Listening to Researchers: Meeting Stakeholder Needs for Comparative Effectiveness Research - A PCORI Survey

November 18, 2015

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome

We welcome your questions and comments via the chat function on the right side of your screen.

We welcome your comments via Twitter to @PCORI and #PCORI.

An archive of this webinar will be posted to http://www.pcori.org/events/2015/listening-researchers-meeting-stakeholder-needs-comparative-effectiveness-research-pcori following this event.

If we are unable to address your question during this time, please e-mail your question to us at surveys@pcori.org.

Introductions

Moderator:

- Lori Frank, PhD, PCORI Program Director, Evaluation and Analysis

Presenters:

- Lauren Fayish, MPH, PCORI Program Associate, Evaluation and Analysis
- Thomas Workman, PhD, American Institutes for Research, Principal Investigator

Discussant:

- Joe V. Selby, MD, MPH, PCORI Executive Director

Introductions: Panelists

- **Ming Tai-Seale, PhD, PH**

  Senior Scientist, SutterHealth Palo Alto Medical Foundation Research Institute

  Consulting Professor, Stanford University School of Medicine

- **Teresa Hudson, PharmD, PhD**

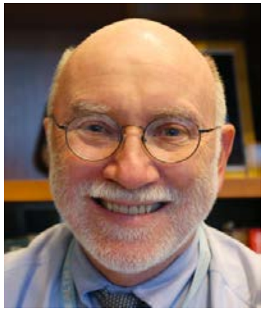
  Associate Director, VA Center for Mental Healthcare and Outcomes Research

  Associate Professor of Psychiatry, University of Arkansas for Medical Sciences

- **Tim Carey, MD, MPH**

  Professor of Medicine, University of North Carolina Chapel Hill

  Director of the Cecil G. Sheps Center for Health Services Research



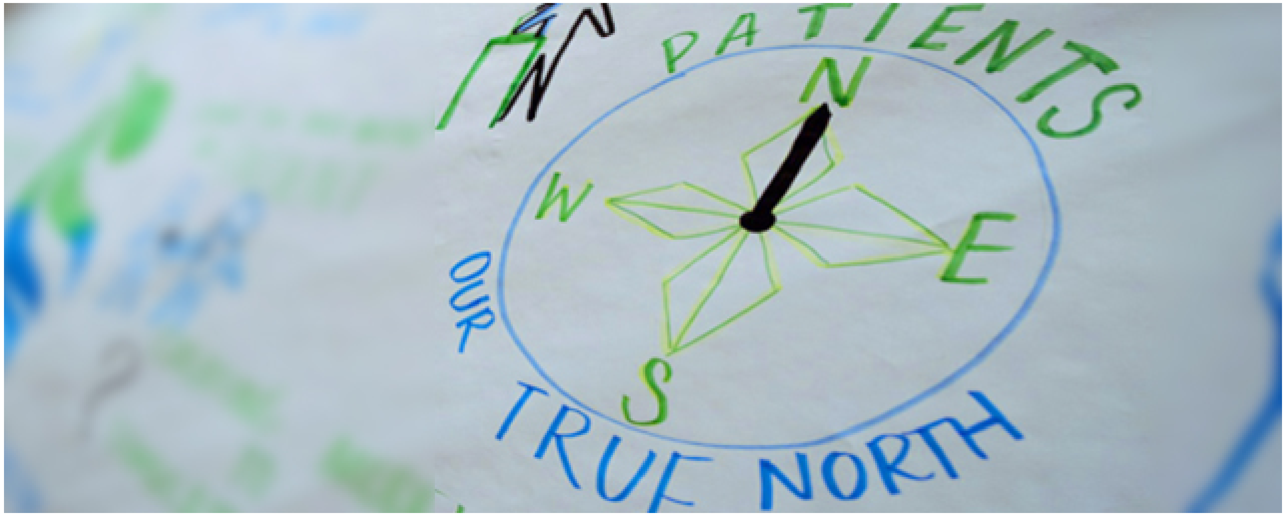
Agenda

- Introduction to PCORI
- Survey background and methods
- Key survey findings & Panel Discussion
  - Experience with and perceived value of CER
  - Patient and caregiver engagement: Experience, barriers, and facilitators
  - Experiences with PCORI

Introduction to PCORI

About PCORI

- An independent research institute authorized by Congress in 2010
- Funds patient-centered comparative effectiveness research (PC-CER) that engages patients and other stakeholders throughout the research process
- Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns

