

COMMUNITY SCIENTIST PROGRAM

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Today's date is

July 15th

Today's Agenda

- Discuss the Community Scientist Project
- Describe benefits to researchers
- Review how to request a session

Email:

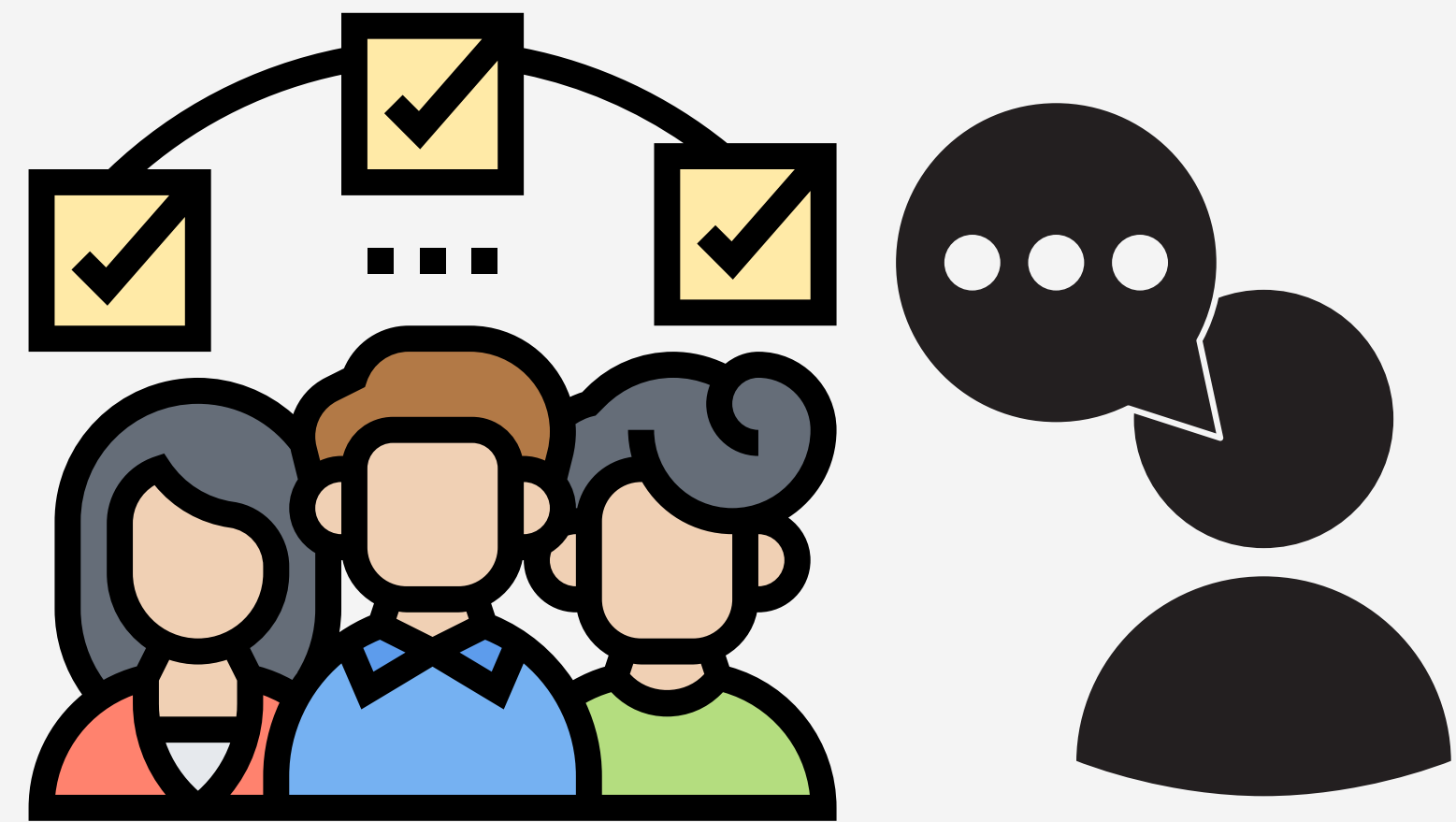
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Quote of the Day

