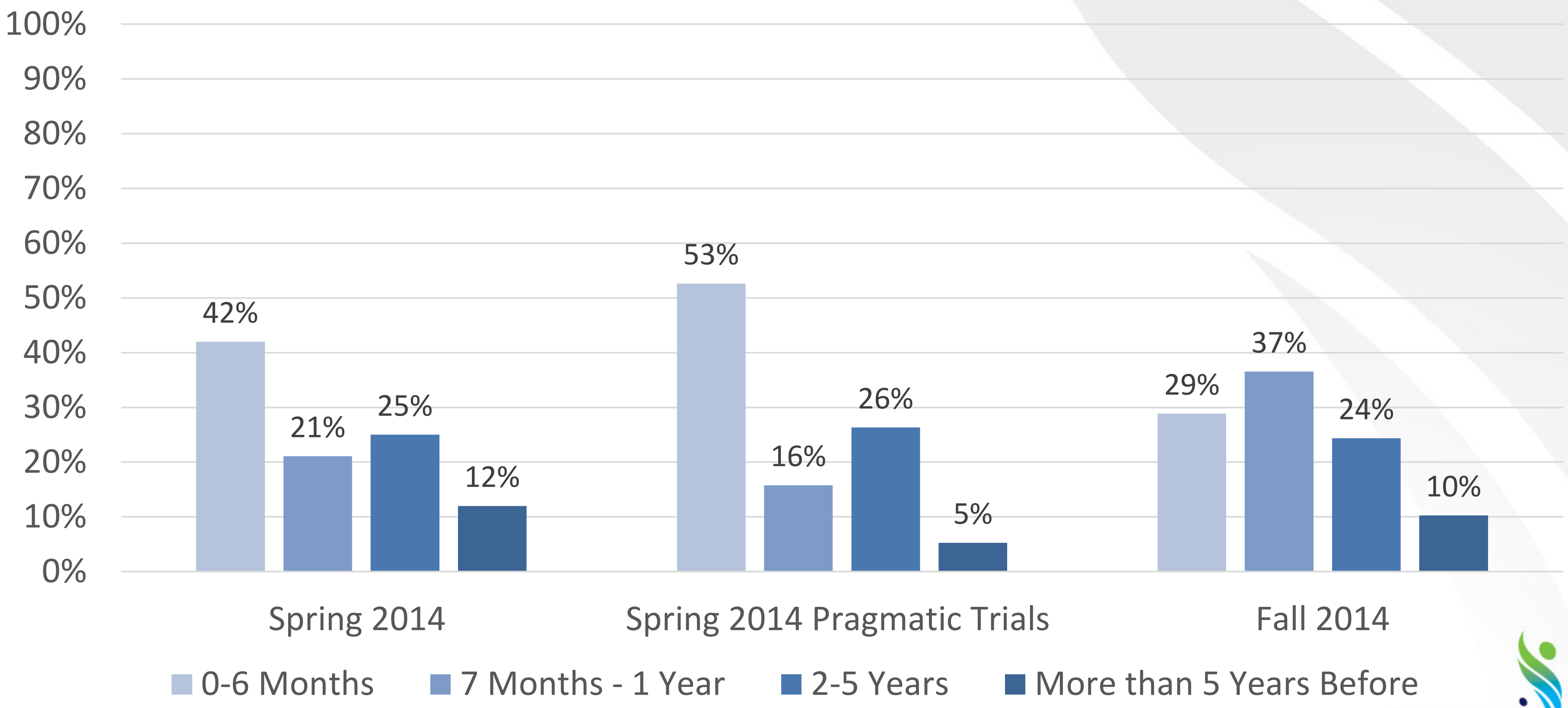
Duration of Partnership Prior to Application

>85% of applicants established a partnership *before* submitting the application.



