TOPIC 1
WHAT IS RESEARCH?
PATIENT CENTERED OUTCOME RESEARCH?

What are key PCOR concepts relevant for CHWs
Patient Centered Outcomes Research

Course Objective:

- Demonstrate understanding of basic research and standards associated with patient centered outcomes research
To start the conversation:

- Are you a patient or a caregiver?
- Have you been approached to participate in a health research study?
  - If so, did you say yes? What type of research/study was it?
- Have you assisted/recruited for a research study?
- Do you recall knowing the results of a research study?
Concept:

- "A general idea referring to a behavior or characteristic of an individual, group, or nation".
  - Pain
  - Patient care
  - Coping
  - Safety
  - Data
  - Dignity
Define these concepts in your workbook/discussing in pairs:

- What is research/research studies?
- What are health and social service programs?
- What is research involving human subjects?
Definitions

**Research** is an organized, planned process of collecting and analyzing information (data) to obtain more knowledge, increase our understanding or to answer a specific question about a certain topic.

- A "researcher" or "investigator" is the person who conducts research to gain new knowledge. Participation is **voluntary**.

- Health and healthcare research focuses on **outcomes** or results. Outcomes research tries to understand what happened as a result of using some type of **action** (also called an intervention) to improve health. It is **not known if the treatment/intervention will work** or be of **direct** benefit to participants, but rather is intended to benefit other patients, the community or the society in the future.
Health and Human Services

- Direct activities, goods, screenings, samples provided to recipients who are eligible/qualify.
- Are community or individual benefits which we know they work; have either been test/evaluated in the past or have worked elsewhere.
  - Please write examples in your workbook.
Service Programs vs Research Studies

- Are they the same thing?
  - True
  - False
  - Don’t know

- Explain your answer!
Basic Steps of a Research Study (Design)

- Find a topic to study → What, When
- Create questions → What, Why
- Define a group/population → Who, When
- Select design & measurement → How
- Collect evidence/data → How
- Interpret evidence/data → Why
- Dissemination → Tell about what you did and found out!
When research calls for **getting personal information from, or about people**, then the researcher is doing research involving human subjects. Research can involve such things as asking simple questions about the foods people like, or it can involve looking at the good and bad effects of one or many drugs for treating a disease.

- Studies can also get information about people without directly speaking to them, or asking them to do things.
- A study may take personal **information from medical or school records** in order to answer a research question.
PCORI is an independent nonprofit, nongovernmental organization authorized by Congress in 2010 located in Washington, DC.

Committed to continuously seeking input from patients and a broad variety of stakeholders to guide the research that PCORI funds. This patient-centered outcomes research (PCOR) focuses on answering patients and caregivers’ questions about the results and issues that are of greatest interest and concern to them. PCOR is based on the belief that patients have unique perspectives that can change and improve healthcare.

PCOR requires that patients and other stakeholders participate at every stage of the research, from the selection of the questions to be studied to the sharing of the results.
Patient Centered Outcomes Research (PCOR)

- Compared to traditional research, PCOR often involves patients, caregivers, and other non-researcher stakeholders in unique ways.

- In PCOR, patients and other stakeholders often act as human subjects or research participants. They may also serve as advisors to study teams, members of study teams, or investigators.
Patients, caregivers, and clinicians need to be equipped with the best available information for making informed decisions. They are research partners.

Please write on page 7 of your workbook the roles each one play or activities they do.
Researchers look for funding. They define the possible explanation of why and the way the study will be conducted.

Patients define what is important to answer and how that answer will impact them. They provide input on ways to get the info.

Stakeholders define how the questions and the results will play out in real world and in existing settings. They inform the process.
<table>
<thead>
<tr>
<th>Relevant to me?</th>
<th>With me?</th>
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<tbody>
<tr>
<td>Patient-Centeredness:</td>
<td>Patient and Stakeholder Engagement:</td>
</tr>
<tr>
<td>Does the project aim to answer questions or examine outcomes that matter to patients/caregivers?</td>
<td>Are patients/caregivers and other stakeholders involved as partners in research, as opposed to being merely study participants?</td>
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PCOR Engagement Principles

USE PCOR ENGAGEMENT PRINCIPLES

- Stakeholder involvement at all stages of PCOR ensures that the work responds to relevant and important issues, that it develops products that are accessible and user-friendly, and that ultimately research reaches its intended audiences.

- To promote the capacity for CHW engagement in PCOR by developing and implementing a structured research training program for CHWs.
CHWs: Partners/Stakeholders in PCOR

Patient or caregiver themselves act as advocates of their community.

Being a CHW, you can assist in **very unique ways**:  
- To inform the questions to ask, the ways to gather that information/data  
- To identify people that might be interested  
- To recruit subjects/participants  
- To inform them about benefits and risks of participating in the research study  
- To collect and inform how to interpret data  
- To help tell the story and to whom
Andrea Jenson, PCORI Patient Partner

https://www.youtube.com/watch?v=pNmw255muzk
What are the Eugene Washington PCORI Engagement Awards?
Lia Hotchkiss, who directs the award program, explains. 1:16 mins

https://vimeo.com/158661405
Patients with rare diseases can become empowered through involvement in patient-centered research, says University of Maryland researcher Eleanor Perfetto, PhD. 1:22 mins

https://vimeo.com/156000384
Takeaway Points
In summary: PCOR

- Defined research, research with human subjects as participants and patients
- Explained the reasons why PCOR gets patients involved in the “how to” of the process
- Discussed standards of PCOR
- Identified CHWs as a PCOR Stakeholder
Questions?

Next topics:

- What does it mean to conduct research in an ethical way, protecting the rights of research participants?
- How to ensure all research participants have equal chances, without bias?
- What are the different ways to collect research data; how can CHWs collect data for research studies?
- What is the process of informing the participants about their rights and risks associated with a study?
- How does one track data and report data collected?
- How to report study results and to whom?