



## Engagement Rubric

Updated February 11, 2015

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To cite this document, please use: PCORI Engagement Rubric. PCORI (Patient-Centered Outcomes Research Institute) website. <http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf>. Published February 4, 2014. Updated January 23, 2015. Accessed [*fill in date*]”.

## Engagement Rubric

### General Guidance

- The term “patient partners” is intended to include patients (those with lived experience), family members, caregivers, and the organizations that are representative of the population of interest in a particular study.
- Stakeholder partners may include members of constituencies based on professional, rather than personal, experience. For example, these constituencies can include: clinicians, purchasers, payers, industry, hospitals and health systems, policy makers, and training institutions. Some individuals may fit into several categories.
- The Engagement Rubric is intended to provide guidance to applicants, merit reviewers, awardees, and engagement/program officers (for creating milestones and monitoring projects) regarding 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. This guidance is based on the promising practices identified in the first four rounds of PCORI awards. It is also consistent with [PCORI’s Methodology Standards](#) for patient-centeredness and Patient-Centered Outcomes Research (PCOR) Engagement Principles.
- The Engagement Rubric includes four sections: Planning the Study, Conducting the Study, Disseminating the Study Results, and PCOR Engagement Principles.
- The Engagement Rubric is designed to help applicants show their work when describing how input from patient and stakeholder partners will be incorporated throughout the entire research process.
- Include patient and stakeholder partners in all relevant sections of the application, such as the biosketches, the budget, and the dissemination and implementation assessment.
- Avoid relying entirely on patient partners who have dual roles on the project (e.g., relying on stakeholders or researchers who also happen to be patients). Including at least one patient partner who has no other role on the project is important.

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### Engagement Rubric: Guidance for Completing Each Section of the Engagement Plan

Each numbered section below corresponds to a numbered section in the Engagement Plan.

#### **1. PLANNING THE STUDY: Describe how patient and stakeholder partners will participate in study planning and design.**

##### **Potential activities include:**

- Identifying the topic and developing the research question and comparators to be studied
- Defining the characteristics of study participants
- Designing the study to minimize disruption to patients and other stakeholders participating in the research; aligning study activities to be consistent with ongoing care

##### **Examples of how to demonstrate this in your proposal:**

- Providing letters of support from patient and stakeholder partners that clearly describe the origin of the study topic and the role of the patient and stakeholder partners in defining the question, outcomes, comparators, goals and outcomes, and so on
- Describing meetings, focus groups, and other events convened to engage patient and stakeholder partners in the planning of your study, including key guidance on study design offered by your patient and stakeholder partners
- Discussing how the engagement of patients and other stakeholders helped refine your study's research question, outcomes, comparators, and study design

##### **Real-World Examples:**

- *Mental health study: Patient partners and community members helped craft the study name and materials to reduce the potential for stigma and to reframe the goal of the study as a movement toward emotional well-being rather than away from a mental health challenge.*
- *Diabetes study: Clinicians who reviewed the initial study design indicated that clinical practice is quite variable and suggested that a three-arm approach would be more appropriate for the study. The study design was revised accordingly.*
- *Breast cancer study: Patient partners determined that all women with breast cancer should be eligible versus only women who had completed active treatment.*
- *Chronic pain study: The initial survey tool was lengthy and to be administered over the phone. Patient partners, feeling that a lengthy phone survey would create a barrier for chronic pain patients, shortened and redesigned the tool to be self-reported and -paced, facilitating greater ease of participation.*
- *Post-discharge care study: Clinicians have been actively involved in the analysis of initial data runs and have asked key questions that have helped refine the study's analytic plan. The study is now looking more closely at variations in patterns of care and outcomes.*

**2. CONDUCTING THE STUDY: Describe how patient and stakeholder partners will participate in the study conduct.**

**Potential activities include:**

- Drafting or revising study materials and protocols
- Assisting with the recruitment of study participants
- Assisting with data collection and data analysis
- Participating in the evaluation of patient and stakeholder engagement
- Serving as a patient representative on a data safety monitoring board

**Examples of how to demonstrate this in your proposal:**

- Providing letters of support from patient and stakeholder partners that clearly describe the role of these partners in conducting and monitoring the study
- Clearly articulating in the application the roles of the patient and stakeholder partners in each component of study conduct (e.g., helping draft survey tools and focus group questions, reviewing participant materials for readability), including the dissemination and implementation assessment
- Including a plan for “check-ins” with patient and stakeholder partners to monitor their perceptions of the extent to which (a) they are meaningfully involved in the study and (b) their participation contributes to the study; planning similar check-ins with other research team members to monitor and evaluate engagement in the project

