

Worksheet 2. Making Research Patient-Centered

This worksheet comprises three steps:

Step 1: Establish a partnership with patients

Step 2: Work with patients on topic identification and question refinement

Step 3: Describe how the research qualifies as patient-centered

Step 1: Establish a partnership with patients

PCORI defines a patient as a (1) person who has lived with and/experienced an illness or injury, (2) a caregiver or family member of such a person, or (3) a member of a relevant advocacy organization.

To complete this section, answer the following questions:

1. Describe the patient population with whom you have an existing relationship. Include descriptions of all three types of patients in PCORI's definition.
2. How long have you been working with this patient population?
3. In what capacity have you been working with the patient population? Several options to answer this question may include:
 - I am a patient, family member or an advocate [Note: All stakeholders, including researchers, can play multiple roles in PCOR research. PCORI recognizes and allows researchers to self identify as patients. However, it is always recommended to identify some patients in your partnership that do not also represent other stakeholder communities.]
 - I am a researcher who partners with patients, family member or advocates
 - I am a research navigator who bridges patients and researchers
4. Describe recent forums, activities and dates of importance in your partnership.

Step 2: Work with patients on topic identification and question refinement

To complete this section, answer the following questions:

1. What activities did you undertake jointly with patients to identify a research topic? These activities may include both a topic nomination and a prioritization process.
2. What criteria did your partnership use to establish topic priorities? Your response may include the following or other options:
 - Appropriateness
 - Magnitude
 - Severity
 - Feasibility of Correcting
 - Replication
 - Duplication
 - Others
3. What procedures did you use to identify and refine research questions related to each priority topic?

Step 3: Describe how the research qualifies as patient-centered

1. How is the study population and setting representative of the patients and communities affected by the condition of study?
2. How is the research focused on outcomes of interest to patients and their caregivers?

PCORI defines involvement of patients and other stakeholder at three levels of “intensity: (1) as partners (co-investigators); (2) as participants (staff, consultants); (3) as advisors (expert and advisory panels).

3. At what level of “intensity” will patients be involved in planning and conducting the research? At what level will patients be involved in translating and implementing research findings?
 - a. Planning the research (defining the research question, choosing the approach, etc.)
 - b. Carrying out the research (data acquisition, interpretation, etc)
 - c. Translating the findings
 - d. Implementing the findings