



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

Patient-Centered Outcomes Research Institute

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

Patient – Centered CER

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

Engagement in Research

Ways of Engaging - ENgagement ACtivity

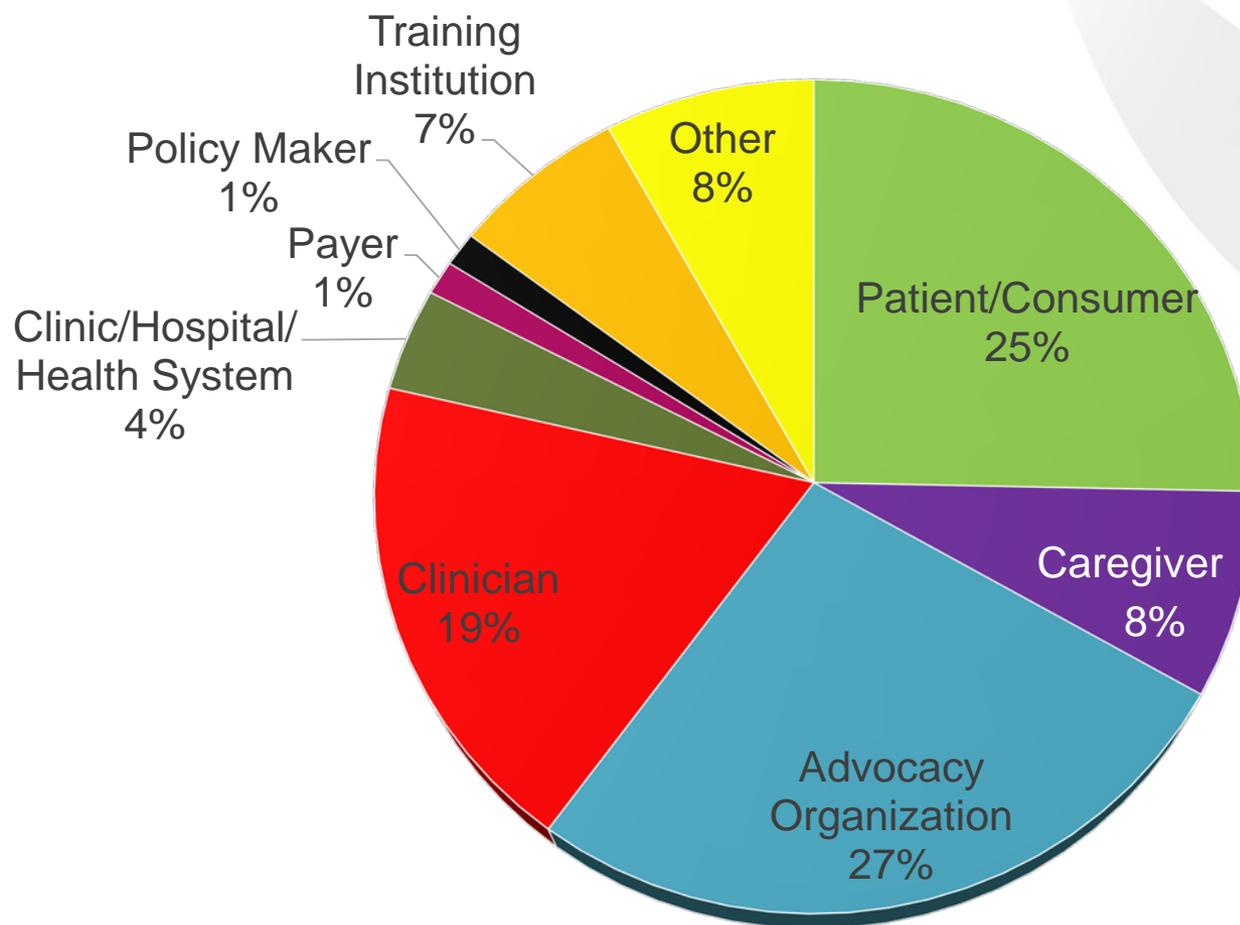
Tool: WE-ENACT

- 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

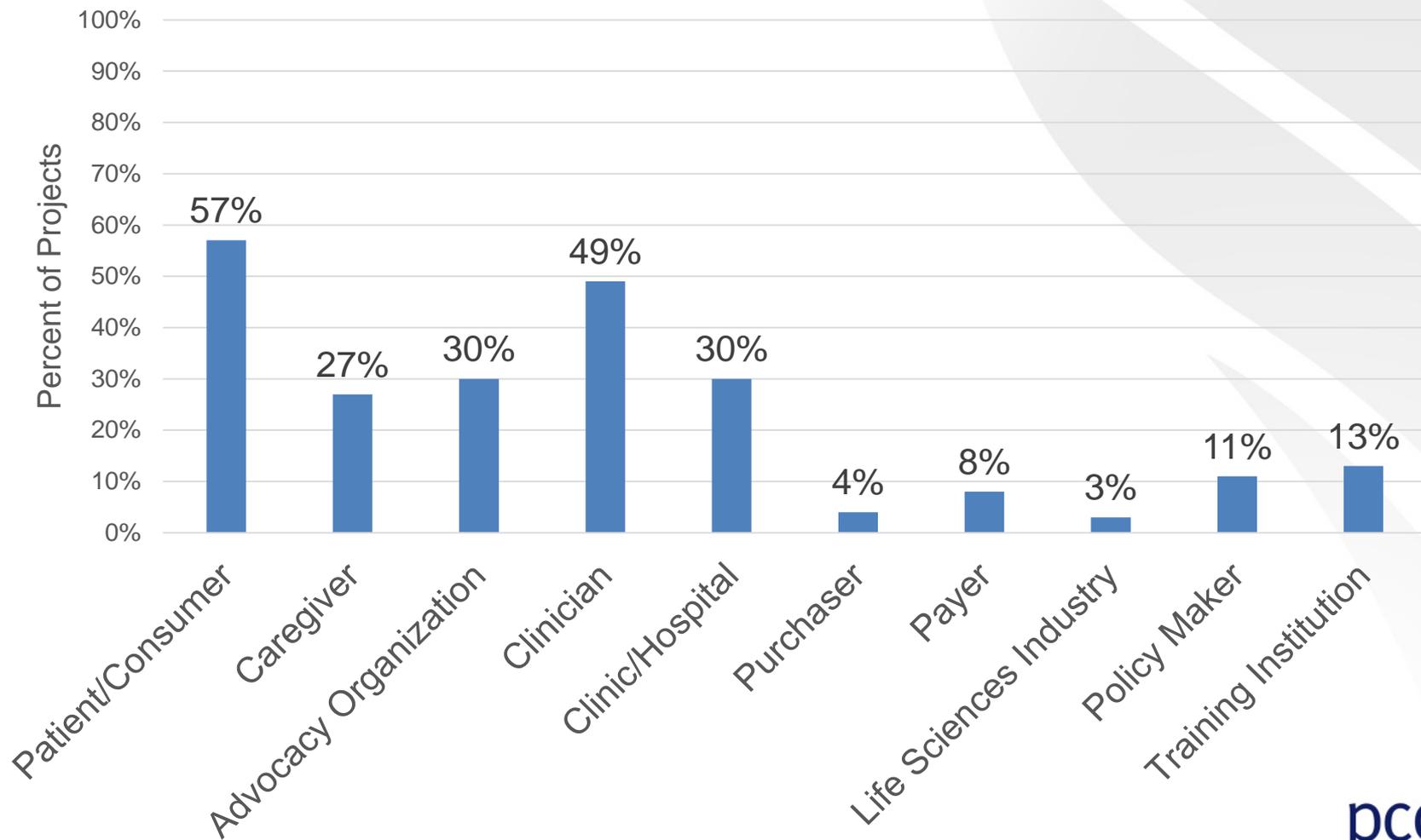
- PIs and patient and stakeholder partners from Cycles I, II, III, and Inaugural Methods Cycle have been invited to respond to the one- year inventory.
- Today's sample
 - 58 PIs or their designees (*data shown in blue*)
 - 75 patient or stakeholder partners, representing 29 projects (*data shown in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

Stakeholder Sample (n=75)