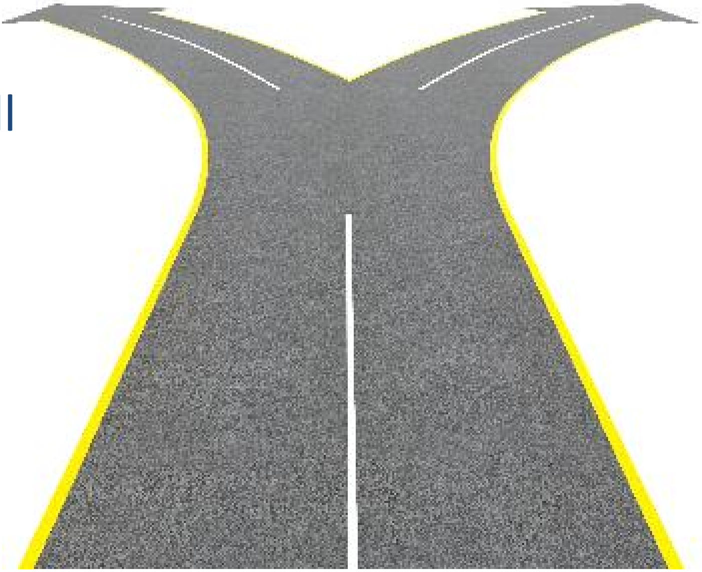


PCORI - Our Mission

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.**

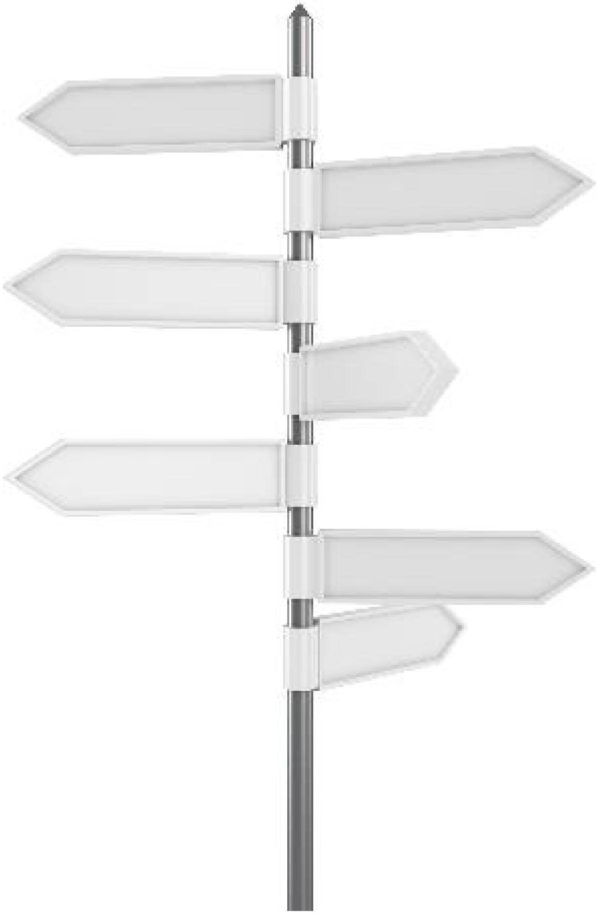
We Fund Patient-Centered Comparative Effectiveness Research

- Measures benefits in real-world populations
- Describes results in subgroups of people
- Generates and synthesizes evidence comparing benefits and harms of at least two different methods to prevent, diagnose, treat, and monitor a clinical condition or improve care delivery
- Helps consumers, clinicians, purchasers, and policy makers make informed decisions that will improve care for individuals and populations
- Informs a specific clinical or policy decision



How is Our Work Different?

- We fund research on which care options work, for whom, under which circumstances.
- We focus on answering questions most important to patients and those who care for them.
- We aim to produce evidence that can be easily applied in real-world settings.
- We engage patients, caregivers, clinicians, insurers, employers and other stakeholders throughout the research process.
- This makes it more likely we'll get the research questions right and that the study results will be useful and taken up in practice.



Who Are Our Stakeholders?

Clinicians

Caregivers/Family Members

Payers

Purchasers

Policy Makers

Patients/Consumers

Industry

Hospitals/Health Systems

Training Institutions

Researchers

Patient/Caregiver Advocacy Organizations

Survey Background and Methods

Background

In late 2014, PCORI conducted surveys of four stakeholder groups:

Patients

Caregivers

Clinicians

Researchers

Researcher Survey: Objectives

- Understand researcher attitudes towards and experience with CER and engaging patients as partners
- Identify barriers to and facilitators of conducting CER and engaging patients as partners
- Understand attitudes toward and experiences with PCORI

Researcher Survey: Methods

- Partnership with American Institutes for Research
- Guided by project-specific multi-stakeholder advisory panel and researcher working group
- Survey development included literature review and cognitive testing
- Recruitment via mailing lists for professional research organizations, relevant AHRQ initiatives, and PCORI (Fall 2014)

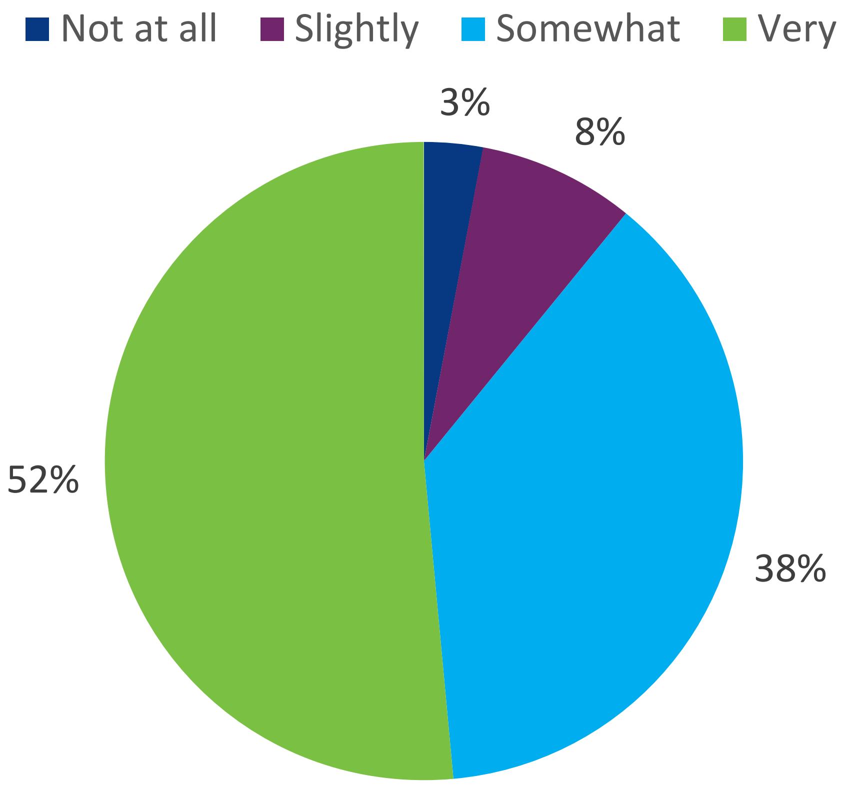
Researcher Survey: Recruitment

- Research organizations, e.g., Kaiser Permanente Division of Research, Center for Effectiveness & Safety Research, and North American Primary Care Research Group (40%)
- PCORI mailing lists (random sample) (33%)
- Institutions previously part of the Agency for Healthcare Research and Quality (AHRQ) iADAPT grants (Innovative Adaptation and Dissemination of AHRQ Comparative Effectiveness Research Products) (12%)
- Evidence-based practice centers (EPCs) (11%)
- Institutions previously part of the AHRQ Centers for Education & Research on Therapeutics (CERTs) (2%)
- Institutions previously part of the DEcIDE (Developing Evidence to Inform Decisions about Effectiveness) Network (1%)

