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Centering Patients in Comparative Effectiveness Research (How It's Done)

THE AAKOMA PROJECT

Dr. Alfiee

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THE AAKOMA PROJECT

The AAKOMA Project
Embrace, Encourage, Enlighten

THE *AFRICAN AMERICAN KNOWLEDGE OPTIMIZED FOR MINDFULLY HEALTHY ADOLESCENTS* PROJECT -

OUR MISSION: TO ADDRESS DEPRESSION & OTHER MENTAL HEALTH NEEDS OF AFRICAN AMERICAN YOUTH AND OTHER YOUTH OF COLOR

We do this through the development and implementation of rigorous, culturally relevant, patient centered, community-engaged research and clinical care

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Through the use of Community Based Participatory Research (CBPR) and traditional behavioral clinical trials we develop culturally relevant interventions that inform:

1. The public about the unique mental health needs of African American and racially diverse youth (especially in the areas of depression and treatment engagement)
2. The mental health field about the unique perspectives of African American and racially diverse families regarding depression, treatment engagement and mental health disparities.

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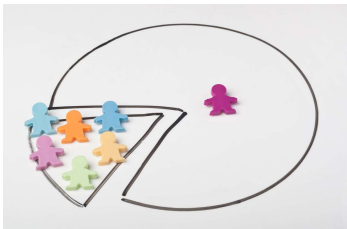
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MENTAL HEALTH NEEDS OF PEOPLE OF COLOR

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Barriers to Care

Generally, mental health disparities for people of color exist in four areas:

1. Decreased access to/less availability of mental health services -
   Includes issues with costs; insurance; availability of clinics and hospitals esp. for mental health concerns.
2. Lower likelihood of receiving required services -
   As a result of abovementioned reasons; cultural stigma; failure to acknowledge mental health needs.
3. Experiences with poorer quality of care -
   Lack of cultural competence of providers and treatments; provider bias.
4. Underrepresentation in the field of mental health research:
   Both in the role of participant and researcher.

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PATIENT CENTERED RESEARCH

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Improving the Status Quo

How can we improve provision of care and diminish the service provision gap across racial groups?

Direct examination of current levels of knowledge and attitudes of youth of color surrounding the field of mental health many inform better practices.

Means of reducing barriers to care and research involvement:

- Cultural competence
- Developing alternate and innovative forms of tx to improve access and availability
- Promoting mental health awareness
- Community collaboration
  PCOR, CER, CBPR

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AAKOMA, CER & PCOR

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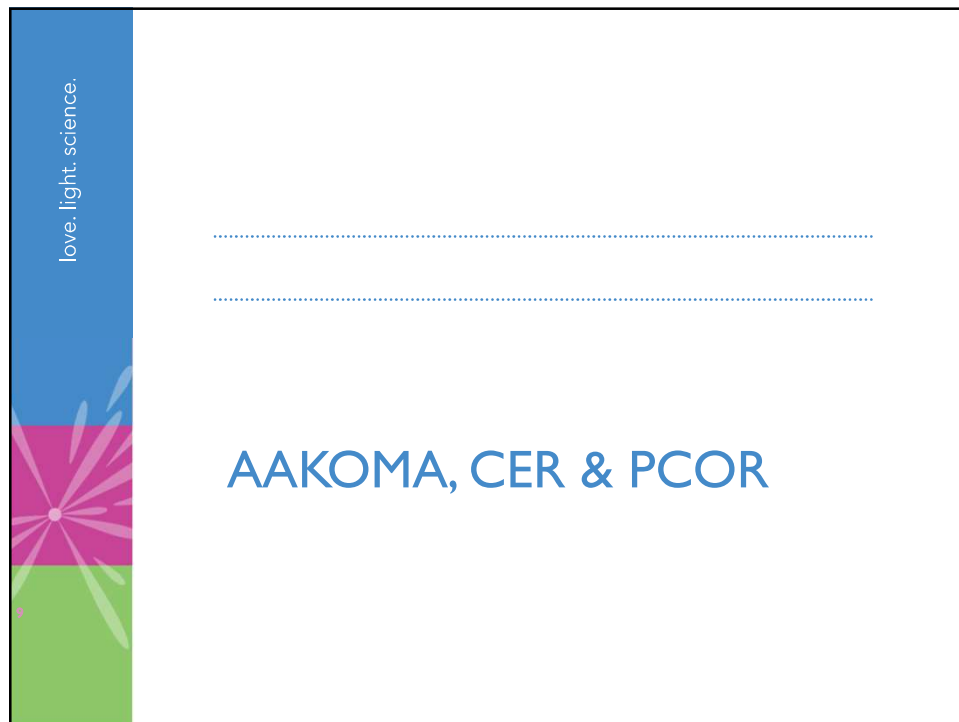
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Objectives of our Research

1. For participants to understand the details of Comparative Effectiveness Research and Patient Centered Outcomes Research.