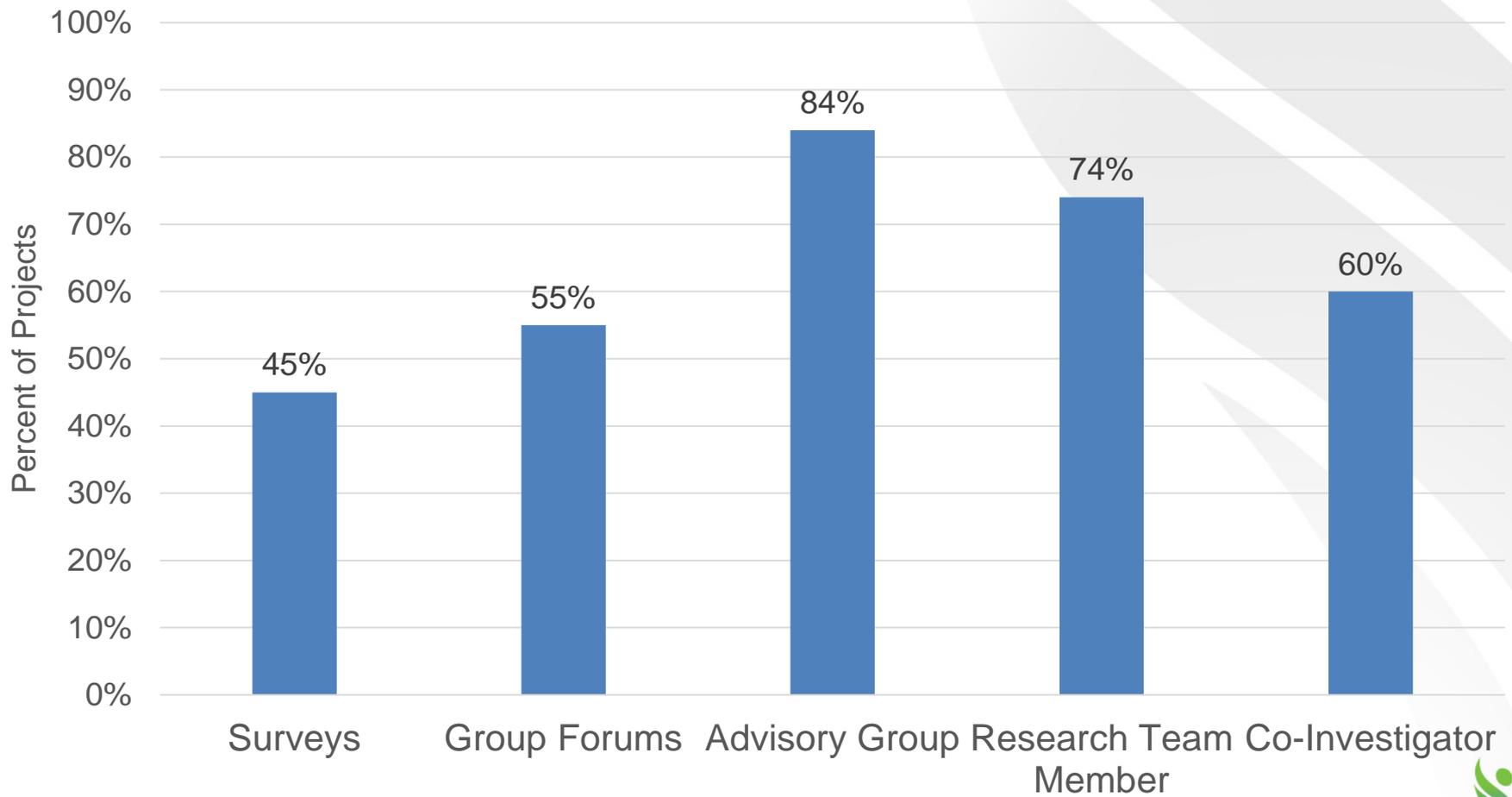
Types of Stakeholders Engaged

Researcher Report



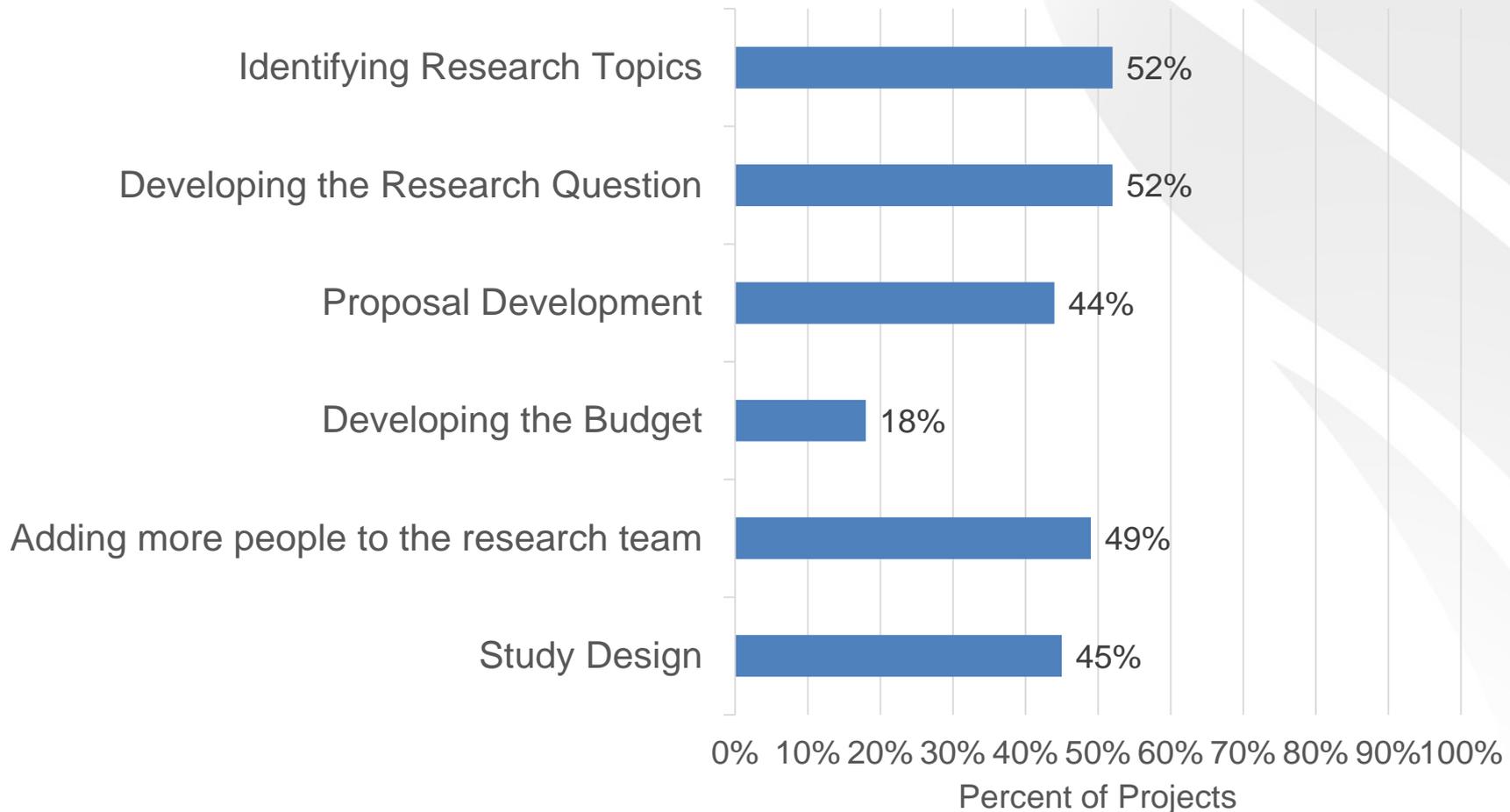
