

PCORI Brief Report

Authors

November 2023

Survey Aims and Methods

Our survey sought to capture the engagement with and attitudes toward patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) of representatives from organizations that serve justice-involved women.

PCOR helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options.

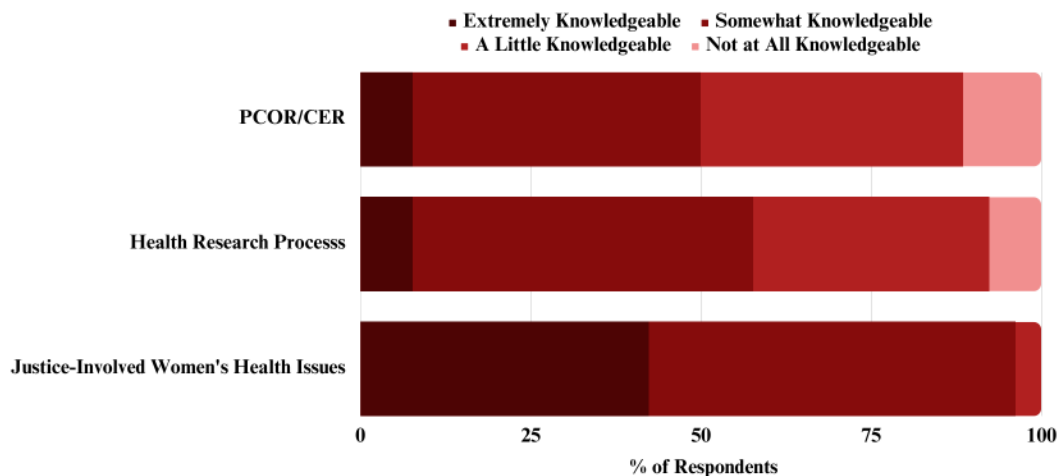
CER is research that identifies what clinical and public health interventions work best for improving health. Interventions include not only direct clinical care such as diagnosis and treatment protocols, but also innovations in health care delivery, organization, and financing, as well as public health interventions in the community, including those intended to modify health awareness, lifestyle, diet, or environmental exposures.

A total of **26** representatives from organizations that serve justice-involved women responded to our survey.

Main Findings

KNOWLEDGE OF HEALTH RESEARCH

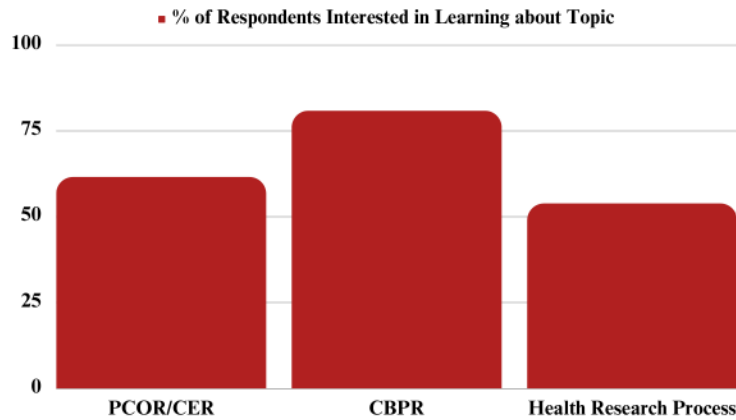
50% of our respondents felt either somewhat or extremely knowledgeable about PCOR/CER, 57.7% felt either somewhat or extremely knowledgeable about the health research process in general, and **96.1%** felt either somewhat or extremely knowledgeable about issues affecting justice-involved women's health.



