



## **PCORI Evaluation Group**

Fourth Meeting

Friday, March 28, 2014

Patient-Centered Outcomes Research Institute

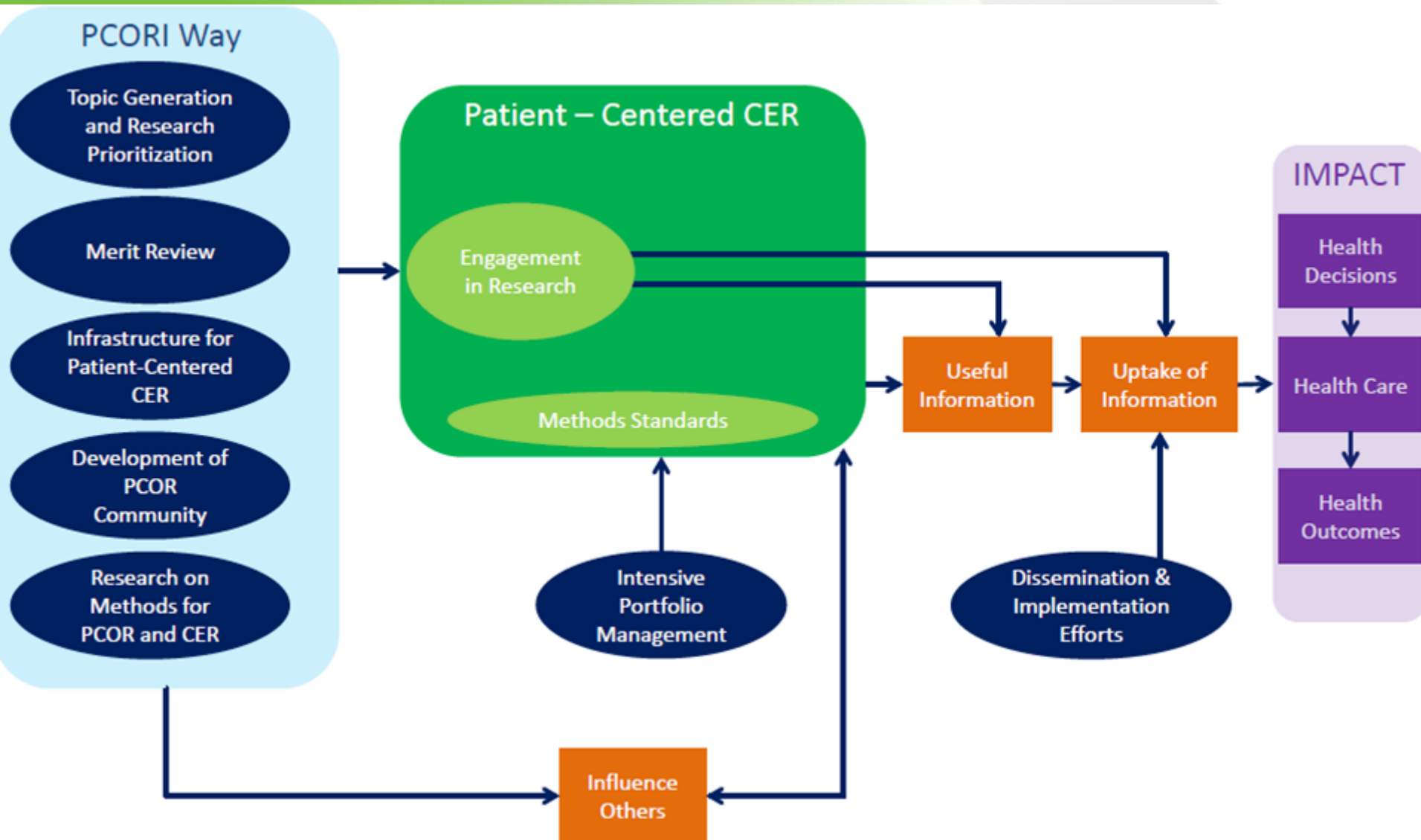
# Agenda for Today

- Review Plans for Measuring Engagement in PCORI-funded Projects
  - Discuss Engagement Activity Inventory

