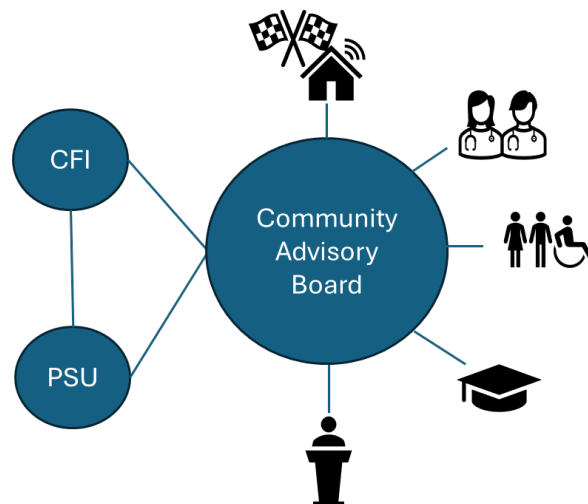


Patient-Centered Comparative Effectiveness Research (CER) Training Workbook

Helping Nursing Home Community Partners Initiate and Maintain Engagement in Patient-Centered CER



This training support material was funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (EACB-34735). The statements presented in this workbook are solely the responsibility of the author(s) and do not necessarily represent the views of PCORI®

Introduction Module: Engaging in Stakeholder-Driven Research: Research Fundamentals Learning Package Video Module

A video-based module that features patients, clinicians, and members of the PCORI healthcare community describing engagement in stakeholder-driven research.

What **type of stakeholder can you be** in a Patient-Centered Project within the Nursing Home Stakeholder Community (select all that apply)?

- Patient
- Patient Partner (e.g. Family Member)
- Patient Advocate (e.g. Ombudsman)
- Clinician/Formal Caregiver (e.g. Physician, Nurse, Nurse Assistant etc.)
- Investigator/Researcher
- Other (describe)_____

At **what capacity do you feel you can currently engage** as a stakeholder in a Patient-Centered Project?

- Inform** – researchers share information with the community I can inform others of the project (e.g. communicating project plans to the NH stakeholder community).
- Consult**- I can consult on project decisions when researchers seek feedback from the community on aspects of the research (e.g. offering opinions, advice, feedback on a project).
- Participate**– I can directly collaborate with other stakeholders on key phases of the research project (e.g. recruitment, data collection etc.)
- Collaborate**- I can bring gaps/problems within the NH stakeholder community to a research network to address together.
- Lead** – With shared leadership, I can encourage independent initiatives within a research network that's lead to patient/caregiver/organizational generated research projects in my community.

Notes.

What **do you need to increase your capacity** to engage in Patient-Centered Projects? (Think skills, resources, organizational structures etc.)?

1. Identifying Barriers

Instructions: List potential **barriers** for **your stakeholder engagement** in patient-centered research projects. Consider factors such as communication, trust, and resource availability.

Barrier	Description	Impact on Research
Example: Lack of trust	Stakeholders may not trust researchers due to past experiences.	Reduced participation and engagement.

2. Identifying Facilitators

Instructions: List potential **facilitators** that can enhance **your stakeholder engagement**. Think about strategies, tools, and practices that can foster positive relationships.

Facilitator	Description	Impact on Research
Example: Regular communication	Keeping stakeholders informed through regular updates.	Increased trust and collaboration.

Facilitator	Description	Impact on Research

3. Identifying Resources

Instructions: Identify **resources** needed for **your effective stakeholder engagement**.

Consider both tangible and intangible resources such as:

- Human resources?
- Financial resources?
- Physical resources (equipment/facilities)?
- Policies and procedures?
- Information (knowledge, software, communication systems, data)?

Resource	Description	How to Access
Example: Funding for community meetings	Financial support to organize and host meetings with stakeholders.	Apply for grants or seek institutional support.

Reflection

Instructions: Reflect on your learning from this module and how you can apply it to your current engagement capacity. Write down your thoughts and any insights gained.

Module 1. Developing Research Questions

This module explains how studies are created through research questions, and the kinds of questions that patient-centered outcomes research tries to answer. It describes initial decisions that must be made when creating a study and provides a simple formula to remember each element.

How likely are you to **engage as a stakeholder** in *Patient-Centered Outcomes Research* within the nursing home setting?

- Extremely Unlikely
- Unlikely
- Neutral
- Likely
- Extremely Likely

How likely are you to participate in **the development of research questions** for *Patient-Centered Outcomes Research* within the nursing home setting?

- Extremely Unlikely
- Unlikely
- Neutral
- Likely
- Extremely Likely

Notes.

What **do you need to increase your capacity** to engage as a stakeholder in the development of a research question for *Patient-Centered Outcomes Research* within the nursing home setting/context?

1. Identifying Barriers

Instructions: List potential **barriers** for your stakeholder **engagement in the development of research questions for Patient-Centered Outcomes Research**. Consider factors such as communication, trust, and resource availability.