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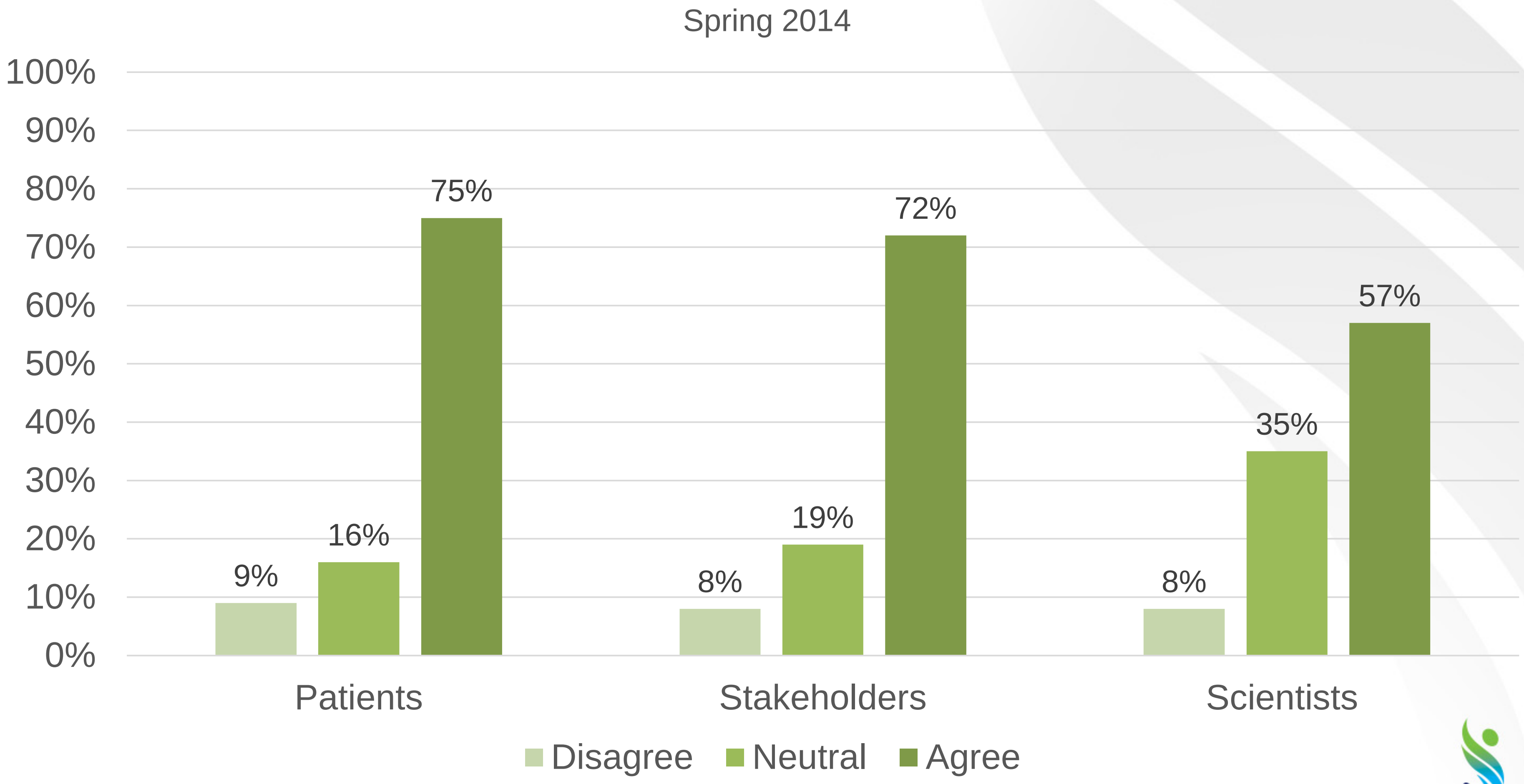
Summary and Discussion: Applicant Survey Findings

- Engagement rubric and sample engagement plans were perceived as helpful and as facilitating plans for engagement.
- Most applicants reported understanding PCORI’s requirements for patient and stakeholder engagement.
- Most applicants established a stakeholder partnership(s) prior to applying to PCORI.