Approaches to Engagement

Researcher report

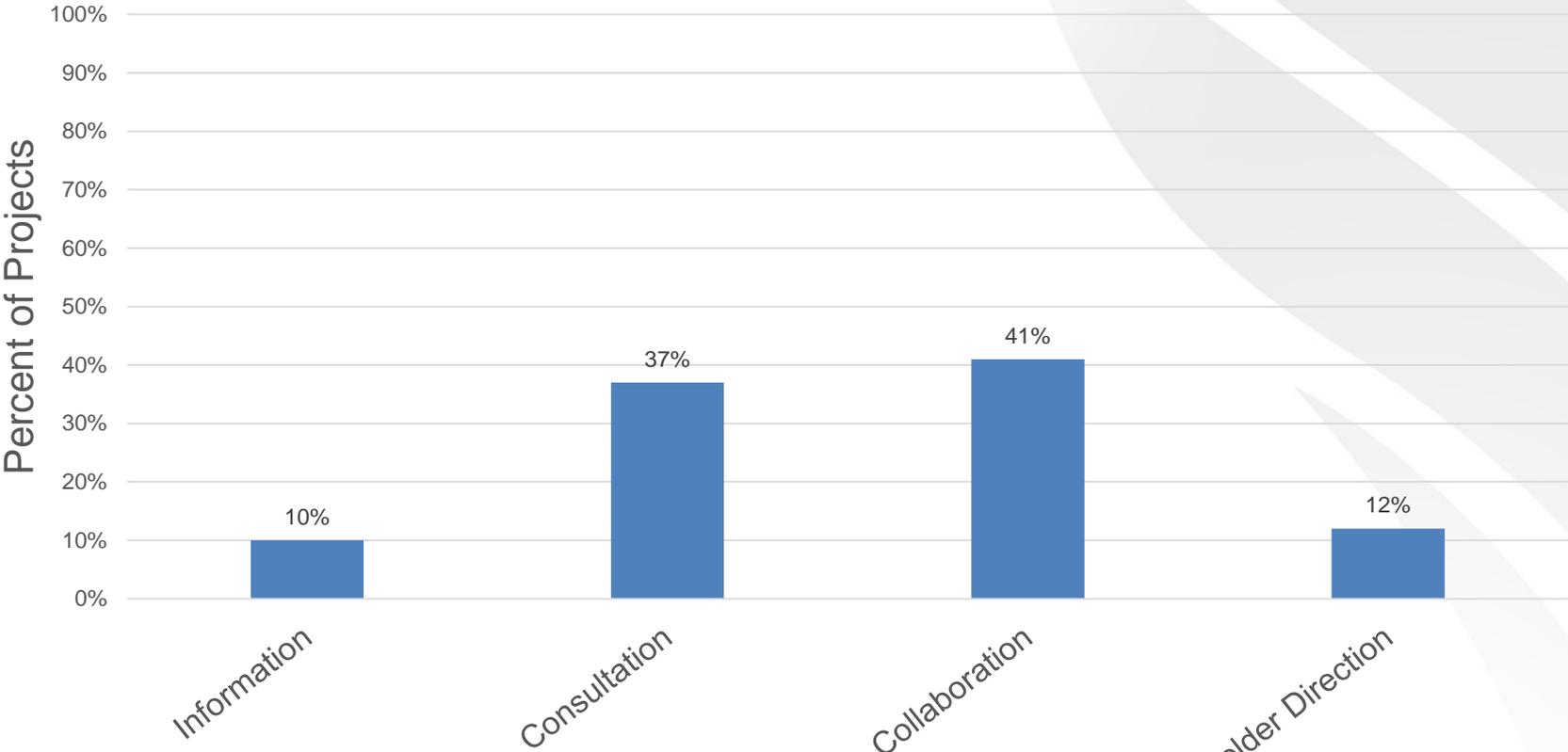


Engagement in Planning the Study

