



Training Module 1: Patient Centeredness and Working Together as a Care Team

Participants: Researchers and Patient and Family Caregivers (PFC)

Format: Small/Large Group Discussion and Mini Lecture

Objectives:

1. Describe what patient-centered means.
2. Explain what patient-centered outcomes research is.
3. Demonstrate how the partnerships PCOR establishes differ from other types of research.

Length: 1 hour, 45 minutes

- I. Icebreaker (10 minutes)
- II. Small Group Discussion (40 minutes)

Assign researchers and patient and family caregivers (PFC) to small groups in pairs. Small groups should have four to six people in each. A researcher should take the role of scribe and a PFC should be prepared to report out. The groups will listen to and read the following scenarios and then answer the discussion questions provided.

- III. Large Group Discussion (40 minutes)

Bring the small groups back together. Ask a PFC from each small group to report their answers back to the larger group. Write these on white board or large notepad. Wrap up most salient points from the discussion.

- IV. Mini Lecture (15 minutes)
Patient-Centered Outcomes Research and Unite for Better Health Outcomes Primer



Scenario 1.

A breast cancer survivor with lymphedema throughout her right arm:

I remember a visit when a nurse insisted that he was going to start my IV on my right arm because he said, “You have your best veins over here. And I got to use this.” I said, “no you cannot use this.” He starts tapping my arm. I said, “get someone in here.” I reached to get the alarm for the nurse and said to him, “would you please tell her (the nurse).” He was determined that he was going to get that IV started from my right hand.

What could the patient have done differently to ensure a better experience?

What could the provider have done differently?

Discuss how you would recommend that the patient and provider work together as a team.



Scenario 2.

Family Caregiver of a cancer patient with a collapsed lung:

I remember they were doing a scan and the doctors outside were looking at the scan and I heard one doctor say, “Yeah, we punctured one of her lungs”. When they came back in- you know this is my sister and I am in medical school. I am very aware of what is going on. I have a question, “Did you all puncture my sister’s lung?” Because they kept talking around the subject. “Oh the scan was fine. She looks good”. But I heard their conversation. I felt like I did need to ask them. And they were like, “Yea they did a little bit but we are going to get her through breathing treatments”. I feel like if I didn’t ask, were you all going to tell us that? That was one of the things about communication.

How should healthcare professionals communicate difficult or unfavorable information to patients and their caregivers?

Explain how you would have handled this situation.



Scenario 3.

Prescription sent to pharmacy without the patient knowing why:

They didn't tell me but I showed up to the pharmacy and I have a prescription for 50 thousand milligrams of vitamin D. Plus, I already take vitamin D. Thousand milligrams of vitamin D or something. So I said to him, "why?". Everybody I know, no matter their color, no matter if they stayed in the sun, or under the sunroof- everybody got a 50 thousand milligrams prescription of vitamin D. I said, "what is this." Is this some kind of under-cover experiment like those people down there in Alabama a million years ago? The pharmacist said, "No". I didn't get it. Maybe I should have. I'm not taking 50 thousand nothing! Without somebody explaining in great detail why.

In what ways do you think providers and patients should communicate regarding information during and after visits?

What could the patient, the pharmacist, and the doctor have done differently to ensure quality in health care?