

**Hybrid Effectiveness-Implementation Trial of
Guided Relaxation and Acupuncture for Chronic Sickle Cell Disease Pain**

GRACE Trial

HEAL Innovation Research Discussion

Engaging Participants in Research

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GRACE Trial – UG3/UH3

- Pragmatic effectiveness-implementation study using a SMART design
- 3 medical centers:
 - UI Health
 - Duke Health
 - UF Health
- UG3
 - Human-centered design based on principles of community-based participatory research (CBPR)
 - Pilot study completed to inform proposal development
 - Qualitative approach being used to inform
 - Implementation of study procedures
 - Recruitment and retention
 - Dissemination

Engaging Communities

Disparities emerge due to

- Lack of inclusion in
 - Problem identification
 - Study development
 - Implementation decisions
 - Imposed vs informed

Best Practices

- Sustained engagement
 - Evidence
 - Trust
- Inclusion of concerns before study is developed
- Collaborative decision-making
 - Implementation
 - Dissemination

Patient Input: Implementation Blueprint

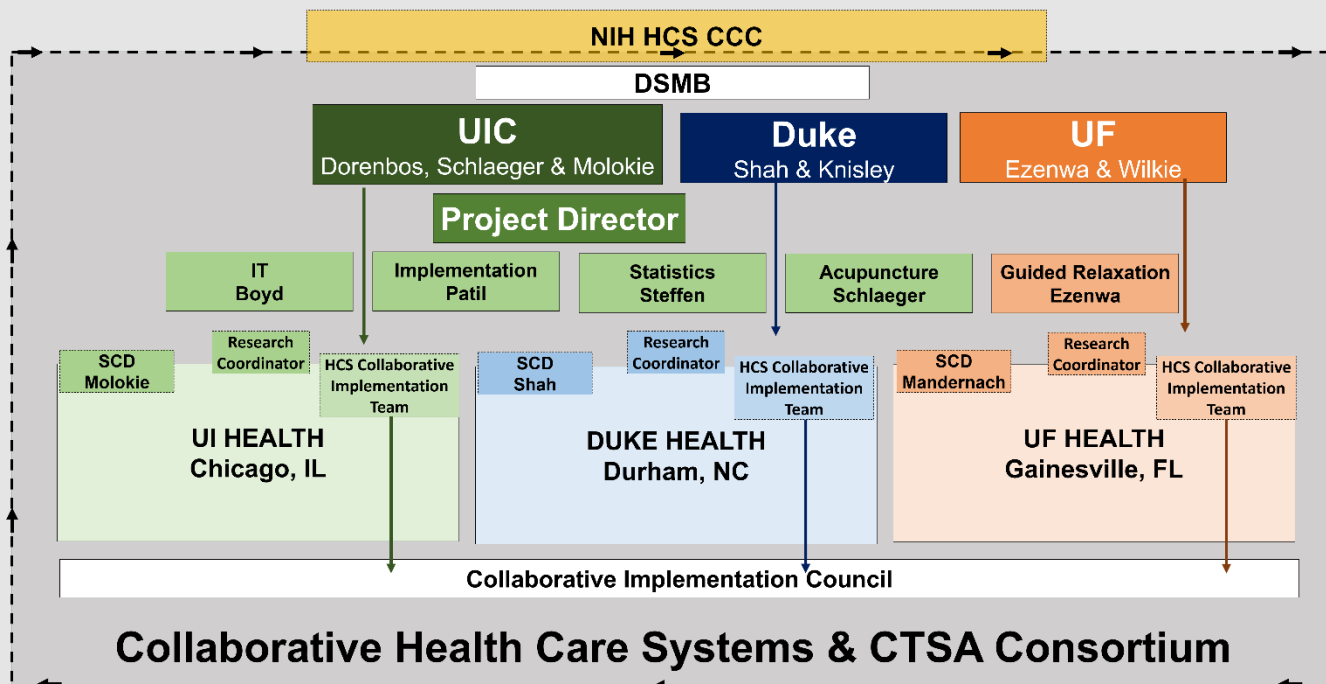
- Pilot survey: All (n=57) used some form complementary and integrated health
- Access to therapies desired included:
 - Relaxation/meditation
 - Acupuncture
- 7 adults with sickle cell disease attending clinic are collaborating on the building of our implementation blueprint
- Reflections on study participation and understanding of the design
 - “sickle cell patients just want to know that you're not there to harm them or that what you're doing there is to help them ...and when they participate in the studies that the care or benefits that they're getting won't be put at risk. ”
 - *"I am willing to try it... I am a person that believes that, in order to know if something works, you have to try it. Some people look at it, as guinea pigs and everything and some of us like me just say how do you know, unless you try. So yeah, I'm willing to try it."*
 - “... you [will] only be switched out if you're unresponsive versus the people who are responsive the treatment”



Citizen Scientists

Collaborative Implementation Council

Structure of the Study Team



- Collaborative scientific work that include members of the sickle cell disease community
- *“Because I’m very for research into sickle cell, better solutions, not even just a cure, but to better deal sickle cell. And volunteers really is what these medical facilities, medical practices need, and I feel like a lot of sickle cell patients, they’re scared to volunteer for certain things, but we always talk about how we want the research done, we need to also be able to help in this research, you know.”*
- Serve on our council locally and together
 - Recommendations for implementation activities and dissemination
- Hope for future is options for treatment that reduce reliance on opioids for the control and treatment of chronic pain
- Impact on policy