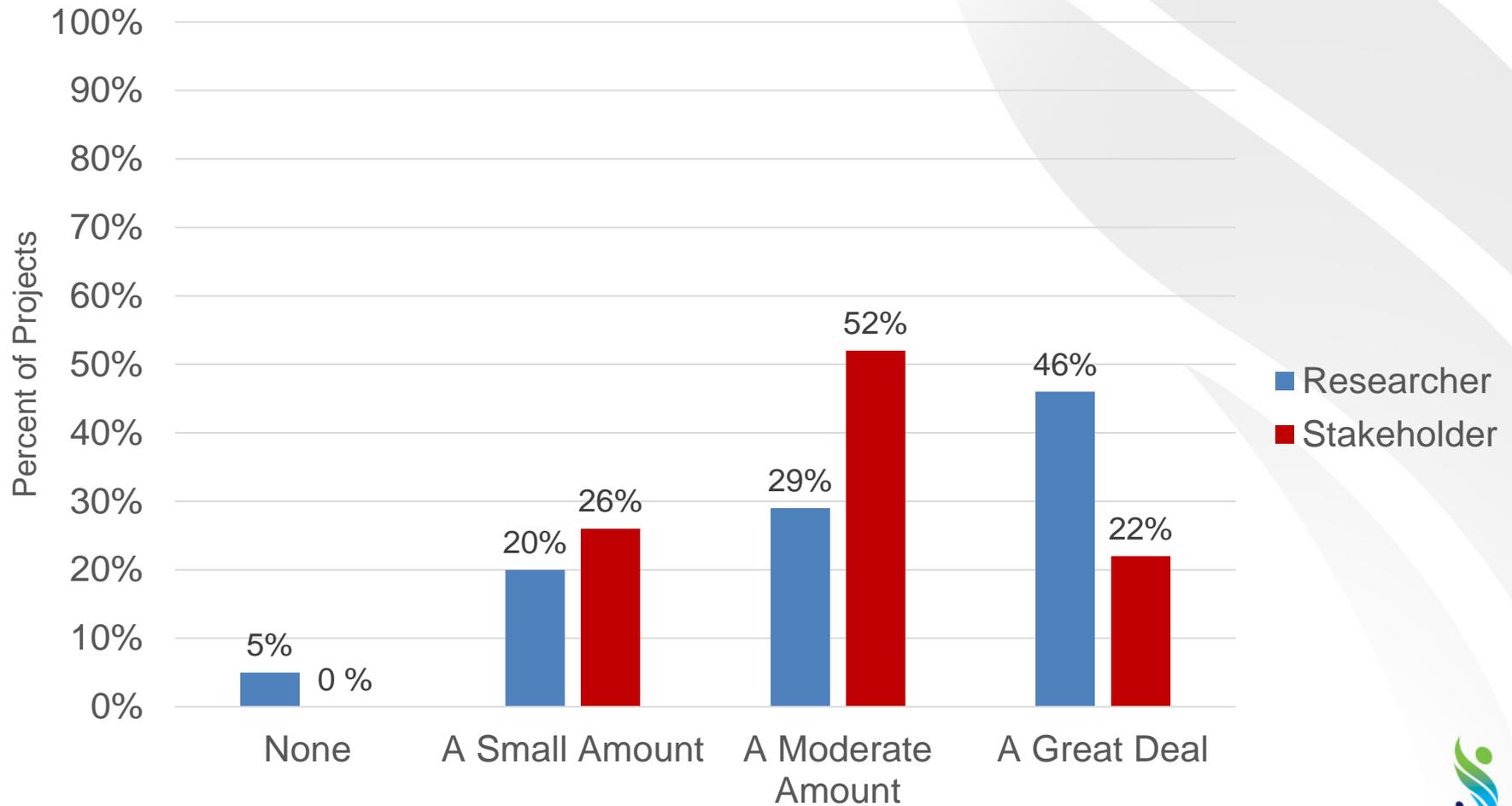
Researcher Report



Identifying Research Questions: Level of Engagement Researcher Report



Identifying Research