Whatever you do, do it well.
- Walt Disney

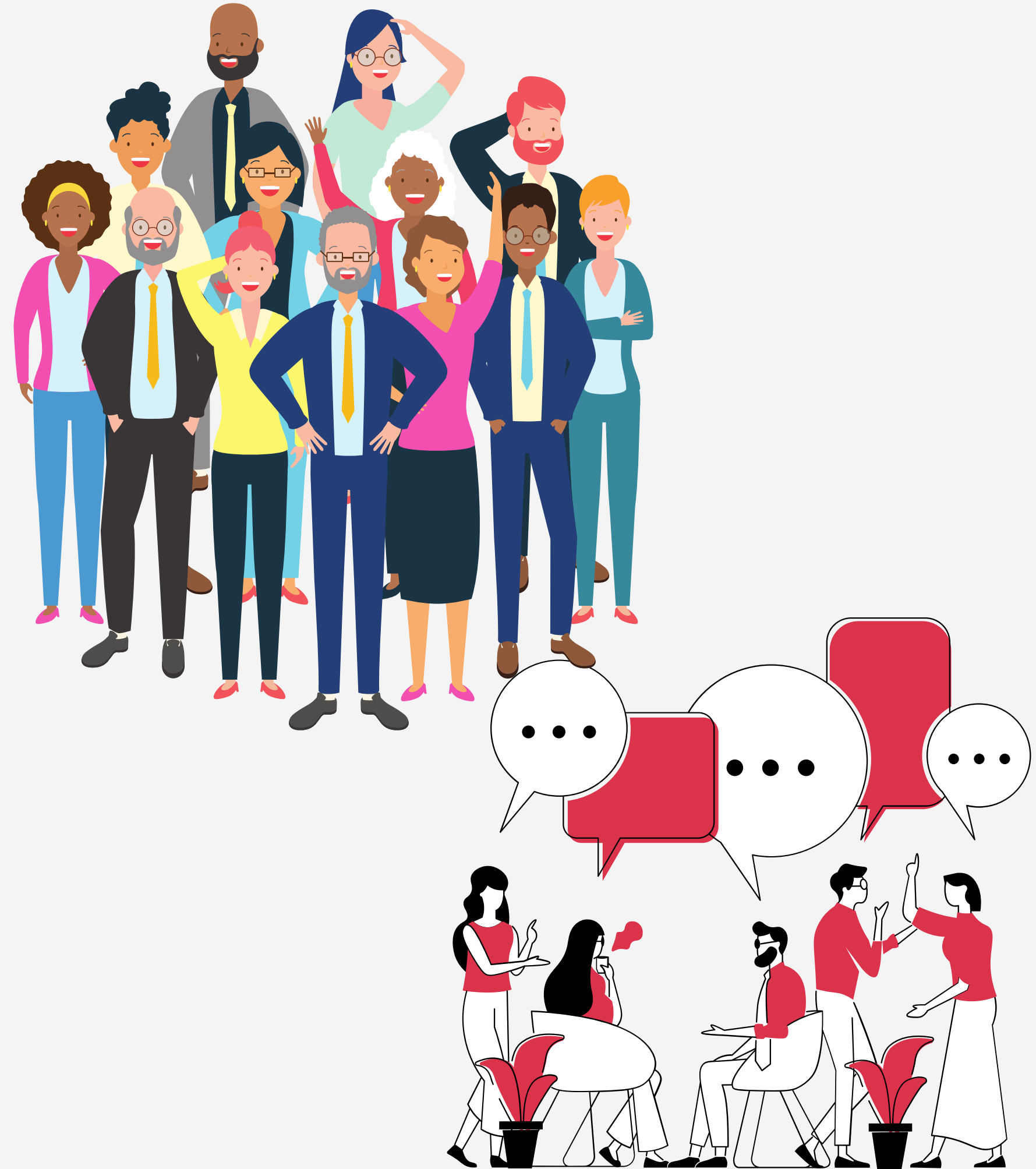
Community Scientist Project

- 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



Community-Engaged Translational Research



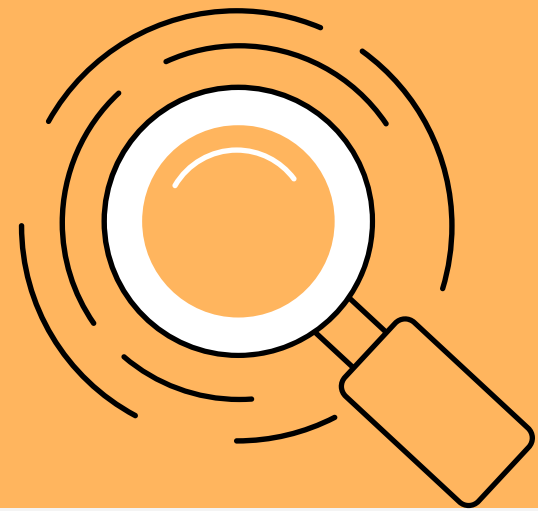
- Stakeholder engagement is increasingly recognized as a valuable tool in clinical and translational research
- Stakeholder engagement can play an important role in increasing public trust and the understanding of scientific research and its impact
- Funding agencies (e.g., PCORI, NIH) are increasingly 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
- Are 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

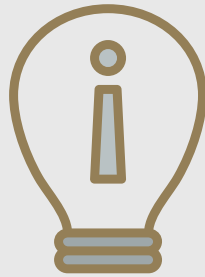
- Serve as a sounding board to ensure research addresses local community interests
- Provide advice on the development of culturally appropriate studies and recruitment strategies
- Share input on developing research questions
- Help identify strategies to improve community health
- Share input on literacy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