Reviewer Survey Results

"The Engagement Rubric Helped me Identify Gaps in my Assigned Applications"



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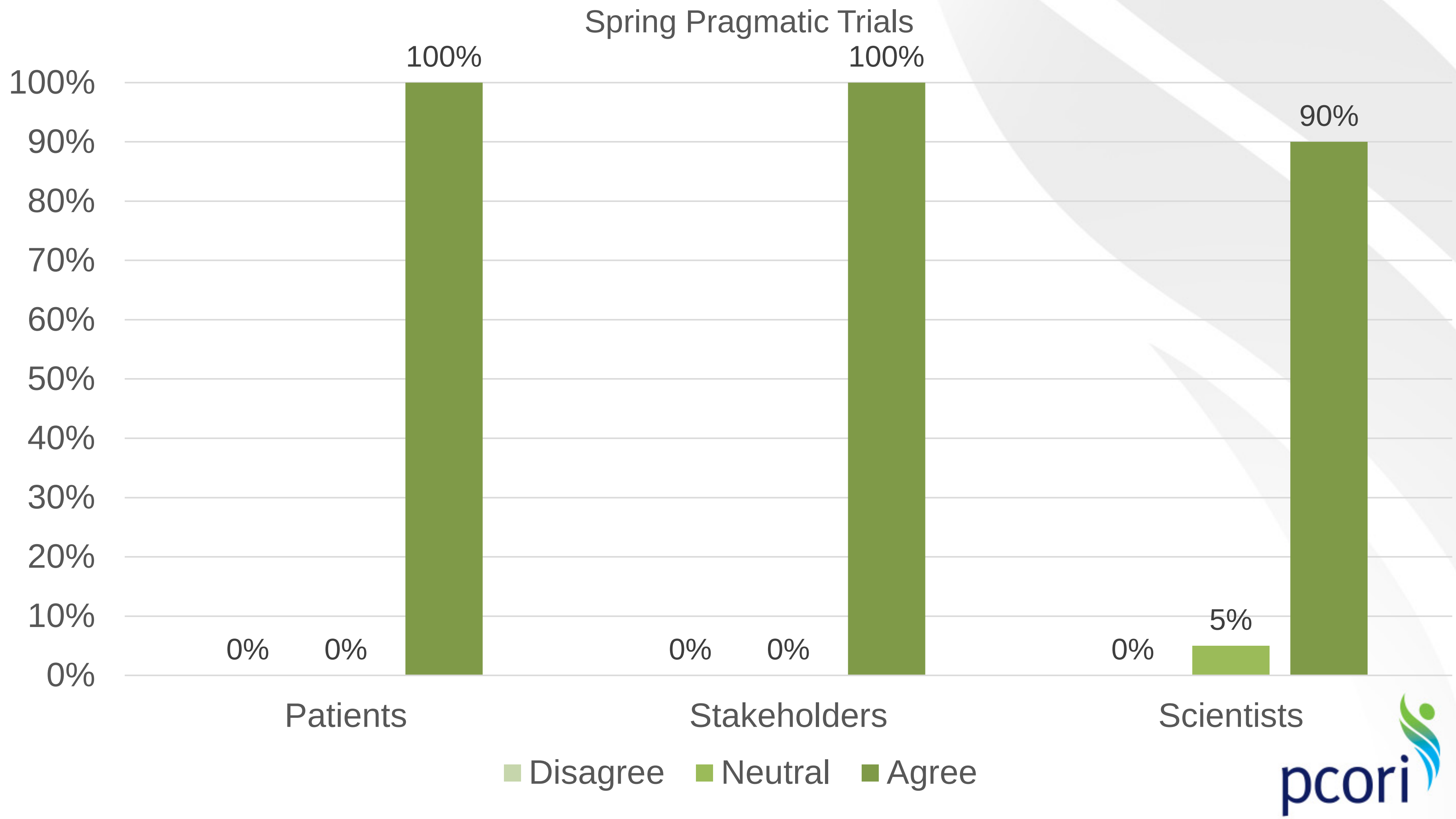
"The Engagement Rubric Helped me Evaluate Patient and Stakeholder Engagement in my Assigned Applications"