**Real-World Examples:**

- *Chronic pain study: The informed consent document was developed with patient partners to make it understandable to study participants.*
- *Preeclampsia study: The study team is recruiting via a national network of local health departments and community health centers, as well as through a preeclampsia advocacy group’s website and Facebook page.*
- *Asthma study: Clinicians and patients both provided guidance on who should deliver the intervention, when it should be provided during the process of care, and how it should be delivered.*
- *Cardiology study: Study materials were posted on a popular patient website. Patient feedback has been welcomed from those viewing the materials online.*
- *Pediatric psychiatry study: parents of children with psychiatric diagnoses are administering a part of the intervention, as well as advising the research team.*
- *Falls prevention study: A caregiver of aging parents who have experienced falls is serving as a patient/caregiver representative on the project’s data safety monitoring board.*

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### 3. **DISSEMINATING THE STUDY RESULTS:** Describe how patient and stakeholder partners will be involved in plans to disseminate study findings, and ensure that findings are communicated in understandable, usable ways.

#### Potential activities include:

- Identifying partner organizations for dissemination
- Planning dissemination efforts
- Participating in dissemination efforts, such as authoring manuscripts and presenting study findings
- Identifying opportunities to present or share information about the study, even as it is in progress

#### Examples of how to demonstrate this in your proposal:

- Clearly identifying the role of patient and stakeholder partners in planning the dissemination of the study's findings
- Including patient and stakeholder partners on a project committee that will oversee dissemination
- Including patient and stakeholder partners in dissemination and implementation assessment

#### Real-World Examples:

- *Trauma study: The research team is convening a policy summit with relevant professional societies during the third year of the study to focus on identifying ways to speed the implementation of findings into practice.*
- *Neurology study: The research team presented at a neurology patient advocacy conference to inform the community that this research was ongoing and to stay tuned for future results.*
- *Cardiac study: A patient dissemination board is helping craft the dissemination plan and advise the research team on how to best share study findings.*
- *Chronic pain study: Patient partners are co-authoring manuscripts, presenting at scientific and lay conferences, and sharing study findings through their networks.*

### 4. **PCOR ENGAGEMENT PRINCIPLES:**

**Reciprocal Relationships:** Describe the roles and decision-making authority of all research partners, including patient and stakeholder partners.

#### Examples of how to demonstrate this in your proposal:

- Explaining how decisions are made within your research team, including the decision-making authority that patient and stakeholder partners have and in what circumstances
- Including patient and stakeholder partners as key personnel, with biosketches illustrating how the skills and experiences of the patient partners prepare them to function effectively in this role

**Co-learning:** Describe plans to ensure that patient and stakeholder partners will understand the research process and that researchers will understand patient and stakeholder engagement and patient-centeredness.

#### Examples of how to demonstrate this in your proposal:

- Providing training and educational opportunities, such as patient and stakeholder partner training in human subjects protection

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- Incorporating training that is provided by patient advocacy organizations, patients/survivors, and clinicians/caregivers for the researchers providing the intervention (e.g., training in better communication with patients, led by patient instructors)

**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.*

**Examples of how to demonstrate this in your proposal:**

- Including compensation for patient partners in the budget at an appropriate level
- Holding meetings at a time and in a location that accommodates patient and stakeholder partners.
- Providing compensation for transportation and related expenses
- Making accommodations to encourage the full engagement of a range of patient and stakeholder partners, and to ensure that the research team includes a diversity of members (e.g., a project that focuses on Latino health should consider including Spanish-speaking individuals on the research team and may wish to conduct patient and stakeholder meetings in both Spanish and English)

**Trust, Transparency, Honesty:** *Describe how major decisions are made inclusively and information is shared readily with all research partners, including patient and stakeholder partners; how patient and stakeholder partners and research partners express commitment to open and honest communication with one another; and how the study team commits to communicate study findings to the community studied, in a meaningful and usable way.*

**Examples of how to demonstrate this in your proposal:**

- Describing how the research team—including patient and stakeholder partners—will communicate with each other, the frequency of this communication, the roles of each member of the research team, and the decision-making authority of each member of the research team