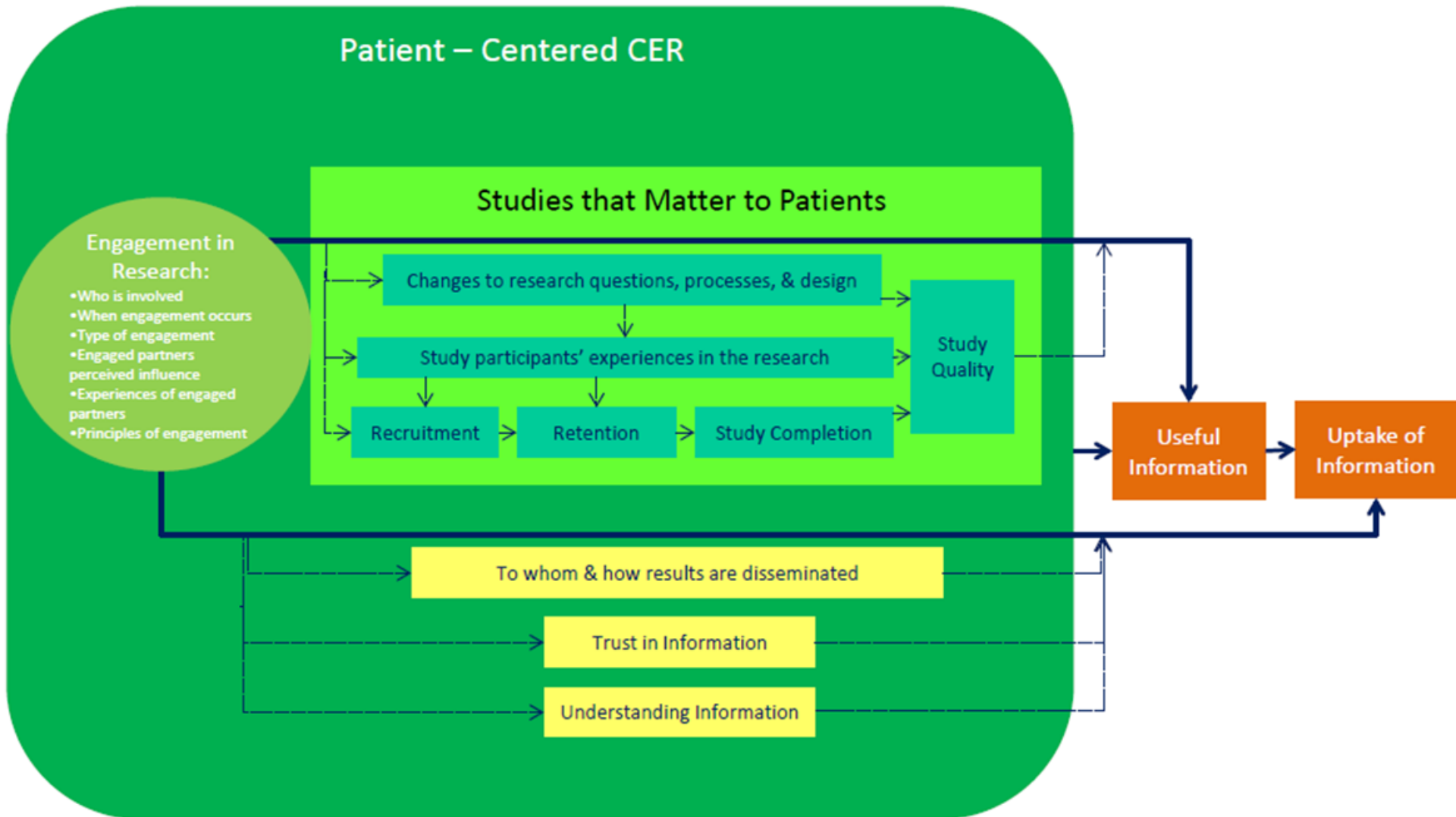
*And, if time allows,*

- Review Plans to Survey Patients, Clinicians, and Researchers
  - Discuss Draft Items for Patients and Clinicians