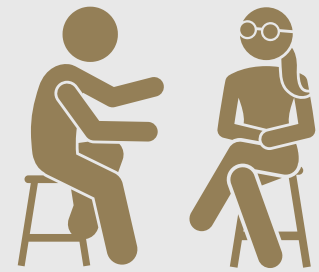
Domains of Community Scientist Impact

1

PROPOSAL DEVELOPMENT

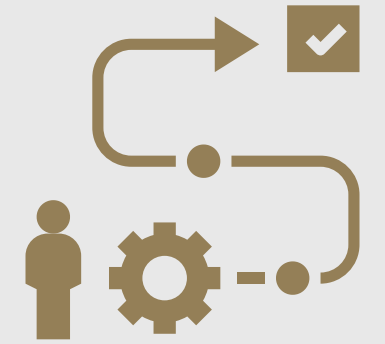


- TOPIC GENERATION
- RESEARCH AIMS

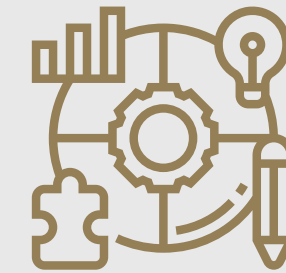


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RESEARCH DESIGN



- DEFINE POPULATION
- CULTURAL APPROPRIATENESS
- RESEARCH METHODOLOGIES

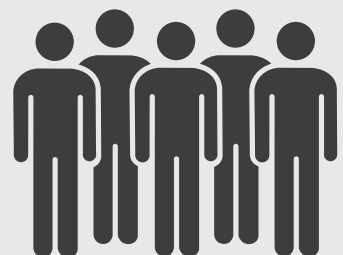


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INFRASTRUCTURE