2. For participants to learn about the general knowledge and attitudes of youth of color surrounding the field of mental health treatment and research.

3. For participants to understand and be able to apply the tenets of CER and PCOR in similar communities to increase mental health research engagement.

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PCORI ENGAGEMENT AWARD

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Engaging Black Faith Communities to Address Mental Health Disparities via Curriculum Development

Goals of our <u>Funded</u> EA Project:

1. Build a network of African American youth patients, leaders, caregivers, parents, community members and other stakeholders invested in developing skills in PCOR and CBPR.

2. To evaluate and identify:
   a) Factors that help or hinder *Faith Based Mental Health Promotion*
   b) Factors necessary to support training in PCOR and CER

3. To collaboratively develop a patient and stakeholder focused training curriculum in PCOR, CER, and CBPR for African American youth mental health.

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EA Project: Accomplishments

~ Engaged **15 faith communities** across the project period to create our stakeholder network.

~ Recruited a total of **203 individuals** to participate in survey completion and group discussion (with 17 focus groups completed).

~ Primary Outcomes:
Curriculum Creation
Capacity Building
Community and Patient Engagement
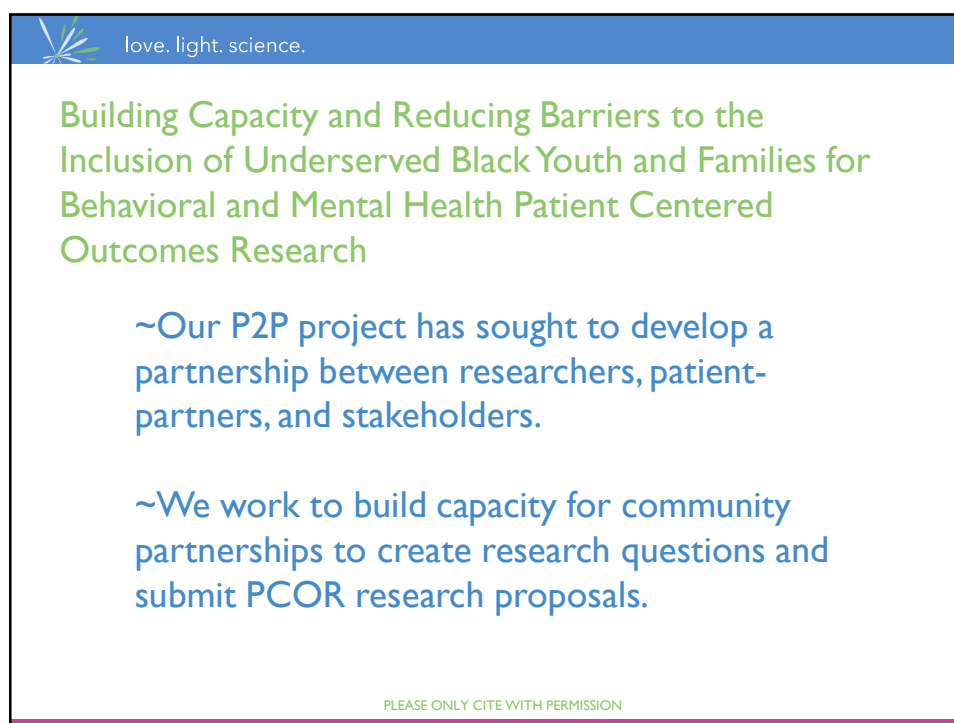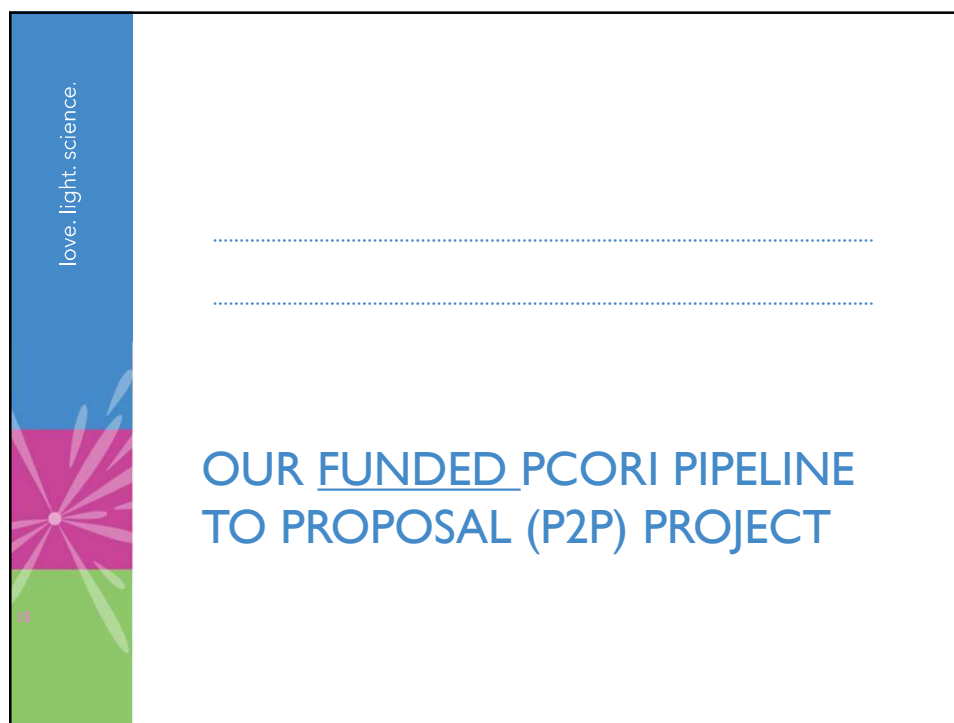
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Adult's Understanding of CER and PCOR