# Model for Evaluating the Overall Impact of PCORI



# Model for Evaluating Engagement in Research



# Multiple Purposes for Measuring Engagement

- 🌐 **Describe** engagement in PCORI funded projects
  - Enhances communication with awardees, other researchers and potential research partners, external stakeholders
- 🌐 **Evaluate** engagement in PCORI funded projects
  - Determine effect of engagement on PCORI strategic goals and other key outcomes of interest
  - Evaluate Engagement Rubric
  - Identify best practices for Engagement
  - Inform PCORI funding requirements for engagement

# Challenges for Measuring Engagement

- 🌐 Engagement is a relatively new concept
- 🌐 Measurement of engagement in the literature is limited
- 🌐 Complex set of behaviors
- 🌐 Subjective
- 🌐 Dynamic

# Domains of Interest for Describing Engagement

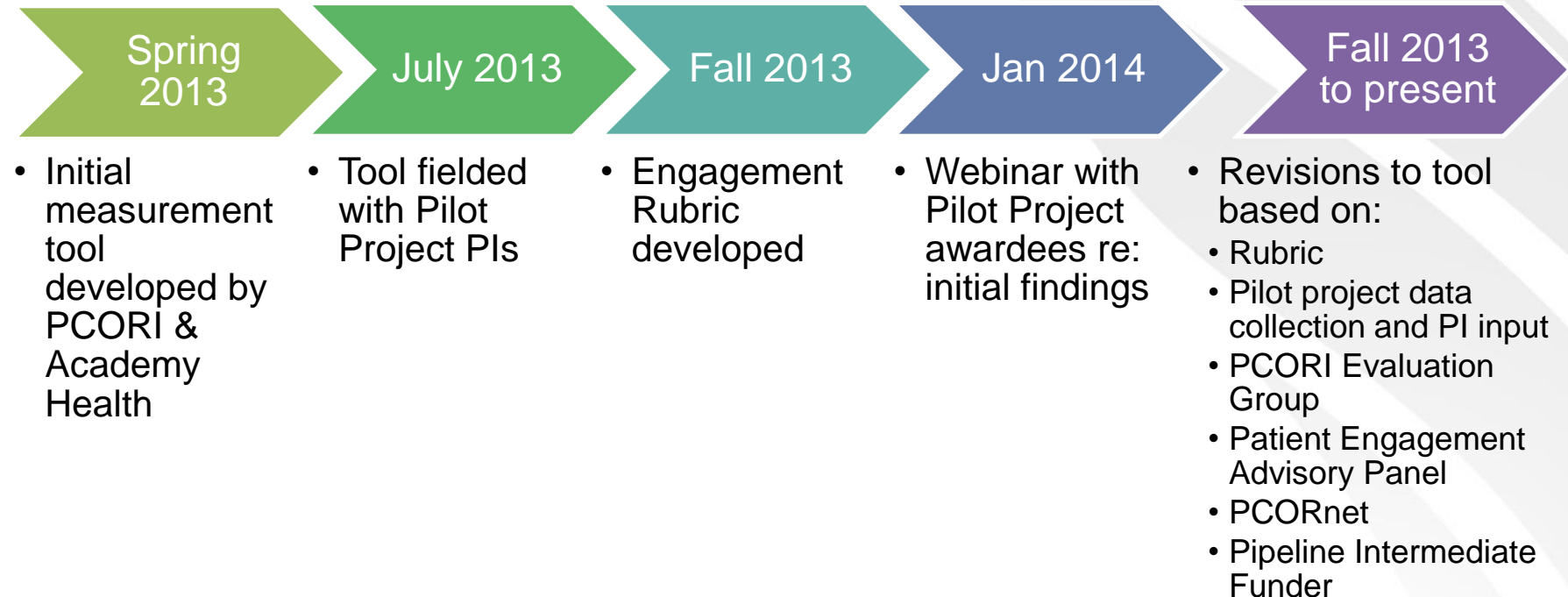
- Who is engaged
- Partnership characteristics – how formed, length, frequency of engagement, etc.
- Level of engagement
- When in research process are they engaged
- Perceived level of influence of partners
- Effects of engagement on research questions, study design, study implementation, and dissemination of results
- Challenges, facilitators
- Lessons learned for engagement
- PCOR principles (respect, co-learning, etc.)