Questions: Perceived Influence



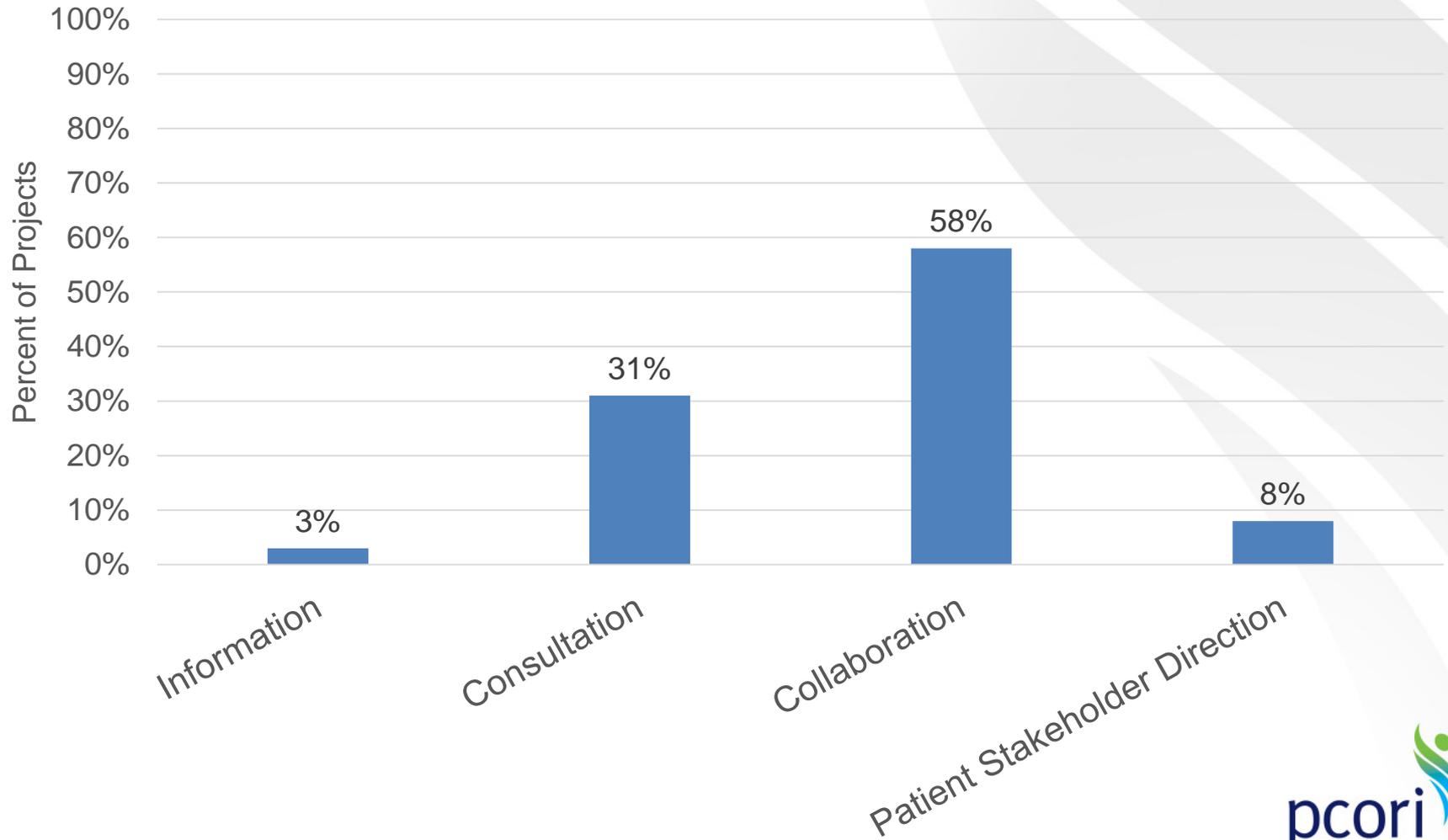
Identifying Research Questions: Impact of Research Engagement