Researcher Survey: Sample (N=508)

- 68% from medical school or academic setting
- 41% with 16+ years research experience, 21% <6 years experience
- 78% have been a Principal Investigator on a research study
- 34% practicing healthcare clinicians
- 61% female

Researcher Familiarity with PCORI

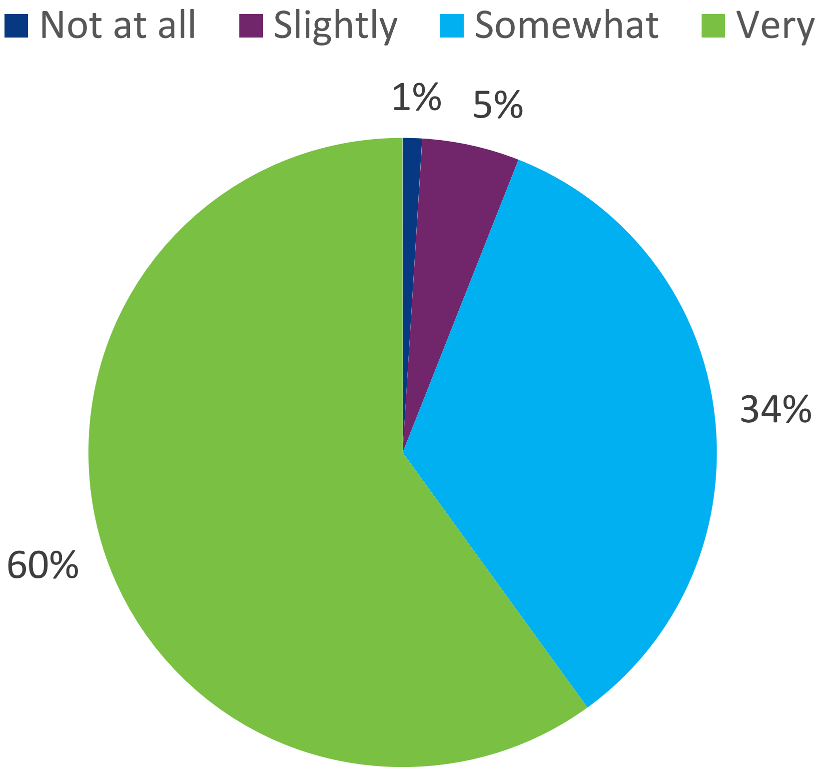


Most researchers were familiar with PCORI. 59% of those had applied for PCORI funding.

Key Findings & Discussion

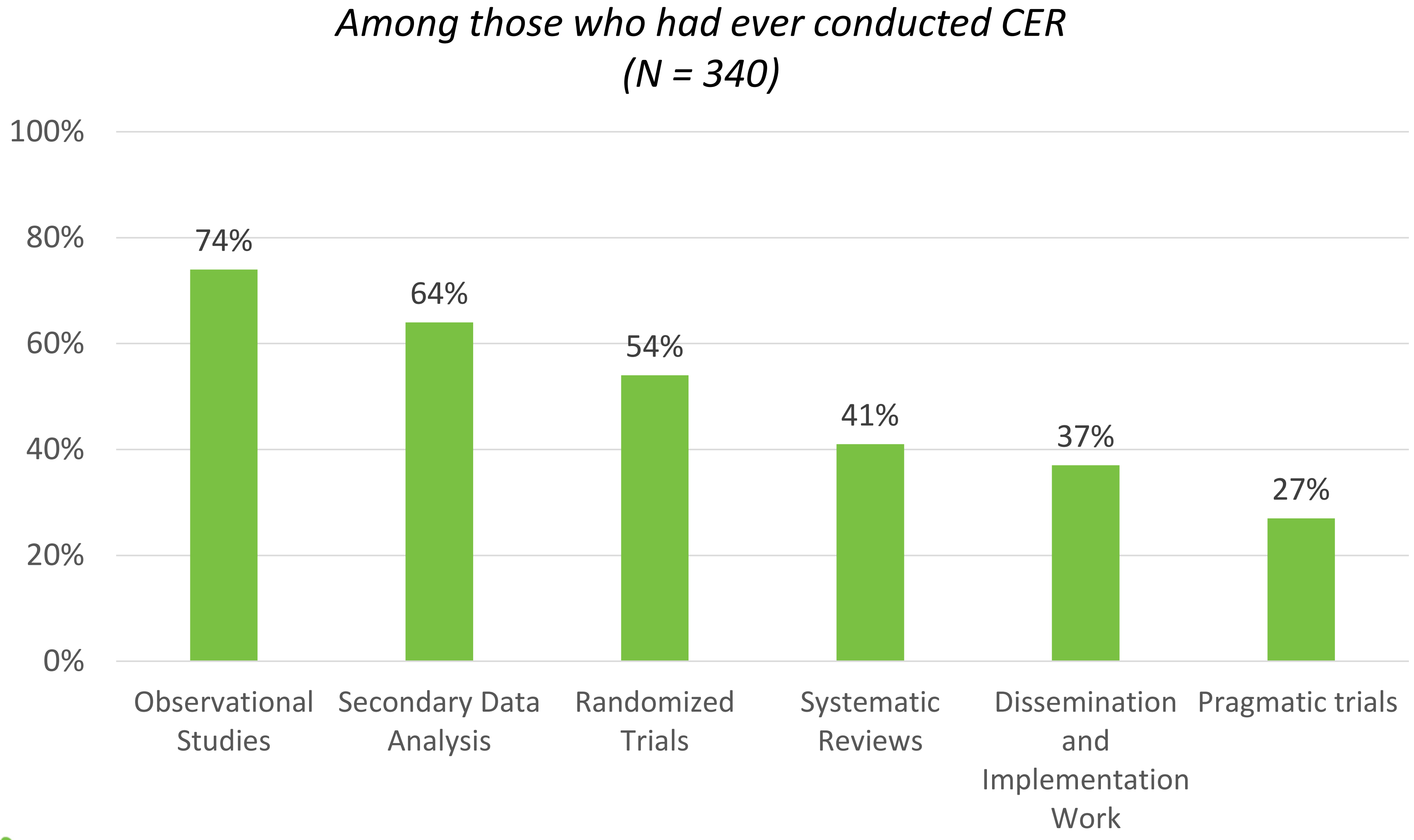
Experience with and Perceived Value of CER