# ENgagement ACTivity Inventory (ENACT)

- Self-report tool intended to describe engagement in funded projects
- Versions developed for:
  - PCORI Pilot Projects
  - CER projects
  - PCORnet projects (to describe engagement of patients and other stakeholders in network development)



# Development of the ENgagement ACTivity (ENACT) Inventory



# Data collection decisions

- 🌐 Collect multiple perspectives
  - $\geq 1$  each of scientist, patient and stakeholder partners (as applicable)
  - Identified via proposal, PCORI program staff, and PI/partner inquiry as needed
- 🌐 Field at baseline and 12, 24, and 36 months post-contract execution (for 3 year projects)
- 🌐 Minimize time burden
  - Electronic skip patterns
  - Brief data updates following baseline data collection

# Measuring impact: *Changes to research questions, process, and study design*

- Perceptions of scientists and patient and stakeholder partners provided via the ENACT Inventory
  - Perceived level of impact on:
    - each stage of the research process (question framing, study design, recruitment, etc.)
    - the way researchers and partners work together on this project
    - Research projects, other work, or relationships outside this specific project
  - Description of specific impacts of engagement on each of the above

# Measuring Impact: *Recruitment, Retention, and Study Completion*

	Recruitment	Retention	Study completion
Primary indicator	Recruitment proportion: % of those eligible who enroll	Retention proportion: % of participants enrolled who complete the study	Recruitment completion: enrollment completed (Y/N)
Other indicators	<ul style="list-style-type: none"><li>• Recruitment timing: % of projects ahead of, consistent with, and behind planned recruitment schedule</li><li>• Recruitment proportion-hard-to-reach: % of those eligible who enroll among hard-to-reach populations</li><li>• Eligibility: % of people presenting to study who are eligible</li></ul>	Retention proportion- hard-to-reach: % of hard-to-reach participants enrolled who complete the study	Recruitment completion – hard-to-reach: enrollment completed for hard-to-reach populations (Y/N)

# Measuring Other Impacts

- What is the effect of patient and stakeholder engagement:
  - On the functioning of the ***Study Team?***
  - On ***Study Design?***
  - On the Experience of ***Study Participants?***

# Next Steps

- Finalize ENACT
- Administer to studies at the 12 month mark
- Report initial results at end of year
- Incorporate ENACT into project start-up (baseline) and routine monitoring (yearly progress reports)
- Develop additional metrics for impact of Engagement
- Develop study protocols

# Scientific Survey Project: Objectives

- To understand patient, health care provider, and researcher
  - attitudes toward and perceptions of CER.
  - understanding of and attitudes toward patient and other stakeholder engagement in research.
- To understand barriers to and facilitators of use of CER results in health decisionmaking and clinical practice.
- To develop methods to facilitate use of CER in health decisionmaking and clinical practice.