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

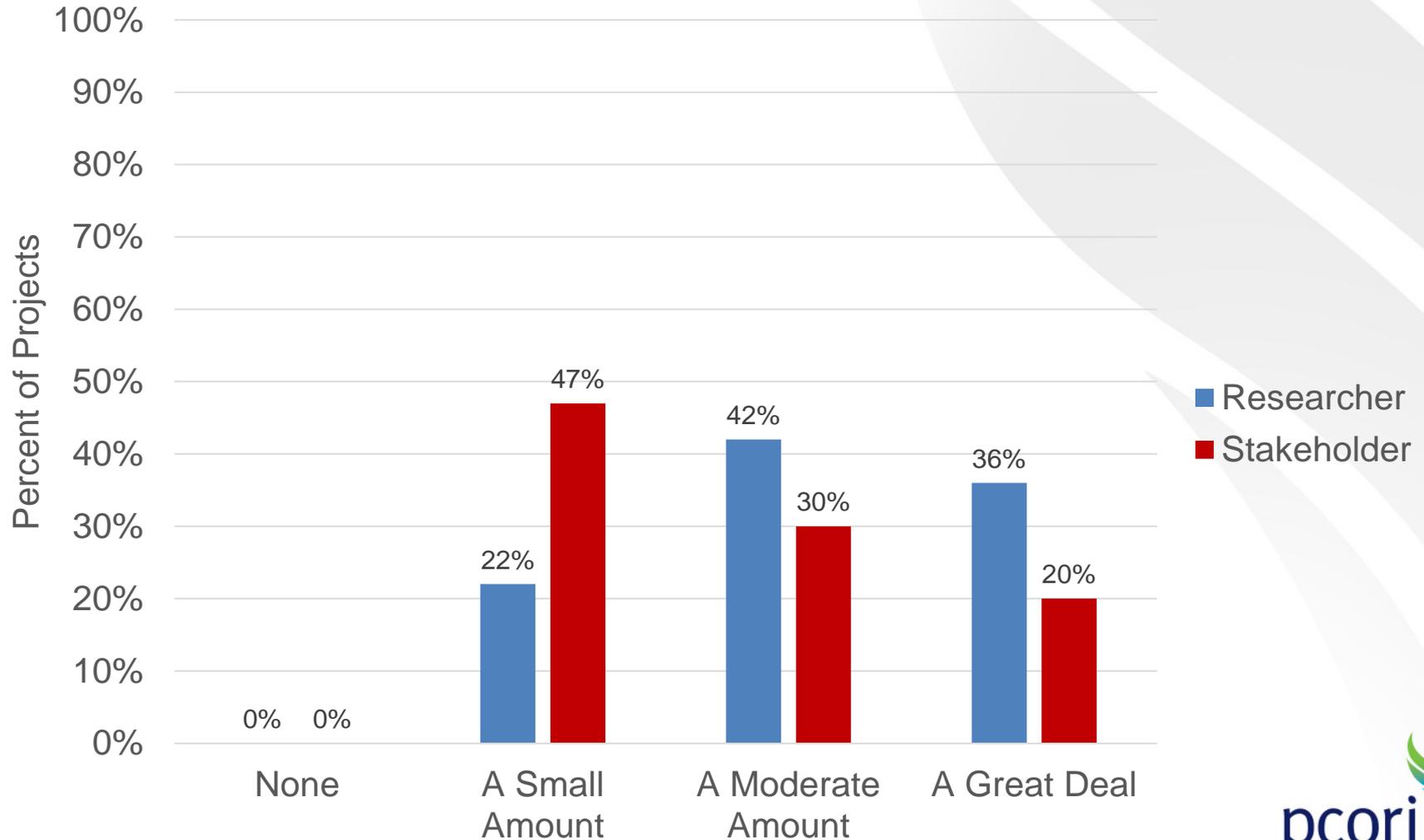
“Topics were more tailored to parent and family concerns.”