Researcher Familiarity with Comparative Effectiveness Research (CER)



Most researchers were familiar with the concept of CER.

Experience with Different Types of Comparative Effectiveness Research (CER)



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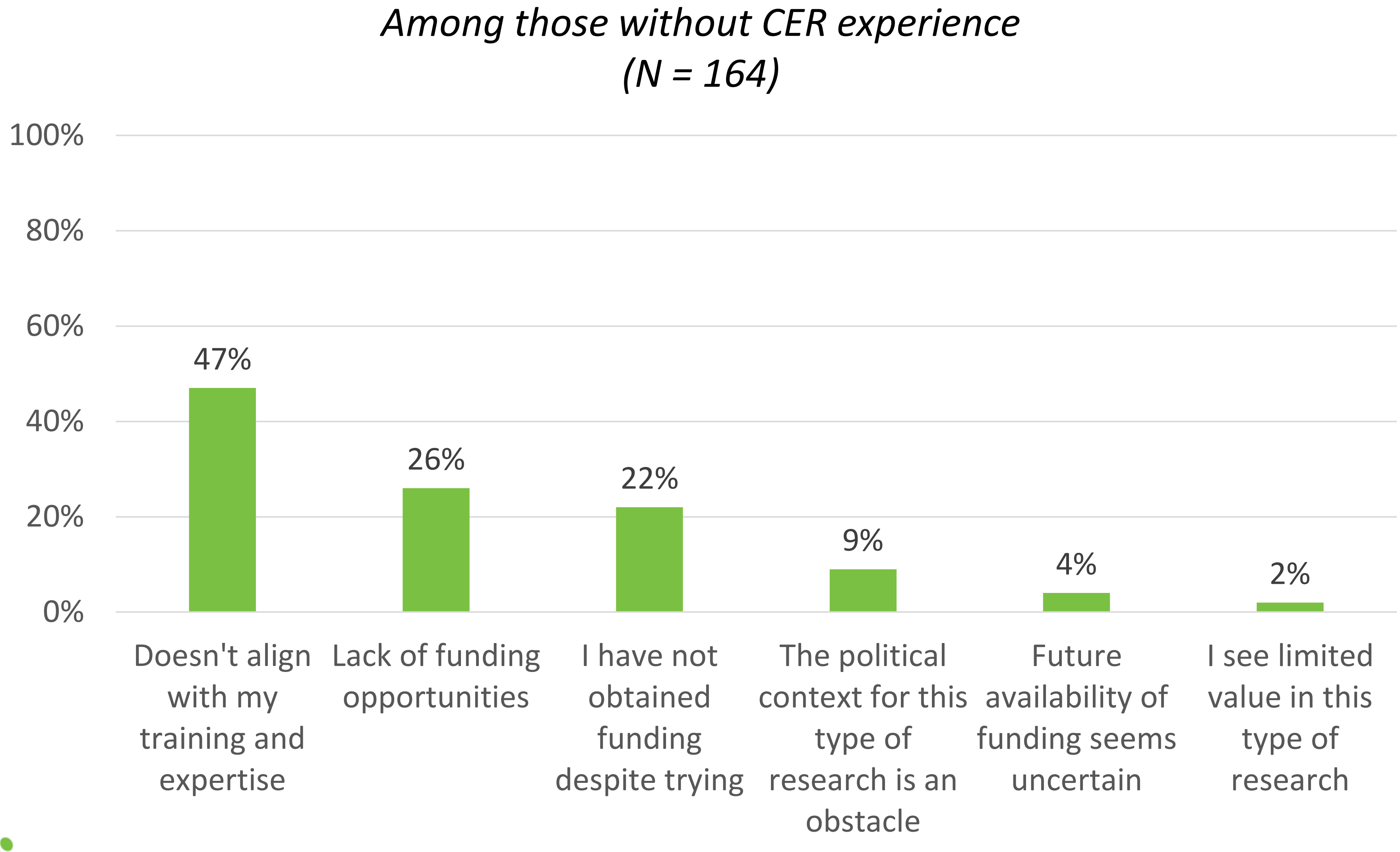
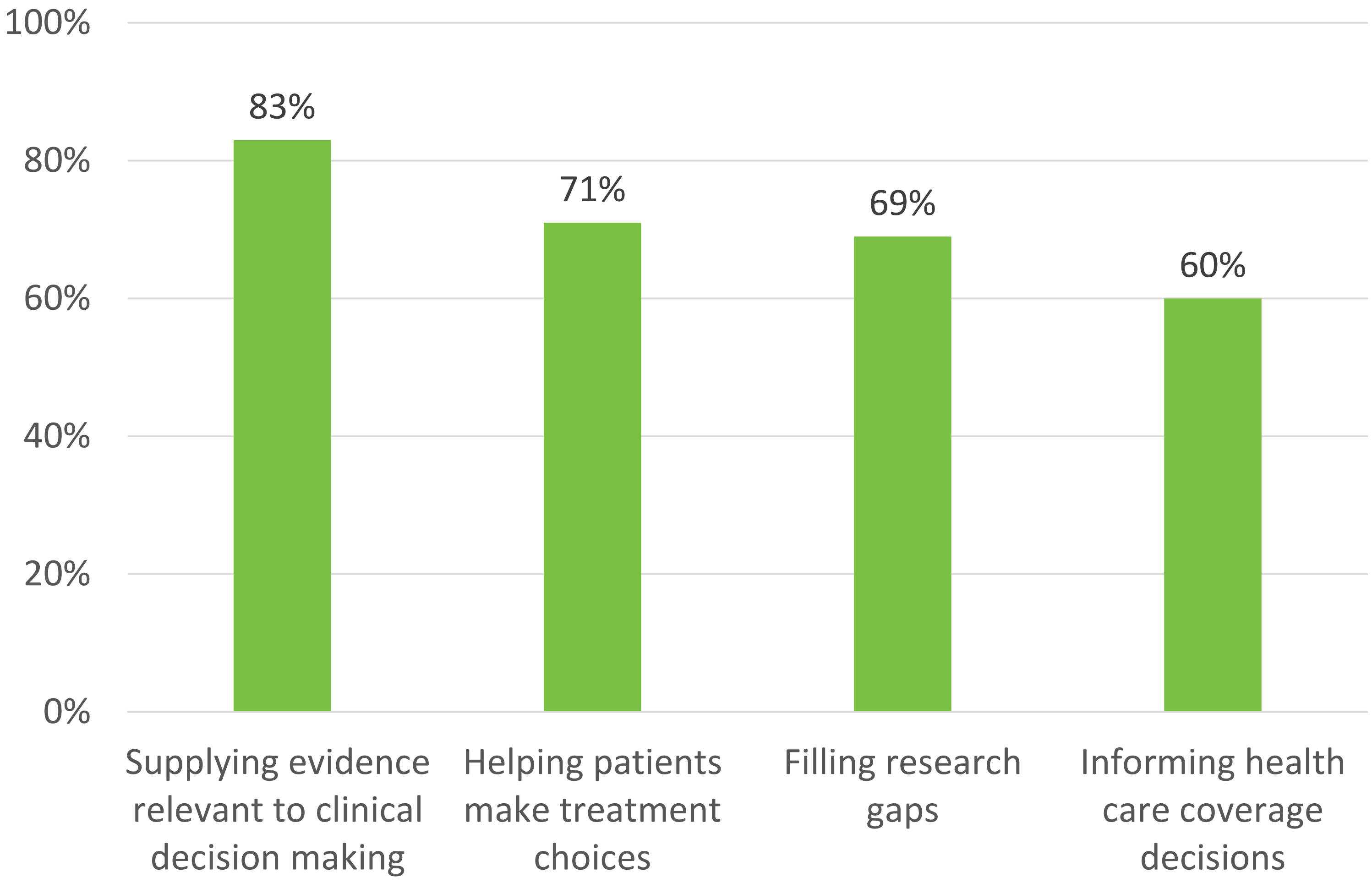
Reasons for Not Conducting Comparative Effectiveness Research (CER)