Main Findings

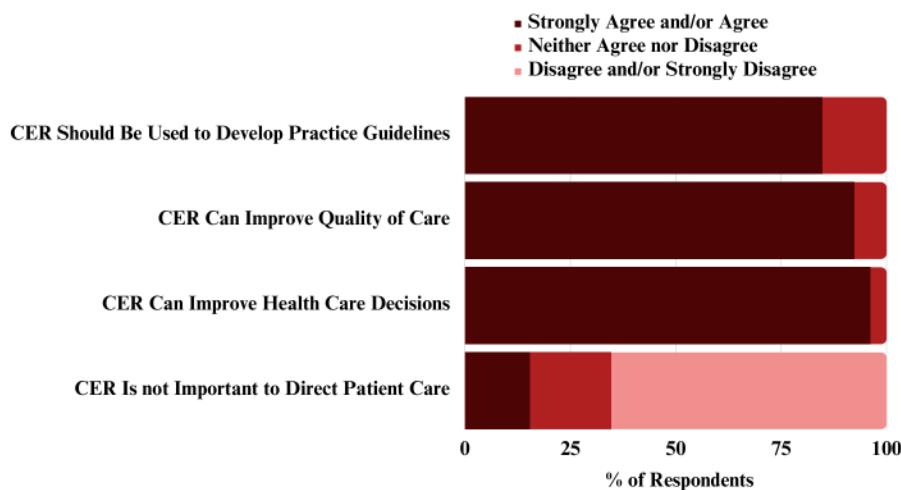
TOPICS OF INTEREST

61.5% of our respondents were interested in learning more about PCOR/CER, 80.8% were interested in learning more about community-based participatory research (CBPR), and 53.8% were interested in learning more about the health research process overall.



ATTITUDES TOWARD CER

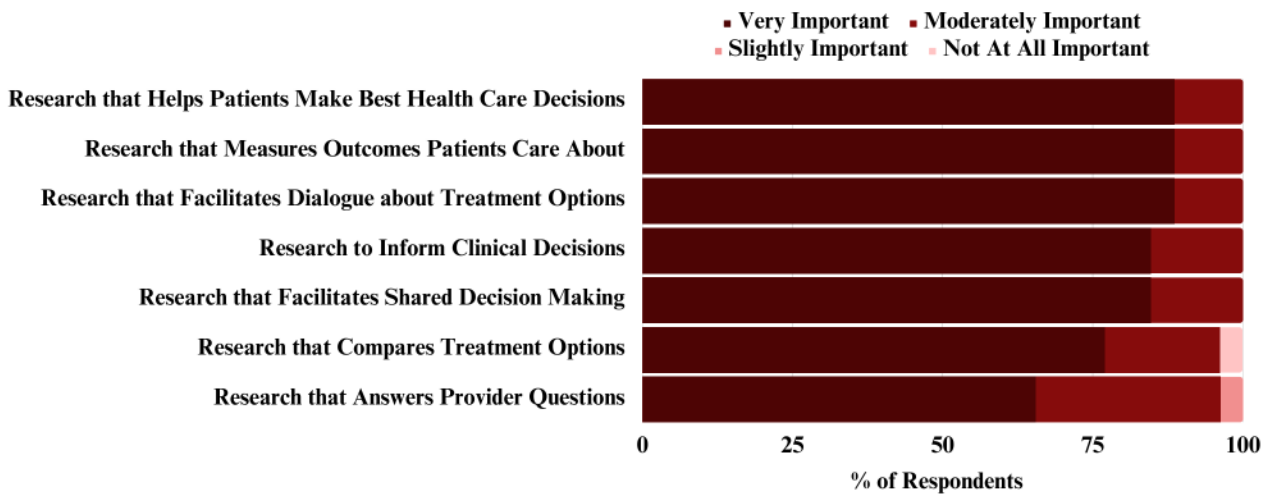
84.6% of our respondents agreed CER should be used to develop practice guidelines, 92.3% agreed CER can improve quality of patient care, and 96% agreed CER can improve how patients and providers make health care decisions. **No respondents expressed disagreement with any of the above statements, only agreement or neutrality.** Only 15.4% of our respondents expressed that CER is **not** important to direct patient care delivery.



Main Findings Cont.

PERCEIVED IMPORTANCE OF PCOR & CER

- When asked questions related to the importance of PCOR/CER:
 - **88.5%** of our respondents expressed research that helps patients make the best health care decisions is very important.
 - **88.5%** expressed research that measures outcome patients care about is very important.
 - **88.5%** expressed research that facilitates dialogue with patients about treatment options is very important.
 - **84.6%** expressed research to inform clinical decisions is very important.
 - **84.6%** expressed research that facilitates shared decision making is very important.
 - **76.9%** expressed research that compares different treatment options is very important.
 - **65.4%** expressed research that answers questions providers care about is very important.