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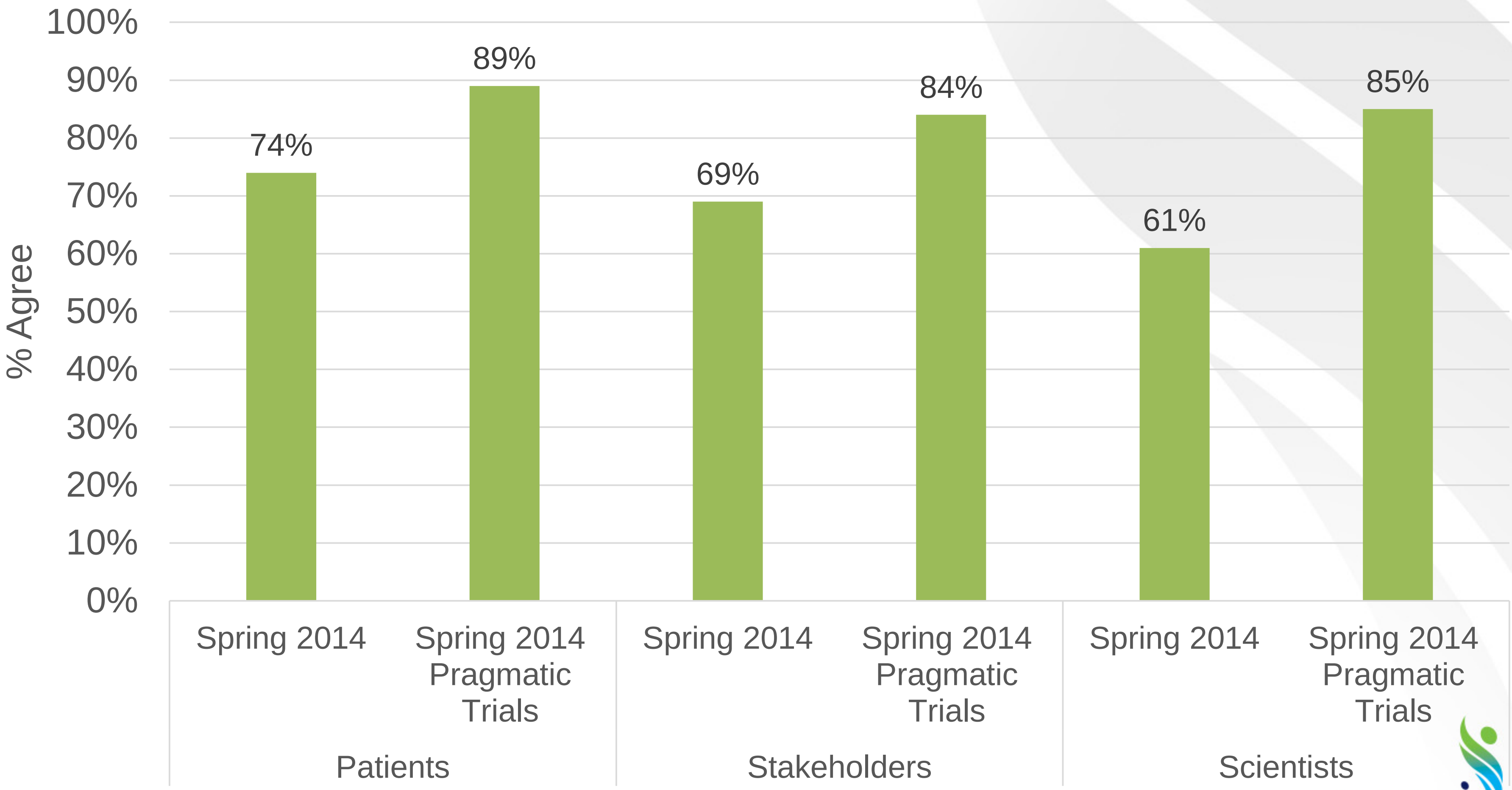
“The Engagement Rubric was Helpful in Framing the Discussion about Engagement During the In-person Merit Review Panel”



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Reviewer Survey Summary

- Most reviewers agree that the Engagement Rubric was helpful for:
  - Evaluating assigned applications
  - Framing the discussion about engagement

Thank You!

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Wrap-up

Sue Sheridan, MIM, MBA

Director of Patient Engagement

Patient-Centered Outcomes Research Institute

1 Hour Break

The reception will begin at 6:00 p.m. in Crystal Ballroom Salon A.