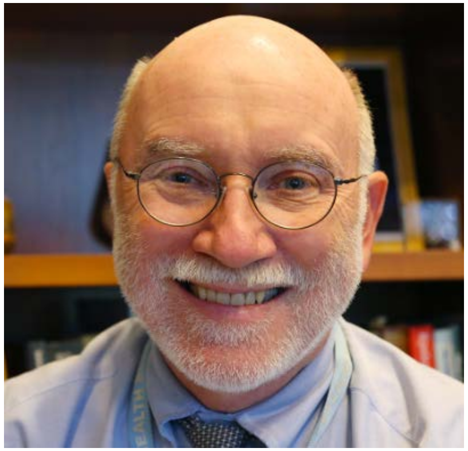
Perceived Value of CER (*% “Very Valuable”*)



Summary: Experience with and Perceived Value of CER

1. Among this sample of researchers familiar with CER, many have experience conducting some forms of CER, while fewer reported experience conducting randomized and/or large pragmatic studies.
2. Lack of alignment with expertise and lack of funding support are common reasons for not conducting CER.
3. While many researchers recognize the value of CER for informing treatment decisions, opportunities exist to expand knowledge on the uses of CER.

Panel Discussion



Ming Tai-Seale

Teresa Hudson

Tim Carey

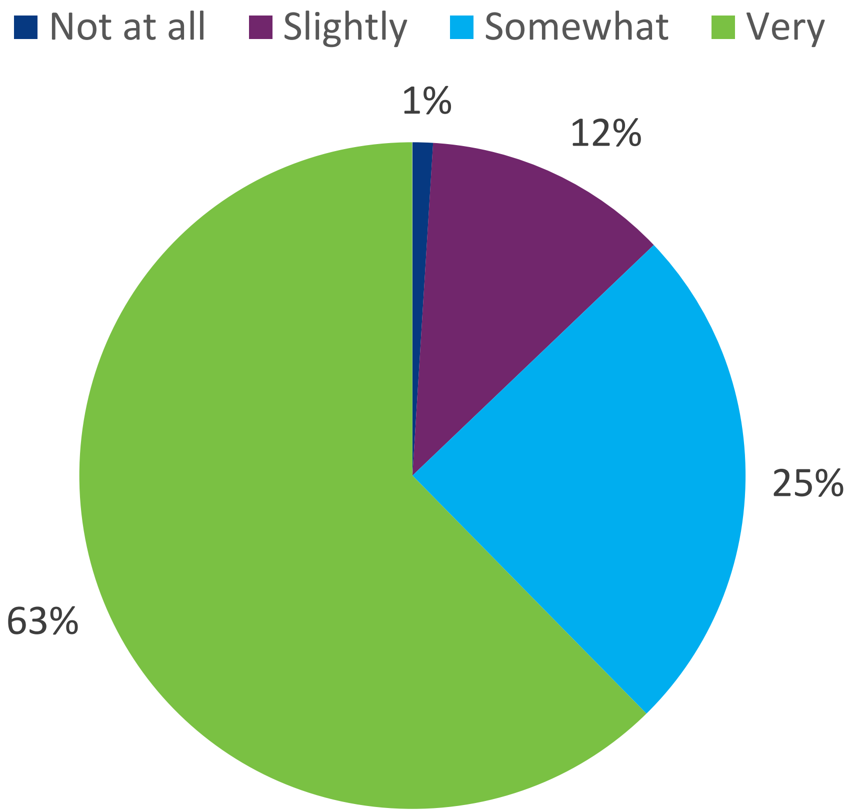
Key Findings & Discussion

Patient and Caregiver Engagement: Experience, Barriers, and Facilitators

Familiarity and Experience with Engagement

- Most respondents were familiar with engaging patients and caregivers as partners (81% very or somewhat familiar)
- 65% of sample reported experience with engagement
- Among those, engagement most commonly occurred for:
  - Identifying research topics (62%)
  - Developing research questions (59%)
  - Participant recruitment or data collection (58%)