Barrier	Description	Impact on Research
Example: Lack of trust	Stakeholders may not trust researchers due to past experiences.	Reduced participation and engagement.

2. Identifying Facilitators

Instructions: List potential **facilitators** that can enhance your **stakeholder engagement in the development of research questions for Patient-Centered Outcomes**. Think about strategies, tools, and practices that can foster positive relationships.

Facilitator	Description	Impact on Research
Example: Regular communication	Keeping stakeholders informed through regular updates.	Increased trust and collaboration.

Facilitator	Description	Impact on Research

3. Identifying Resources

Instructions: Identify **resources** needed for effective stakeholder engagement in **the development of research questions** for *Patient-Centered Outcomes Research*.

Consider both tangible and intangible resources such as:

- Human resources?
- Financial resources?
- Physical resources (equipment/facilities)?
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Module 2. Designing the Research Study

This module introduces several common ways a team can design a study to compare two or more treatment options. It also explains how each design determines what information to gather, how to gather it, who to gather it from, and how that information is used to answer the research question.

How likely are you to participate in **the designing of a research study** for *Patient-Centered Outcomes Research* within the nursing home setting?

- Extremely Unlikely
- Unlikely
- Neutral
- Likely
- Extremely Likely

Notes.

What **do you need to increase your capacity** to engage as a stakeholder in the **designing of a research study** for *Patient-Centered Outcomes Research* within the nursing home setting/context?

1. Identifying Barriers

Instructions: List potential **barriers** for your stakeholder **engagement in designing Patient-Centered Outcomes Research studies**. Consider factors such as communication, trust, and resource availability.

Barrier	Description	Impact on Research
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Instructions: List potential **facilitators** that can enhance your **stakeholder engagement in designing Patient-Centered Outcomes Research studies**. Think about strategies, tools, and practices that can foster positive relationships.

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Resource	Description	How to Access
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Module 3. Planning Patient-Centered Consent and Study Protocols

This module focuses on an important aspect of collecting information from people in a research study: consent. It discusses informed consent and how research teams obtain it from people recruited for a study.

How likely are you to participate in **planning consent and study protocols** for *Patient-Centered Outcomes Research* within the nursing home setting?

- Extremely Unlikely
- Unlikely
- Neutral
- Likely
- Extremely Likely

Notes.

What **do you need to increase your capacity** to engage as a stakeholder in the **planning of consent and study protocols** for *Patient-Centered Outcomes Research* within the nursing home setting/context?

1. Identifying Barriers

Instructions: List potential **barriers** for your stakeholder **engagement in planning consent and protocols** for *Patient-Centered Outcomes Research*. Consider factors such as communication, trust, and resource availability.

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Example: Lack of trust	Stakeholders may not trust researchers due to past experiences.	Reduced participation and engagement.

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Instructions: List potential **facilitators** that can enhance your stakeholder **engagement in planning consent and protocols** for *Patient-Centered Outcomes Research*. Think about strategies, tools, and practices that can foster positive relationships.

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Resource	Description	How to Access
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Module 4. Sampling, Recruiting, and Retaining Study Participants

This module explains how a research team decides the number of study participants. It also explains how a team chooses sample characteristics such as age, gender, or type of condition the people in the study should have or not have so that the findings are as useful as possible to all patients.

How likely are you to participate in **sampling, recruiting, and retaining study participants** for *Patient-Centered Outcomes Research* within the nursing home setting?

- Extremely Unlikely
- Unlikely
- Neutral
- Likely
- Extremely Likely

Notes.

What **do you need to increase your capacity** to engage as a stakeholder in the **sampling, recruiting, and retaining study participants** for *Patient-Centered Outcomes Research* within the nursing home setting/context?

1. Identifying Barriers

Instructions: List potential **barriers** for your stakeholder **engagement in sampling, recruiting, and retaining study participants** for *Patient-Centered Outcomes Research*. Consider factors such as communication, trust, and resource availability.

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Module 5. Understanding and Sharing Research Findings

This module describes the ways stakeholders help the research team make sense of the collected information and determine findings. It also explores how a study's findings can be used in different settings and how findings are shared so that they can inform healthcare choices.

How likely are you to participate in **understanding and sharing findings** for *Patient-Centered Outcomes Research* within the nursing home setting?

- Extremely Unlikely
- Unlikely
- Neutral
- Likely
- Extremely Likely

Notes.

What **do you need to increase your capacity** to engage as a stakeholder in the **understanding and sharing findings** for *Patient-Centered Outcomes Research* within the nursing home setting/context?

1. Identifying Barriers

Instructions: List potential **barriers** for your stakeholder **engagement in understanding and sharing findings** for *Patient-Centered Outcomes Research*. Consider factors such as communication, trust, and resource availability.

Barrier	Description	Impact on Research
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Reflection

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