This inventory includes a pool of items to describe engagement from the patient and stakeholder point of view. PCORI administers this tool at multiple time points in the project (baseline and once a year) by specifying time references in each item by specifying time references in each item (e.g., “in the first year” or “since the project began”). The instrument is administered electronically with appropriate skip patterns so that respondents only receive a subset of the questions.

**Ways of Engaging- Engagement Activity Tool (WE-ENACT)**

PCORI research helps patients and health care 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.

We want to learn about patient and stakeholder research engagement in this PCORI research 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 who to study;
- Choosing study outcomes;
- Tracking study progress; or
- Sharing study findings.

1. Have you engaged in this PCORI research project in ways other than as a research subject?
   - ☐ Yes
   - ☐ No → go to Q27

2. Think about your role on this PCORI research project <insert time>. In which ways have you been engaged in the research? *Mark all that apply.*
   - ☐ Co-Investigator(s): People involved in creating and running the project.
   - ☐ Research team member(s): People on the research team who are advisors or experts. This also includes people listed as research staff but not Co-Investigators.
   - ☐ Advisory group(s): People who are on an advisory panel, community advisory board, steering committee, executive committee, or other type of advisory group for this project.
   - ☐ Group Forum(s): People who are in focus groups, deliberative engagement forums, Delphi panels, community forums, town hall meetings, public workshops, or other type of group forum for this project.
   - ☐ Survey(s), questionnaire(s), or opinion poll(s): People asked to answer a set of questions used to provide input on the research process.
   - ☐ Other: please describe ____________________

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014
3. Please pick the community that best reflects your role for this research project.

☐ Patient/consumer
☐ Caregiver/family member of patient
☐ Advocacy Organization (e.g., patient/consumer or caregiver advocacy organization)
☐ Clinician
☐ Clinic/Hospital/Health System Representative
☐ Purchaser (small or large employers)
☐ Payer (public or private insurance)
☐ Life Sciences Industry
☐ Policy Maker (government official)
☐ Training Institution (non-research health professions educator)
☐ Other – please describe ________________________________

4. [Answer only if Q3= caregiver, otherwise skip to question 5] For whom are you a caregiver? Pick the one that best reflects your role for this research project.

☐ Your child (under age 21)
☐ Your child (age 21 years or older)
☐ Your Parent
☐ Your Grandparent
☐ Your spouse or significant other
☐ Your friend
☐ Other – please describe ________________________________

5. Please share how you became involved in this research project.

6. Had you worked with any of these researchers before this research project?

☐ Yes
☐ No → go to question 8

7. How long have you worked with these researchers?
   ____Years   ____ Months

8. What was the main reason you wanted to engage in this research project? In your answer, please tell us about how you expected to impact the research project.

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014
Engagement: When and what

Instructions: Now we are interested in learning more about when and how you engaged in this PCORI research project.

9. How often have you met with the researchers to work on this research project? This includes meeting in person, by phone, or online.
   □ Never
   □ Once
   □ 2 to 5 times
   □ 6 to 12 times
   □ 13 to 24 times
   □ 25 or more times

10. In which parts of the research project have you been engaged? Select all that apply.
    □ Identifying research topics
    □ Developing the research question
    □ Proposal development
    □ Developing the budget
    □ Adding more people to the research team
    □ Study design
    □ Recruiting or retaining study participants
    □ Data collection
    □ Data analysis
    □ Results review interpretation, or translation
    □ Sharing study findings
    □ Other – please describe

11. [For each part of the research project selected in Q10] For each part of the research project below, we want to learn about:
    • How you were engaged. What did you do?
    • What was changed or different because you were engaged in the research?

    You can fill in as much or as little of this table as you like.

(Question continued on next page)

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014
<table>
<thead>
<tr>
<th>How you were engaged</th>
<th>The impact you had</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Example: Developing the research question  I explained to others on the research</td>
<td>The research questions were changed to include the questions important to patients</td>
</tr>
<tr>
<td>team what research questions matter most to patients</td>
<td></td>
</tr>
<tr>
<td>• Example: Proposal development</td>
<td>I reviewed the research proposal</td>
</tr>
<tr>
<td>• Identifying research topics</td>
<td></td>
</tr>
<tr>
<td>• Developing the research question</td>
<td></td>
</tr>
<tr>
<td>• Proposal Development</td>
<td></td>
</tr>
<tr>
<td>• Developing the budget</td>
<td></td>
</tr>
<tr>
<td>• Adding more people to the research team</td>
<td></td>
</tr>
<tr>
<td>• Study design</td>
<td></td>
</tr>
<tr>
<td>• Recruiting or retaining study participants</td>
<td></td>
</tr>
<tr>
<td>• Data collection</td>
<td></td>
</tr>
<tr>
<td>• Data analysis</td>
<td></td>
</tr>
<tr>
<td>• Results review, interpretation, or translation</td>
<td></td>
</tr>
<tr>
<td>• Dissemination/sharing study findings</td>
<td></td>
</tr>
<tr>
<td>• Other (as described)</td>
<td></td>
</tr>
</tbody>
</table>

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.
Contributions and initial learnings

Instructions: Now we want to know more about how you may have influenced the research project. We also want to know what you have learned about engagement.

12. **[For approaches to engagement selected in Q2, except Q2 = Surveys]** We want to learn about how you have influenced the research project. Rate the amount of influence you had on each of the parts of the project listed below.