  - Results review, interpretation, or translation (53%)
  - Study design: defining/measuring outcomes (50%)
  - Dissemination (47%)

Researcher Interest in Engagement



The majority of researchers are interested in partnering with patients and caregivers in their research.

Researcher Views on Engagement Roles

How valuable do you think involvement of patients and/or caregivers in the following activities could be to your research?	
	% “Very Valuable”
Participant recruitment or data collection	62
Identifying research topics or agenda	59
Dissemination of findings	57
Developing the research questions	48
Results review, interpretation, or translation	36
Proposal development	27
Study design: identifying comparators, measures, and interventions	24
Data analysis	6

Factors Facilitating Engagement in Research (*% "A Great Deal"*)

- Resources to assist in the training and coordination of patient and/or caregiver partners (63%)

- Guidance in successfully applying for funding that requires patient and/or caregiver partners (58%)

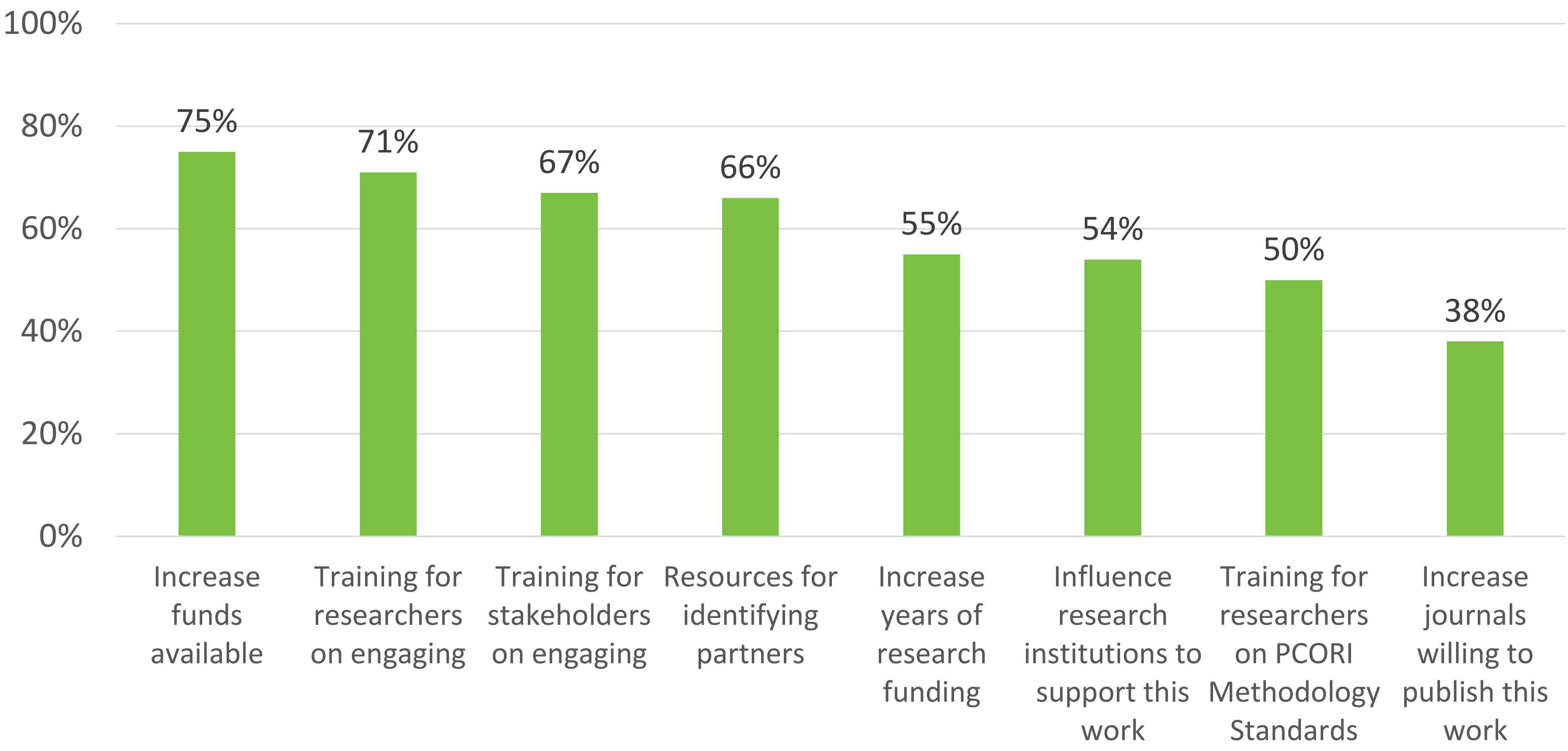
- Empirical evidence showing the value of patient and/or caregiver partners in research (45%)