# Scientific Survey Project

- Guided by multi-stakeholder advisory board and sample specific working groups
- Development of flexible item pools to be used for this and other efforts
- Project Timeline:
  - Cognitive testing: April – May 2014
  - Data collection: June – August 2014
  - Results available: October – November 2014



# Scientific Survey Project

- 🌐 Patient survey: nationally representative sample of patients with chronic or rare conditions
  - N = 1,000 – 1,500
- 🌐 Clinician survey: nationally representative sample of Primary Care Clinicians (MDs, PAs, NPs)
  - N = 1,400
- 🌐 Researcher survey: sampling plan under development

# CLINICIAN SURVEY DOMAINS - 1

## I. GENERAL PRACTICE

- Typical decision making process
- Typical methods of patient education
- Satisfaction with current patient education materials

## II. USING MEDICAL RESEARCH FINDINGS

- Looked for medical research to aid patient care?
- Where provider looked for medical research
- Ways provider uses medical research
- Factors about medical research that are important to providers
- Did medical research meet provider's needs
- Factors about medical research important for patient decision making
- Usefulness of various resources in decision making process
- How well medical research answered questions important to patients
- Value of resources to making treatment recommendations

# CLINICIAN SURVEY DOMAINS - 2

## III. COMPARATIVE EFFECTIVENESS RESEARCH (CER)

- Familiarity with CER
- Types of research that are valuable in creating CER
- Frequency provider uses CER
- Usefulness of CER for clinical practice

## IV. MEDICAL RESEARCH ENGAGING PATIENTS & CLINICIANS

- Familiarity with research that involves patients and practicing clinicians
- Views on the impact of including clinicians on medical research team
- Views on the impact of including patients on medical research team
- Types of research provider thinks clinicians would be valuable in
- Have providers ever worked as part of a medical research team (by task)
- Interest in working as part of medical research team (by task)
- Overall interest in working as part of medical research team
- Facilitators to engaging in working as part of a medical research team
- Barriers to engaging in working as part of a medical research team
- Benefits of working as part of a medical research team

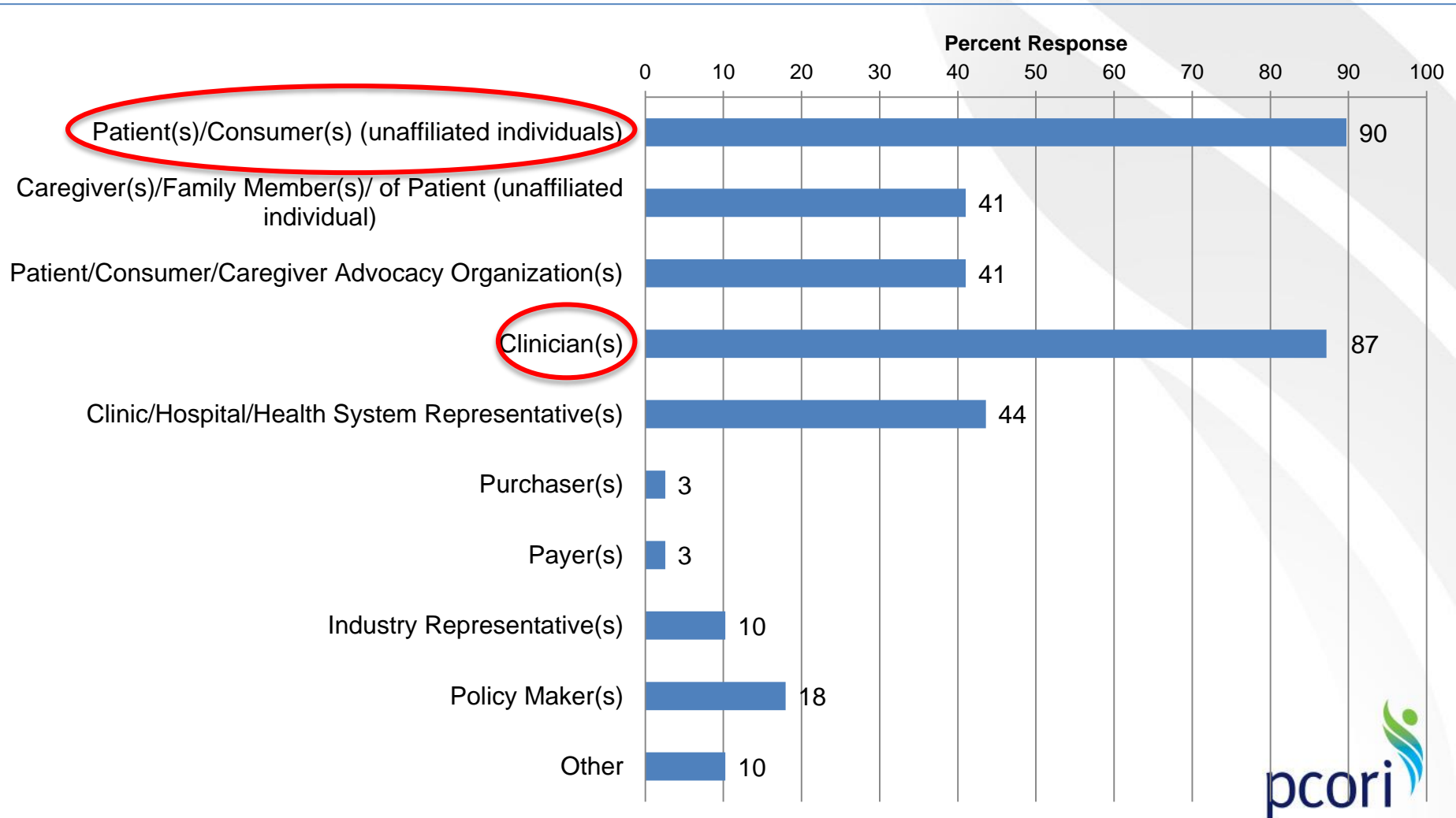
# Feedback on Draft Patient and Clinician Surveys

