

# Patient-centered research and patient-reported outcome measures

Jacob Kean, Ph.D.

Association Professor, University of Utah

Population Health Sciences



# The research conversation is changing

We are moving away from researchers asking only the questions that interest them and toward asking questions that are important to patients and caregivers, as well.

Examples of patient-centered research questions include<sup>1</sup>:

1. “Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”
2. “What are my options and what are the potential benefits and harms of those options?”
3. “What can I do to improve the outcomes that are most important to me?”
4. “How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare?”



<https://tinyurl.com/researchcp-pc>

<sup>1</sup> <http://www.pcori.org/assets/PCOR-Definition-Revised-Draft-and-Responses-to-Input.pdf>

# The answers that matter are changing, too

We are also moving past the idea that clinical measures, such as blood tests, are the most important research outcomes.

Today, patient-reported outcomes (PROs) are important tools used to assess research outcomes, and in addition, are used to determine the effectiveness of new medications and the quality of hospital care.

Patient-reported outcomes:

- Assess the patient's experience without any interpretation by clinicians
- Express how patients view health and wellbeing and provide an assessment of health from a patient's perspective
- Are commonly measures of symptoms (e.g., pain, depression), functioning (e.g., physical functioning), quality of life (e.g., ability to participate in activities), and satisfaction.



<https://tinyurl.com/researchcp-pro>

Webinar #4: Patient-Centered Research and Patient Reported Outcomes

# What conducting patient-centered research means for clinical researchers

- Believing that patients and caregivers “...have unique perspectives that can change and improve the pursuit of clinical questions”<sup>2</sup>
- Believing that the incorporation of the unique perspectives increases the relevance of the research questions and results
- Believing that the increased relevance is likely to improve uptake of the research findings and increase the likelihood that patients will achieve better health
- Acknowledging that engaging patients and caregivers to produce more relevant results takes more time and resources than have been need for clinical research in the past



<sup>2</sup> Frank L, Basch E, Selby JV, For the Patient-Centered Outcomes Research Institute. The PCORI Perspective on Patient-Centered Outcomes Research. *JAMA*. 2014;312(15):1513-1514. doi:10.1001/jama.2014.11100

# What collaborating in patient-centered research means for patients and caregivers

- Understanding that clinicians have knowledge specialized in medicine, and patients and caregivers have knowledge specialized in experience
- Recognizing that the lived experience that patients and caregivers have is essential to the development of relevant research questions and the interpretation of research results
- Embracing a few of key roles:
  - Serve as the voice of the patients with your condition
  - Help the study team monitor the study and make sense of the findings
  - Engage with other patients and caregivers

# What CPRN is doing

- Asking patient-centered research questions that are directly informed by patients and caregivers
- Using, developing and enhancing patient-reported outcomes
- Engaging the CP community to develop a patient-centered research agenda
- Creating opportunities to involve the community in research

