COMMUNITY SCIENTIST PROGRAM

Dr. Jessica Escareno
Assistant Professor
School of Community and Rural Health
Community Scientist Program

- For clinical providers and research scientists who need advice and input from a layperson to improve their research projects or patient materials.

- Rapid feedback from trained community members to ensure research projects are culturally appropriate and relevant to the community.
Community Scientist Program

- CSP gathers rapid feedback from racial minorities and cancer survivors about issues pertaining to research design, implementation, recruitment, retention, and any other barriers to participation.
- Feedback sessions streamline the process of gathering information about community needs, understanding cultural nuances, and understanding of clinical research.
- Create an infrastructure to empower community members to provide meaningful insight into all phases of research.
Stakeholder engagement is increasingly recognized as a valuable tool in clinical and translational research.

Stakeholder engagement can play an important role in increasing public trust and the understanding of scientific research and its impact.

Funding agencies (e.g., PCORI, NIH) are increasingly requiring engagement with patients, caregivers, and other stakeholders for funding.
Other Institutions with Programs

- Meharry- Vanderbilt Community-Engaged Resource Core
- NYU Institute of Community Health Research
- University of Florida Citizen Scientist Program
- University of Minnesota Community Engagement Studio
- University of Utah Center for Clinical and Translational Science
Community Scientists

- Want to learn about research
- Interested in supporting community research
- Want to serve as a voice for their community
- Have been trained on basic research terms
- Compensated for their time $25
**Community Scientists**

- Serve as a sounding board to ensure research addresses local community interests
- Provide advice on the development of culturally appropriate studies and recruitment strategies
- Share input on developing research questions
- Help identify strategies to improve community health
- Share input on literacy of survey measures
Domains of Community Scientist Impact

1. Proposal Development
   - Topic Generation
   - Research Aims

2. Infrastructure
   - Time, Cost, Compensation for Study Participants

3. Research Design
   - Define Population
   - Cultural Appropriateness
   - Research Methodologies

4. Implementation
   - Enhance Approaches for Recruitment/Retention of Participants and Data Collection Methods
Domains of Community Scientist Impact

5 ANALYSIS
- Alternative interpretation of results
- Attention to factors not accounted for in literature
- Context for relevance to patients/community members

6 DISSEMINATION
- Cultural relevance and appropriate language of delivery materials
- Appropriate audiences

7 POST RESEARCH
- Formulating next research questions
- Impact on community
- Participant follow-up
Community Scientist Training

**Topics**
- Orientation
- Research Diversity
- Increasing Research Diversity
- Putting it all together

**Objectives**
- Describe program and processes
- Common research terms
- Why research diversity is important
- Recognize the elements in community-engaged research

**Format**
- Group Discussion
- Presentation and role play
- Presentation and role play
- Videos, mock feedback session
FEEDBACK SESSIONS

- No cost to request a Community Scientist Feedback Session

- 1-hour, facilitated session designed to provide community input about issues pertaining to study design, implementation, recruitment, retention and other potential barriers to participation

- Feedback sessions held monthly via Zoom
FEEDBACK SESSION

Purpose
Project-specific guidance to inform research at any stage

Community Role
Consultant, sharing expertise based on “lived experience

Facilitator and Framework
Member of Community Scientist Program team
Flexible Facilitator Guide

Preparation
Trained in research terms; may preview research documents prior to session

FOCUS GROUP

Qualitative data collection

Research subjects, consented for study with inclusion/exclusion criteria

Member of research team
IRB-approved script

Usually none
RESEARCHER BENEFITS

- Access to community experts from various backgrounds
- Feedback at different stages of the research process
- Community relationships and increase community trust
- A fresh perspective from non-academics
- Exposure and valuable insight into a community’s cultural nuances and historical issues
- Assessment of the feasibility and appropriateness of research before studies are implemented
“... It was very helpful to hear from the community members who would potentially be participants in a trial what appealed to them, what they found confusing and what they thought could be organized differently”

- Mediget Teshome, M.D.
Past Feedback Topics

- Innovative tool development for simple presentation of clinical trial information
- Reaching diverse audiences for lay science communication
- Refining recruitment materials to attract hard-to-reach populations
- Perceptions of community members on coronavirus prevention measures
- How to improve recruitment for wellness study targeted towards prostate cancer patients and their caregivers
COMMUNITY SCIENTIST FEEDBACK SESSION
Preparation & Follow-Up

1. Researcher completes brief application via REDCap
   - Staff conduct initial meeting with researcher to discuss study needs, timeline, etc.

2. Staff identify Community Scientists from our database who can speak to the needs of the study population (e.g. cancer survivor, smoker, etc.)
   - Staff schedule researcher for an upcoming feedback session
   - Send meeting materials to Community Scientists prior to Feedback Session to review
   - Conduct Community Scientist Feedback Session

3. Community Scientists and researchers complete feedback session and evaluation
   - Meeting notes, forms, etc. entered into REDCap database
   - Community Scientists are compensated
Who are our Community Scientists?

**Sex:** 10 men, 43 women

**Race:** 34 African American, 14 Hispanic, 4 Non-Hispanic White, 1 Asian

**Cancer Survivors:** 7

**Sites:** 44 Houston, 9 Northeast Texas
Spread the word

Website: www.mdanderson.org/communityscientist
Feedback Session Request form: https://redcap.mdanderson.org/surveys/?s=WPH7T4LYY3
Program video: https://www.youtube.com/watch?v=aAlwQOicRn4

jescareno@uttyler.edu