- Did we capture the most important domains?
- Suggestions for improvement to increase question understandability? Flow? Etc.?

# Appendix: selected results from initial data collection with pilot projects

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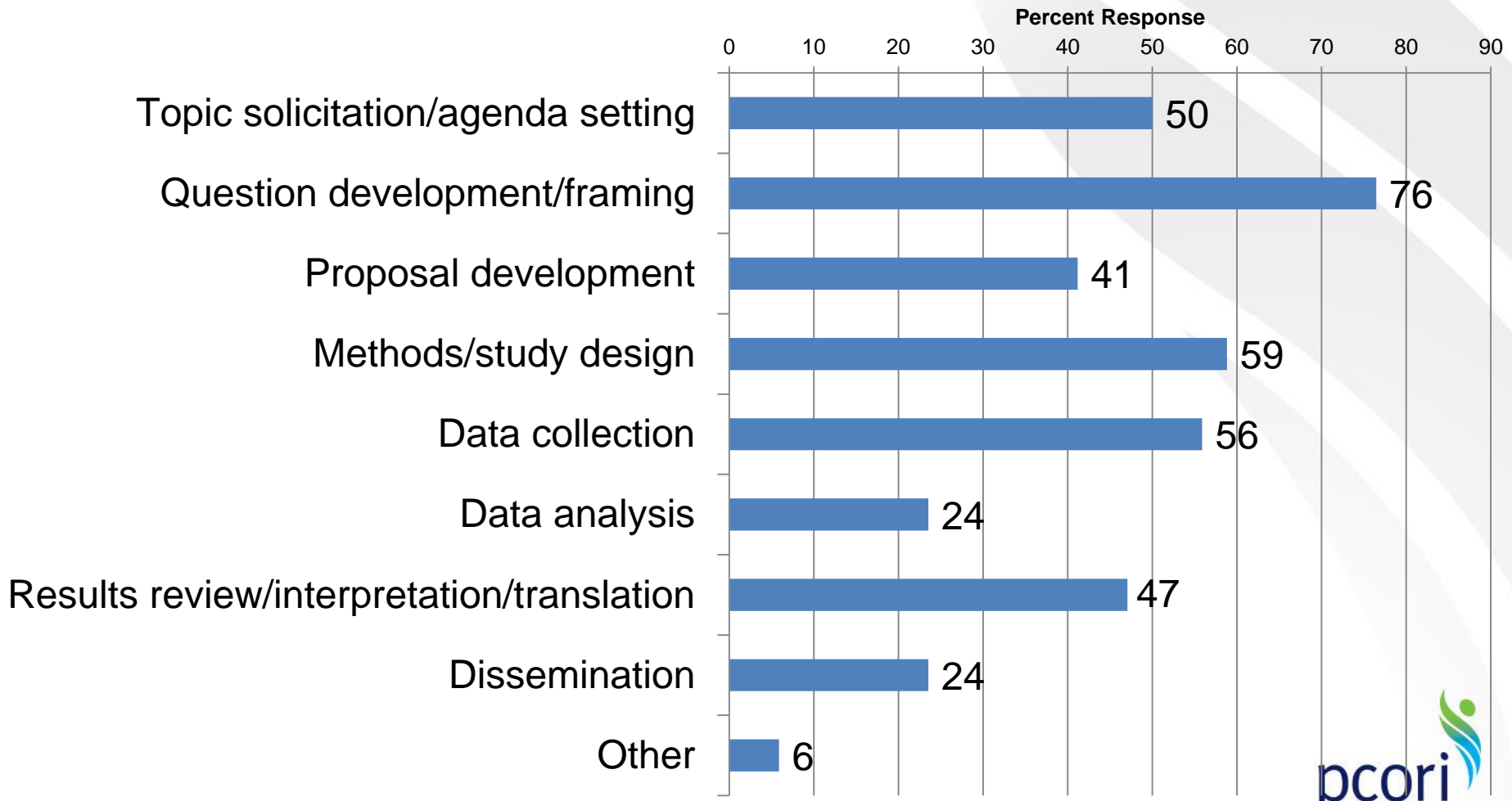
# Engagement of Patient and Other Stakeholder Communities (n = 39 Projects)



# Nature of Patient Involvement

Nature of Involvement	Percent Response
<b>Consultant</b>	35%
<b>Collaborator</b>	53%
<b>Patient-led</b>	6%
<b>Other</b>	6%

# Patient Engagement by Stage in the Research Process (n = 35)





# Initial Learnings on Engagement

Themes include:

- Importance of
  - Choosing the right stakeholders
  - Communicating genuine interest in engagement
  - Facilitators like transportation and face-to-face meetings
- Amount of time needed to build relationships
- Differences among stakeholder communities
- Overall positive experiences for researchers and stakeholders

# Stakeholders Provide New Perspectives

Both patients and clinicians challenge and stimulate you in multiple ways. They offer ideas about alternative strategies to try when things did not work out as expected.

Engaging patients, family members, and clinicians offers many opportunities to shape the research project in ways that are relevant...and to get input and knowledge that only these stakeholders have

Engagement is essential...our project methods and goals have evolved, in some cases dramatically, based on our collaborations with stakeholders

# Stakeholders Contribute to the Research Methodology

They taught us a lot about our expectations for our pilot in regard to outreach to low education groups

They helped us get the right questions into our instruments

They have pilot tested our patient interview tool and provided very valuable feedback about the content and process we are using to interview patients

# Patients and Other Stakeholders Want to Be Engaged

Although it is difficult to enroll subjects in an inpatient setting, our experience is that patients appreciate the opportunity to tell their story and explain their understanding of their illness and reasons for hospital reutilization

Patients and other stakeholders are very interested in contributing to research endeavors as long as they feel it is not tokenism or the desire for involvement is not sincere