

Results of the Patient Centered Outcomes Research Institute (PCORI)

Approach to Engaging ASD Stakeholders in Rural Underserved Areas

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BACKGROUND

- The Patient Centered Outcomes Research Institute (PCORI) was established as part of the Affordable Care Act of 2010 to fund patient-centered comparative effectiveness research.
- PCORI identified the need to address health disparities that exist among patients by connecting researchers with stakeholders to focus on what is most important to patients & their families.

PURPOSE

- To engage and build capacity with families of individuals with ASD and key stakeholders living in rural areas who have reduced access to care & use alternative, unproven, & potentially harmful treatments

OBJECTIVES

- Describe the 2-tiered process of implementing the PCORI mechanism
- Report stakeholder generated comparative effectiveness research questions

SETTING & SAMPLE

Setting: Rural North Central Florida

Participants: High functioning adults with ASD, parents of individuals with ASD, community-based healthcare service providers, & university affiliated ASD researchers.



METHODS

- Initial funding was from UF CTSI (2014) to establish a Community Advisory Board (CAB) of major stakeholders, identify additional stakeholders, and conduct a series of focus groups.
- Next was funded PCORI Tier 1 (2015)
- Followed by funded PCORI Tier 2 (2016)
- Demonstrates how the PCORI mechanism can be implemented to engage stakeholders in rural underserved areas progressing to comparative effectiveness research studies that are of most interest to the stakeholders.

RESULTS

- Results of the CTSI funded study positioned us to successfully apply to PCORI.
- We demonstrated successful engagement of stakeholders in 3 rural underserved areas of our state.
- These highly engaged groups were led by community stakeholders.
- Group leaders also meet monthly with our centrally located Community Advisory Board (CAB) to discuss progress & receive advice.
- Groups established their own names, functions, & priorities for subsequent comparative effective research questions that are most meaningful to them.
- Of most interest to the stakeholders was future research evaluating the effects of distance delivered interventions using state of the art technology and the GFCF diet.

DISCUSSION

- The Patient Centered Outcome Research Institute (PCORI) approach is well-suited to address the needs of underserved & rural ASD stakeholders.
- Engaging stakeholders from the beginning of the research process (i.e., formulating the comparative effectiveness research questions) is critically important to remove “the mystique” that stakeholders may perceive related to autism research & facilitate their involvement throughout the process of conducting comparative effectiveness studies.



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