“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



Study Design: Perceived Influence



Study Design: Impact Researcher Feedback

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

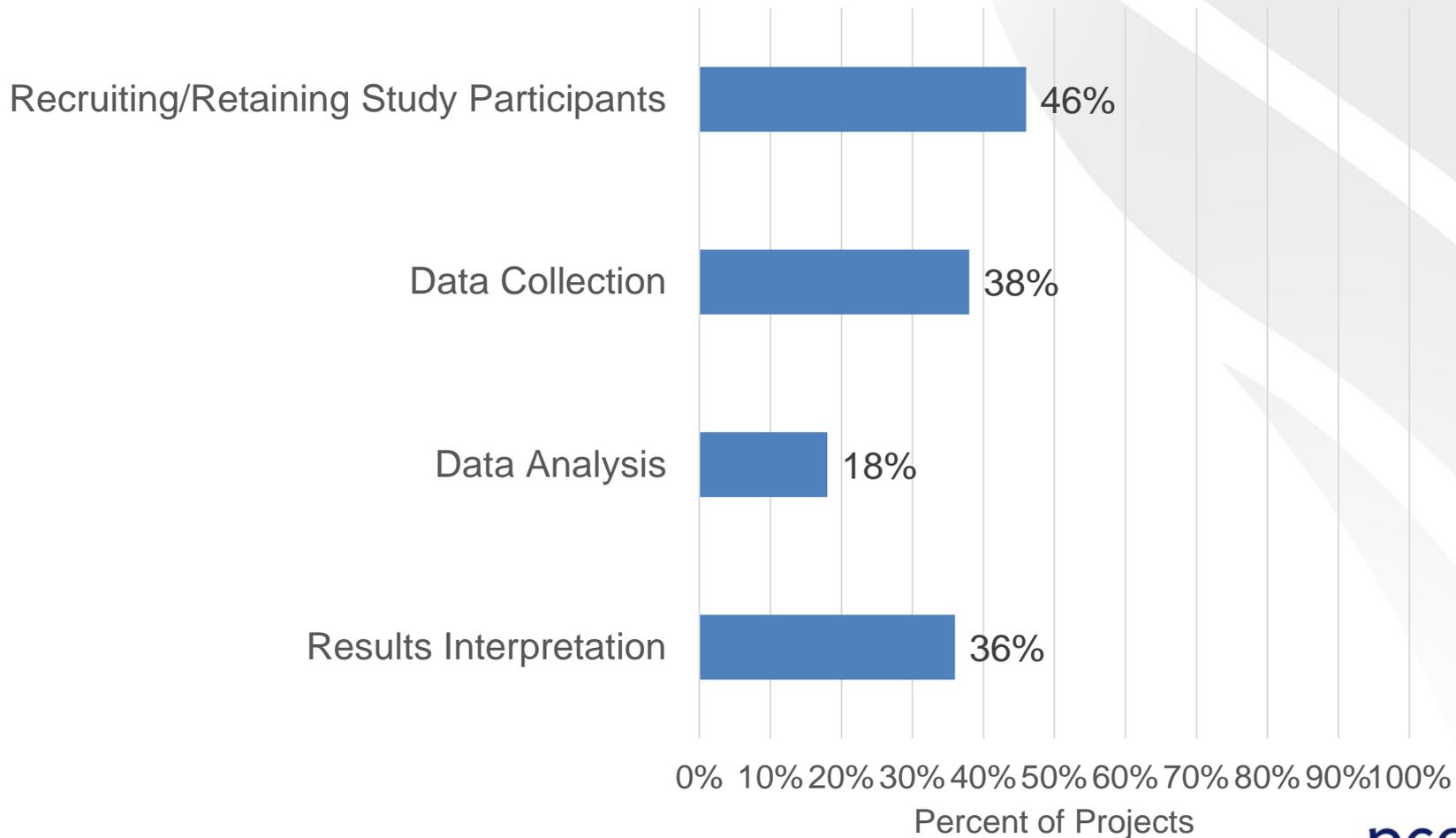
“Our community discussions... led to several modifications of our study design... This led us to include a third group in our research design: community-based group exercise. We also decided to use...[a specific] outcome measure, based upon input from... patients who told us that their biggest concern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

For Discussion

- What information is most notable or surprising?

Engagement in Conducting the Study

Researcher Report



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.”