- Training for me and other staff in co-leading research with patient and/or caregiver partners (39%)

Factors that would Hinder Engagement *(% “A Great Deal”)*

- Lack of infrastructure for involving partners (48%)
- Potential increased resources (e.g., staff) (37%)
- Regulations (e.g., HIPAA, IRB concerns) (34%)
- Added time needed (28%)
- Complexity of managing partnered research (28%)
- Challenges compensating partners (27%)

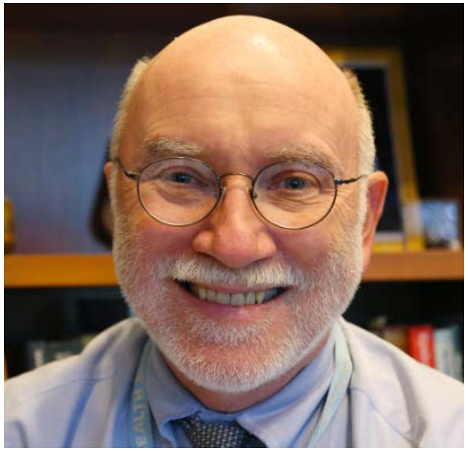
Strategies to Facilitate Engaged Research



Summary: Experience, Barriers, and Facilitators for Engagement with Patients and Caregivers

1. These researchers, who were relatively familiar with engagement, express interest in partnering with patients and caregivers.
2. Researchers see most value for engagement in:
    - Participant recruitment/data collection
    - Identifying research topics/research questions
    - Disseminating findings
3. Key facilitators for research engagement include additional resources and training to support engaged research.

Panel Discussion



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Key Findings & Discussion

Experience with PCORI

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Factors in Pursuing Specific Funding Opportunities (% "*Very Important*")

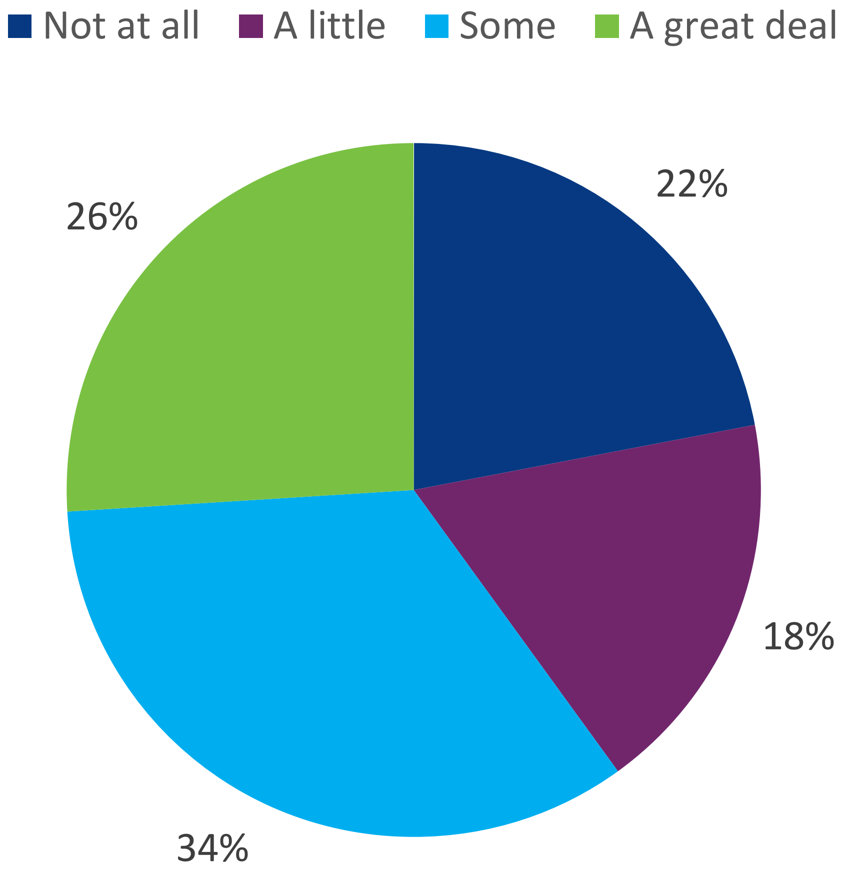
- Alignment with research areas of interest (85%)
- Balance between effort required and likelihood of award (54%)
- Clinical or policy impact of the award (50%)
- Award amount (48%)

Reasons not applied to PCORI (N=182)

- Lack of alignment between PCORI funding criteria and one’s area of research (34%)
- Effort to complete a proposal given the size of the award (34%)
- Lack of clarity in PCORI requirements (23%)
- PCORI’s requirement to engage patients (20%)
- Frequent changes to the application process (19%)

