

PCORI Pipeline to Proposal Tier 1: Experiences and lessons-learned in working with rural families living with autism

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Overview

What is PCORI? The Patient Centered Outcomes Research Institute (PCORI) is a non-profit, non-governmental organization that was congressionally authorized in 2010 to improve the quality and relevance of research evidence available for making informed health decisions. Research funded by PCORI is patient-centered and focuses on addressing concerns most relevant to the patients; it requires involvement of patients and other stakeholders throughout the research process.

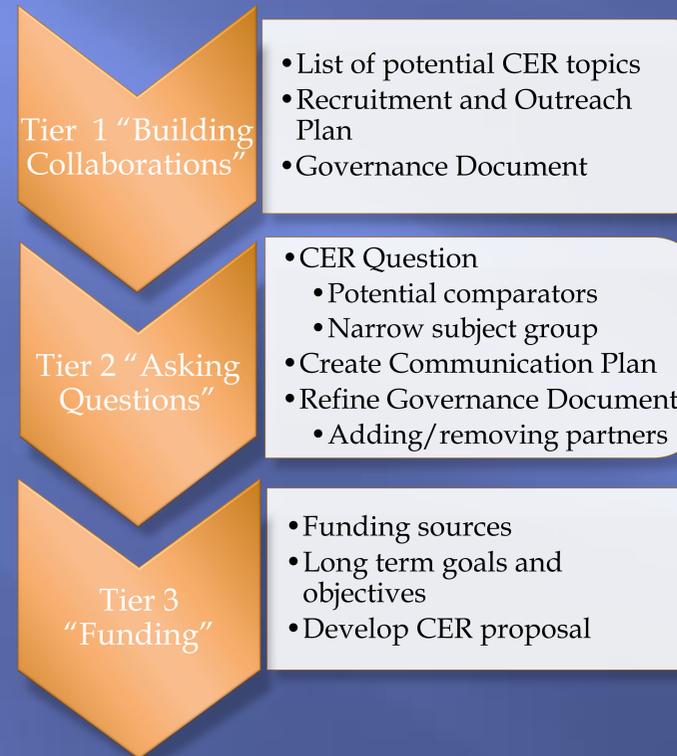
Patient-centered research has several ideological parallels that are consistent with patient-centered care.

Purpose:

1. Describe experiences in implementing our Tier 1 work plan.
2. Present needs and concerns most salient to our community CARE families.

3 Tiers: PCORI Pipeline to Proposal

Which interventions work best for rural families living with autism, and/or under what type of conditions do the interventions work best?



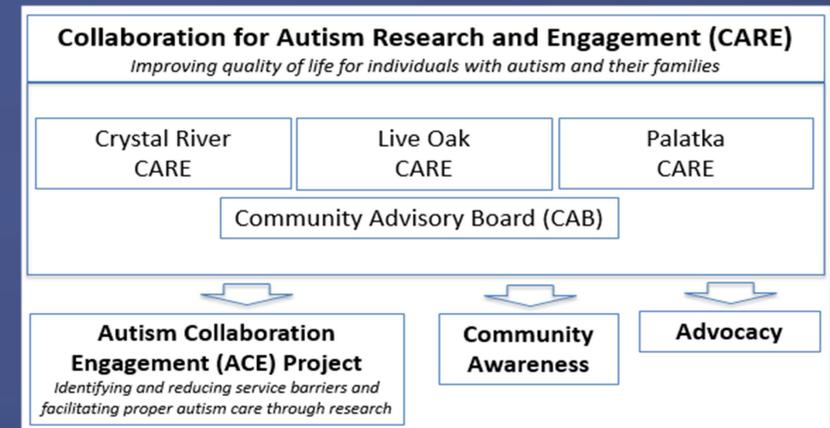
Comparative Effective Research (CER) :

Potential Approaches

- Comparing 2 existing evidence-based (EB) health interventions
- Comparing for whom an existing EB intervention works best
- Comparing the delivery methods of an existing EB intervention
- Comparing different combinations of existing EB interventions

Building Capacity and Forging Collaborations in Autism Research for Underserved Families

(PD Elder)
From Project (ACE) to Collaborative Alliance (CARE)...



Autism Collaboration Engagement (ACE) Project

ACE: A partnership between individuals/families with ASD living in rural Florida and researchers, health and service providers for the purpose of improving care through research.



Role of Community CARE Groups

To identify outcomes and potential healthcare interventions that are meaningful to their everyday lives. These interventions help inform possible comparative effectiveness research (CER).

Shared Governance: Individuals with ASD, Families, Stakeholders, & Researchers

- Allowing groups to identify mission, objectives and initiatives
- Finding communication tools that work best for everyone
- Designating liaisons; developing and articulating roles across Advisory & Community CARE groups
 - Identifying discussion topics & facilitating discussions
 - Understanding research & Informing about evidence based interventions
 - Developing workshops & toolkits (Tier 2 activity)
- Researchers collaborating with families & stakeholders to refine CER topics and then develop CER question(s).

Interventions Community CARE Members Want to Consider Investigating
Peer Mediated Interventions
Parent Implemented Interventions
Social Skills Intervention
Social Narratives
Video Modeling
Technology-Based Treatment
Applied Behavior Analysis (ABA)
Pivotal Response Treatment (PRT)
Picture Exchange Communication System (PECS)

Issues/Topics Requested for Researchers to Focus On
School Issues
Support for parents
Transitioning to adulthood
Provider/specialist availability
Children with ASD not getting early treatment
Medical insurance coverage
Cost/Financial strain
Educational material on ASD for teachers
Dietary concerns

References

1. PCORI. (n.d.). Retrieved June 29, 2015, from <http://www.pcori.org/about-us>
2. American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). American Journal of Occupational Therapy, 68(Suppl. 1), S1-S48. <http://dx.doi.org/10.5014/ajot.2014.682006>

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