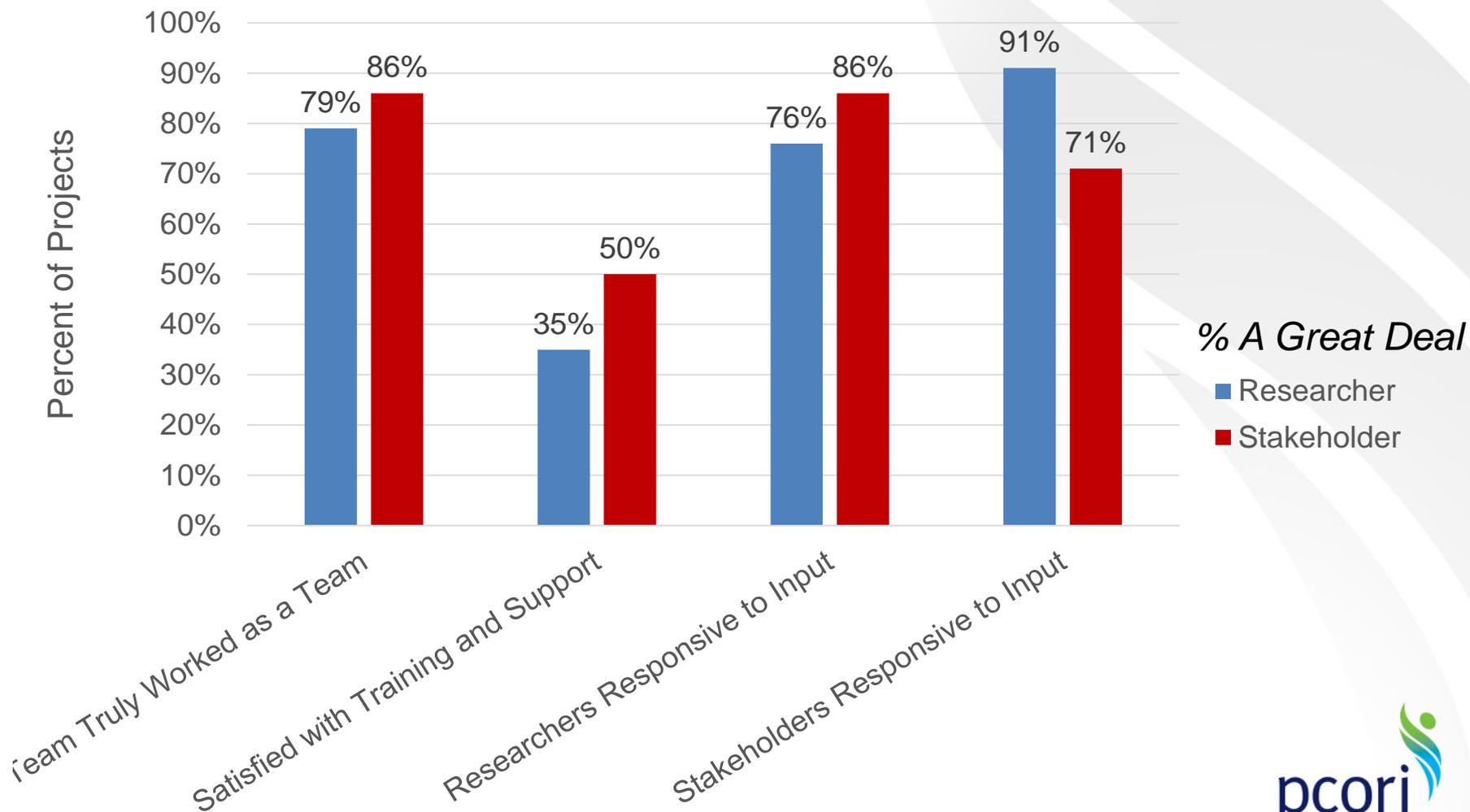
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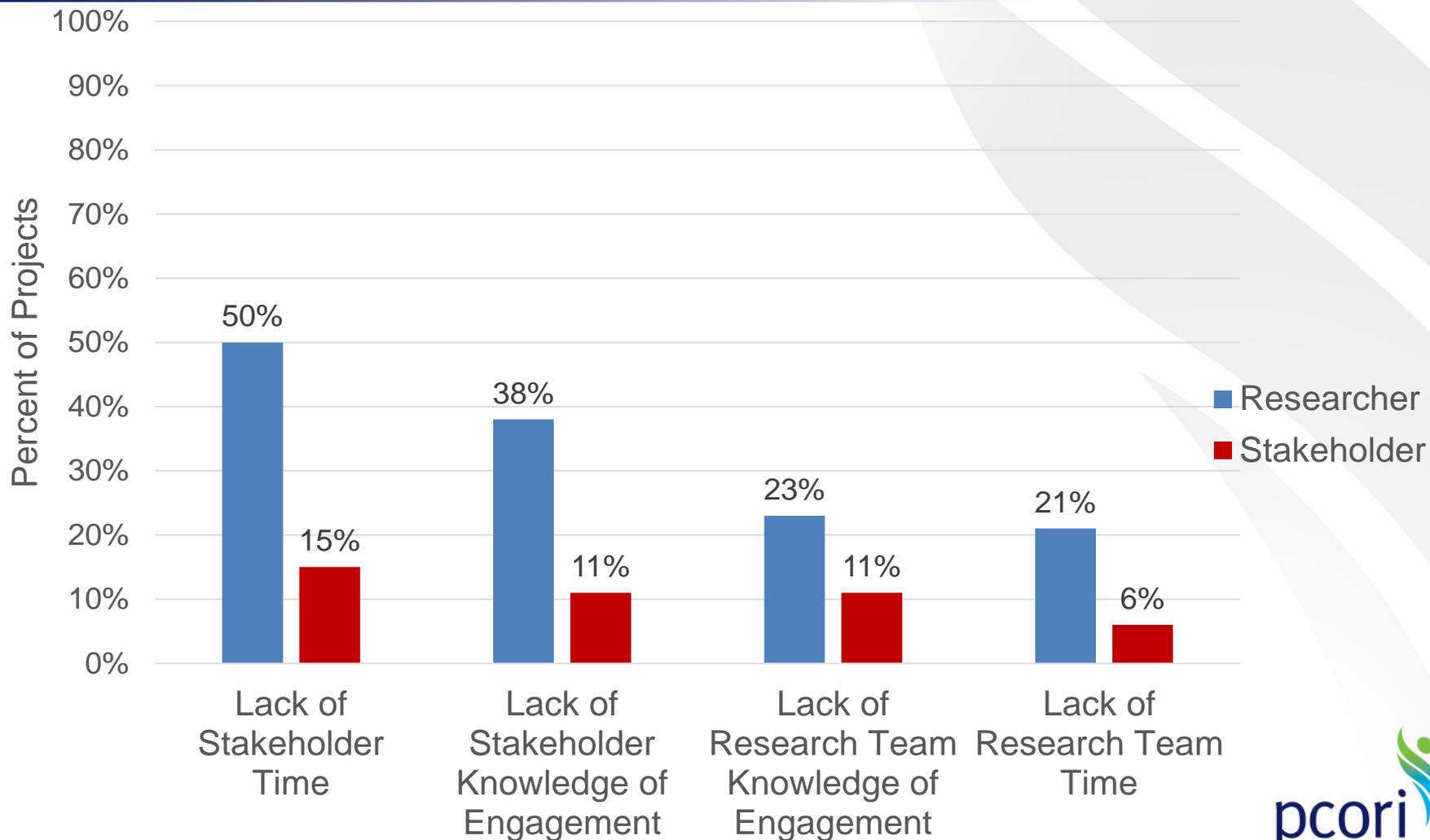
Summary

- 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



Engagement Challenges



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.”

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.”

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.”

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!



Patient-Centered Outcomes Research Institute