<table>
<thead>
<tr>
<th>Amount of Influence</th>
<th>None</th>
<th>A Small Amount</th>
<th>A Moderate Amount</th>
<th>A Great Deal</th>
<th>I don’t know whether I influenced this part</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Identifying research topics</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b. Developing the research question</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. Proposal development</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d. Developing the budget</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e. Networking and expanding the research team</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f. Study design</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>g. Recruiting or retaining study participants</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>h. Data collection</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>i. Data analysis</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>j. Results review, interpretation, or translation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>k. Dissemination/sharing study findings</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>l. &lt;Other, as described in Q10&gt;</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>m. The way the research team and stakeholder partners work together</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014
[These questions are optional. Please think about your experiences with this project.]

13. Please share anything about engaging with researchers on this project that could be improved.

14. We would like to learn from your experience. Please share anything you learned about how to engage with researchers on research projects.

15. Are there other effects your work on this project had on you? This might include your relationships with the researchers or your work outside of this project. If so, please share.

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014
Principles of PCOR

Instructions: Now we are interested in learning more about the way researchers, patients, and/or other stakeholders have worked together on this research project.

16. Please rate the following, thinking about your experiences with the project:

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The project goals were clearly explained to me.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b. The researchers knew the role of the stakeholders on the team and supported the research partners.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. Stakeholders on the team were given the chance to share their views.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d. Different viewpoints were accepted.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e. The researchers responded to input from stakeholders.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f. Patients and stakeholders responded to input from researchers.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>g. The researchers clearly explained how input from patients and stakeholders was used.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>h. The researchers, patients, and stakeholders on the team truly worked together.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>i. The research project is designed to address the needs of patients.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>j. I understood my role in the research process.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>k. I am satisfied with the decision making process.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>l. I received training and support to engage with researchers in the research project.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

17. [Optional]: Please provide any additional thoughts about the principles of PCOR assessed above.

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014
Facilitators and challenges

Instructions: Now we want to learn about things that may have helped you engage in this research project. We also want to learn about things that may have gotten in the way or interfered.

18. Have you faced any of these challenges?
   - The researchers didn’t have enough knowledge about engaging with patients and stakeholders as partners
   - The stakeholders didn’t have enough knowledge about engaging in research as partners
   - The researchers didn’t have enough time for engagement with patients and stakeholders
   - The stakeholders didn’t have enough time for engagement with the project
   - There was a lack of resources for engagement (e.g., funds, meeting space, transportation or parking)
   - The researchers didn’t value patient input
   - I wasn’t appropriately compensated for my time

☐ Yes ☐ No ➔ go to Q22

19. How much did these challenges get in the way of or interfere with engaging with researchers in this project?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Somewhat</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The researchers didn’t have enough knowledge about engaging with patients and stakeholders as partners</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b. The stakeholders didn’t have enough knowledge about engaging in research as partners</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. The researchers didn’t have enough time for engagement with patients and stakeholders</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d. The stakeholders didn’t have enough time for engagement with the project</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e. There was a lack of resources for engagement (e.g., funds, meeting space, transportation or parking)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f. The researchers didn’t value patient input</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>g. I wasn’t appropriately compensated for my time</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

20. [Optional] Please share how you solved these challenges.

21. [Optional] Please share any other challenges you have faced that have not already been captured. How and to what extent have you been able to resolve these challenges?

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014
22. [Optional] Please share anything that helped you engage in this research. For example, this may include training, or different types of support.

23. [Answer only if Q3 = caregiver and Q4 = child (under age 21). Otherwise, skip to Q26] You said that your role for this research project is as a caregiver for your child (under age 21). Has your child (under age 21) engaged in this PCORI research project in ways other than as a research subject? For example, has he or she been involved in things like:
   • Choosing the study questions;
   • Deciding on aspects of the research like who to study;
   • Choosing study outcomes;
   • Tracking study progress; or
   • Sharing study findings?
      ☐ Yes
      ☐ No → go to question 27

24. Were there benefits from engaging children or teens in this project? If so, please share.

25. Please describe any challenges specific to having children or teens engaged in this project.

26. (Baseline only) Have you engaged in research prior to working on this PCORI project, in a way other than as a research subject?
      ☐ Yes
      ☐ No

27. [Optional] Your views are very valuable to us. We welcome any additional input. Please share any additional thoughts or stories about patient and other stakeholder engagement in this PCORI research project.

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014
Demographic Questions

Instructions: Now we have a few questions about you. This information helps us understand who has responded to the survey. These questions are optional.

28. [Optional] Please select your gender
   - Yes
   - No
   - Other

29. [Optional] What is the highest level of formal education you completed?
   - Less than high school
   - High school graduate or GED
   - Post high school training other than college (vocational or technical)
   - Some college
   - College graduate
   - Postgraduate

30. [Optional] Do you consider yourself to be Hispanic or Latino?
   - Yes
   - No

31. [Optional] Which best describes your race?
   - American Indian/Alaska Native
   - Asian
   - Native Hawaiian or other Pacific Islander
   - Black or African American
   - White
   - Other

32. What is your age?
   - 21 and under
   - 22 to 34
   - 35 to 44
   - 45 to 54
   - 55 to 64
   - 65 and older

For information about the WE-ENACT or to inquire about its use please contact surveys@pcori.org.

12.18.2014