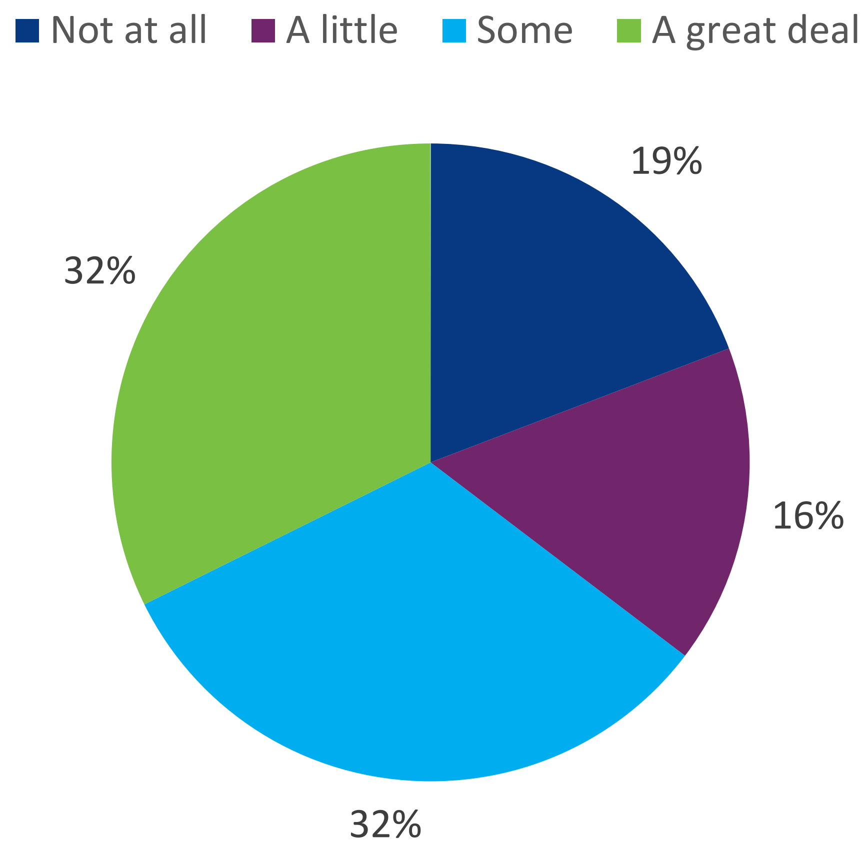
PCORI Influence on Comparative Effectiveness Research Uptake

Among those familiar with PCORI
(N = 462)



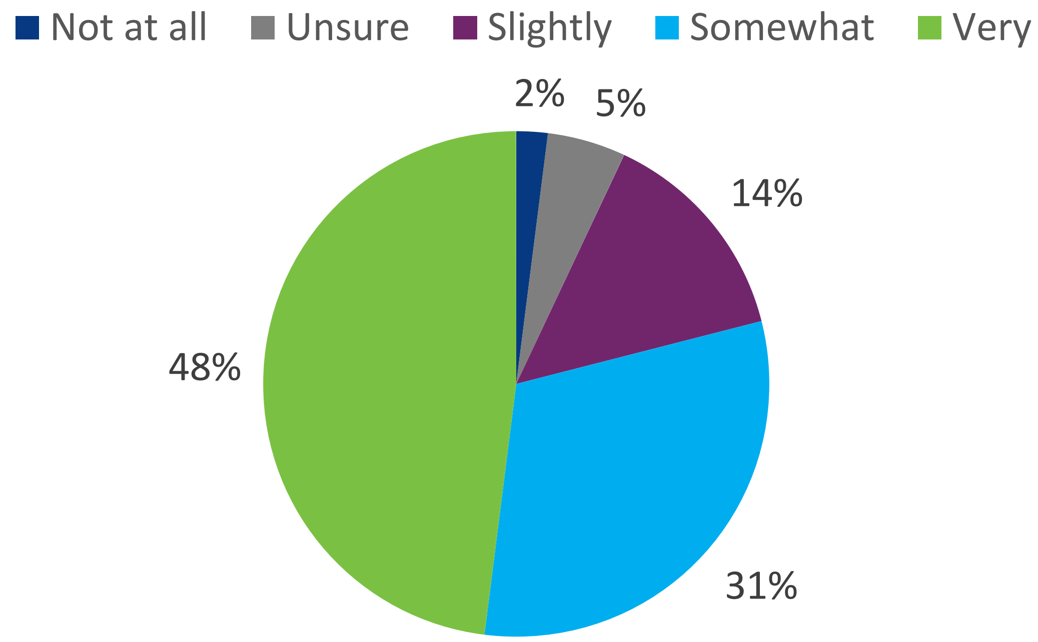
PCORI Influence on Patient and Caregiver Engagement in Research Agenda

Among those familiar with PCORI
(N = 463)



Value of PCORI in Clinical and Health Research

Among those familiar with PCORI
(N =464)



The majority of researchers familiar with PCORI endorse its value for clinical and health research.

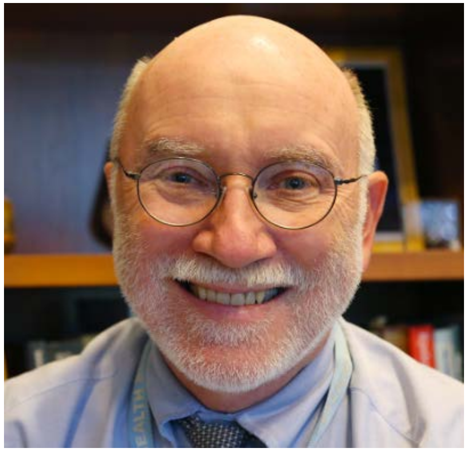
Summary: Experience with PCORI

1. Alignment with area of interest, effort to apply, and clinical implications are important motivators for pursuing funding opportunities.
2. Reasons for not applying for PCORI funding include lack of alignment with areas of interest, researcher view of effort relative to award size, and lack of clarity about requirements.
3. Many researchers, particularly those early in their career, report that PCORI has influenced their decisions to conduct CER and engage patients as partners.

Panel Discussion

Ming Tai-Seale

Teresa Hudson



Tim Carey

Implications for PCORI

Joe V. Selby, MD, MPH

PCORI Executive Director

Healthcare Stakeholder Views Webinar Series

- **Listening to Listening to Patients, Caregivers, and Clinicians: Meeting Stakeholder Needs for Comparative Effectiveness Research - A PCORI Survey**

Archived on PCORI's website:

http://www.pcori.org/events/2015/listening-patients-caregivers-and-clinicians-meeting-stakeholder-needs-comparative

Thank you!

- Acknowledgements
  - Survey respondents
  - Webinar panelists

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- Please send questions or comments to:

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