Youth's Understanding of CER and PCOR

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OUR <u>FUNDED </u>PCORI PIPELINE TO PROPOSAL (P2P) PROJECT

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Building Capacity and Reducing Barriers to the Inclusion of Underserved Black Youth and Families for Behavioral and Mental Health Patient Centered Outcomes Research

~Our P2P project has sought to develop a partnership between researchers, patient-partners, and stakeholders.

~We work to build capacity for community partnerships to create research questions and submit PCOR research proposals.

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P2P Project Goals

1. Strengthen relationships between researchers, patients and stakeholders.
2. Build capacity for community partnerships to create research questions and submit PCOR research proposals.
3. Engage partnerships in research process and development of dissemination and implementation plans.
4. Successfully establish an infrastructure for patients, caregivers, and other stakeholders to increase engagement in research, dissemination and evaluation.

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Tiers of our P2P Project

Tier 1 - COMPLETE	Tier 2 - COMPLETE	Tier 3 - COMPLETE	PCORI Funding Announcement
• 9 months • Build a sense of community. • Develop a network. • Establish community trust. • Identify recruitment strategies. • Develop CER* ideas.	• 12 months • Lay groundwork for proposal. • Complete all PCORI trainings. • Develop a workplan. • Identify potential community partners. • Develop CER questions. • Identify other sources of funding.	• 12 months • Write funding proposal based on CER questions. • Present to the community CER questions. • Expand community partner networks. • Submit letter of intent of funding.	• Funding decision announced. • This funding and approval will permit implementation of the intervention with Black youth • Implement Intervention!

*CER- Comparative Effectiveness Research is the direct comparison of existing health care interventions to determine which work best for which patients and which pose the greatest benefits and harms

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P2P Project: CER Question Development

With our team, we developed CER questions with our community and patient partners that addressed:

1. The need for a trauma based treatment intervention for youth members of their geographic community.

2. The needs and current resources of this population.

3. The community's **cultural sensitivities** was of importance to the group.

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P2P PROJECT: CURRENT STATUS

March 2018 → Letter of Intent **ACCEPTED**

Spring 2018 → Addressing Disparities Grant

SUBMITTED

INITIAL SCORE:

41

STRONG WITH MINOR WEAKNESSES

Partners in Faith for Youth Mental Health
Let's Take Care of our Youth Together!

MindRight

The AAKOMA Project
African American Knowledge Optimized for Mindfully-Healthy Adolescents
Embrace, Encourage, Enlighten

PEN DMV

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FUTURE RESEARCH

- Additional factors that may prevent youth of color from engaging in mental health research and clinical care

- Best practices for encouraging engagement of this population and among other youth of color

- Efficacy and effectiveness of culturally adapted outpatient psychotherapy

- Culturally relevant predictors of treatment effectiveness

- How to tailor interventions to the needs and wishes of patients of color

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