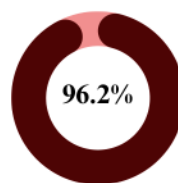
PERCEIVED IMPACT OF PATIENT ENGAGEMENT



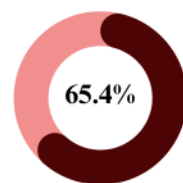
- Of our respondents agreed patients working with researchers **can improve the value of research.**



- Agreed patients working with researchers **can improve health care.**



- Agreed more research studies **should actively engage patients.**

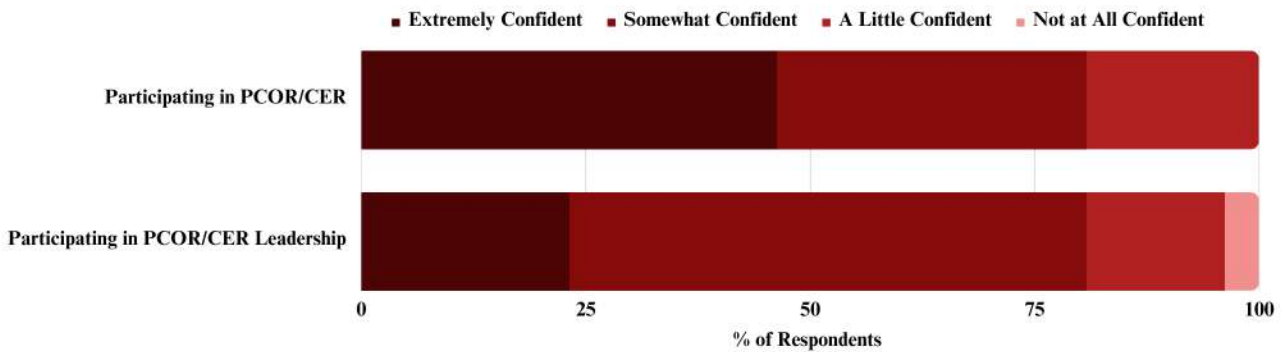


- Expressed **patients have the expertise to contribute meaningfully** to research.

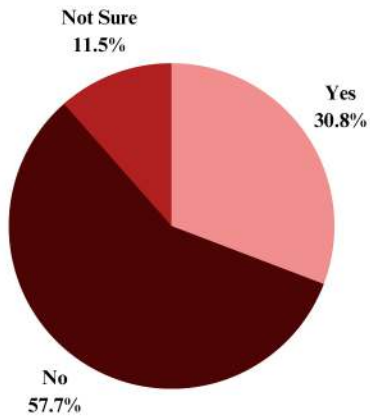
Main Findings Cont.

CONFIDENCE AND EXPERIENCE WITH PCOR & CER

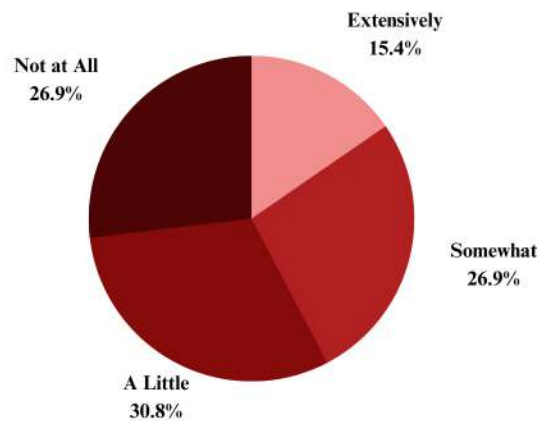
- **80.8%** of our respondents felt either somewhat or extremely confident in participating in PCOR/CER, and **80.8%** felt either somewhat or extremely confident in participating in a PCOR/CER leadership team. Yet, **57.7%** of our respondents had never worked with medical researchers, and **57.7%** represented an organization that either does not engage with health research at all or only engages with health research a little.



Have you ever worked with medical researchers?



To what extent is your organization engaged in health research?



Report Context and Recommendations

Justice-involved women face a unique set of health-related issues that are often understudied and overlooked in health care and health research. PCOR and CER offer the opportunity to capture and address these issues, but both avenues underrecruit and underutilize the experiences of justice-involved women.

Overwhelmingly, representatives from organizations that serve justice-involved women believe in the importance of PCOR and CER and are confident in both their awareness of the health-related issues that justice-involved women encounter as a collective **and** their ability to communicate these issues as participants in research. However, the majority of our sample have never worked with medical researchers, and most do not represent organizations that engage extensively with health research.

These findings indicate that representatives from organizations that serve justice-involved women both want to and are capable of meaningfully contributing to health research in ways that can benefit justice-involved women, and especially PCOR and CER, but that they are rarely enabled to do so. Increased recruitment of these individuals in health research is necessary to remedy this shortcoming and to better gauge and acknowledge justice-involved women's unique health-related issues.

Please contact Dr. Melissa Zielinski, Director of UAMS' HEALS Lab, or Dr. Mollee Smith, Assistant Professor at UAMS and member of the HEALS Lab, via email for more information or for more copies of this report.
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