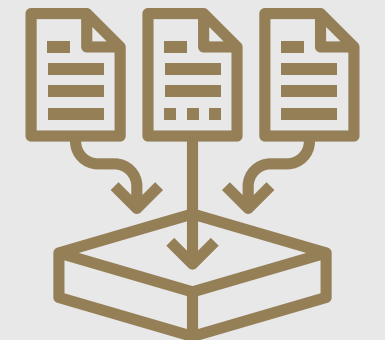


- TIME, COST, COMPENSATION FOR STUDY PARTICIPANTS



4

IMPLEMENTATION



- ENHANCE APPROACHES FOR RECRUITMENT/RETENTION OF PARTICIPANTS AND DATA COLLECTION METHODS

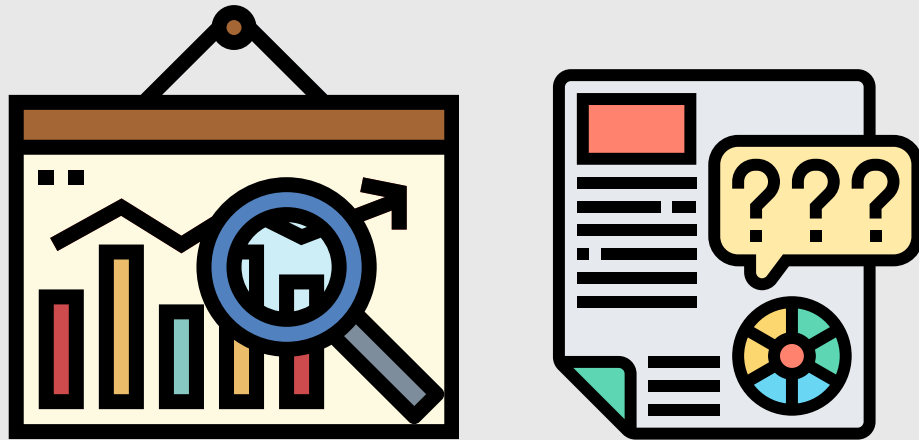


Domains of Community Scientist Impact



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

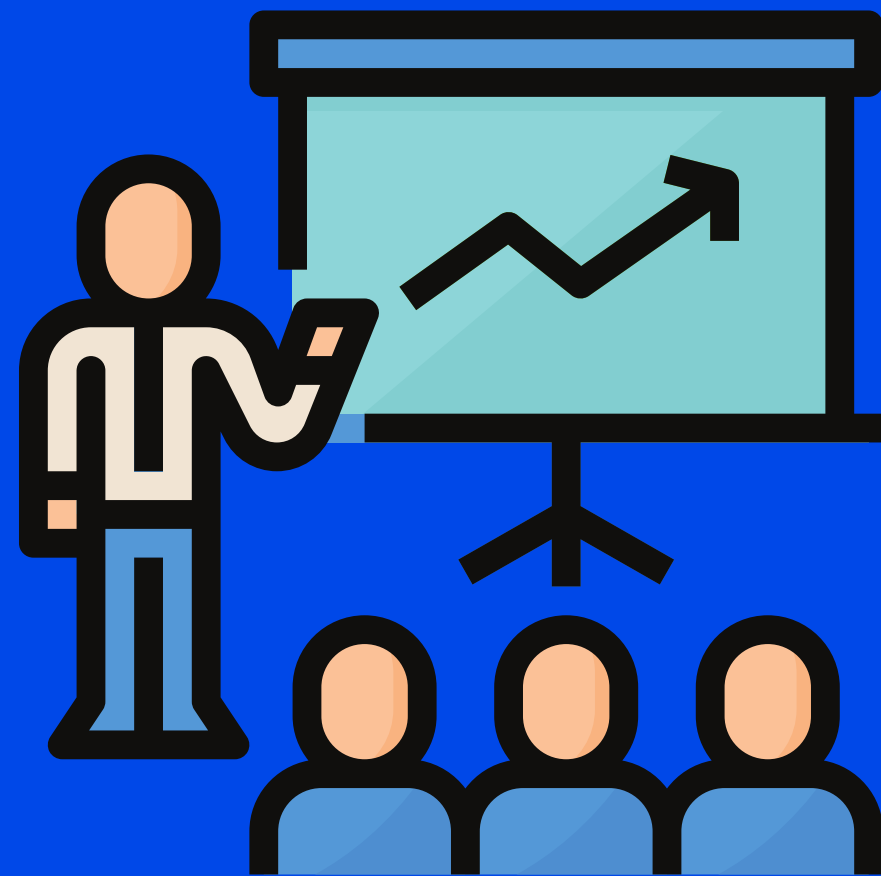
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POST RESEARCH

- FORMULATING NEXT RESEARCH QUESTIONS
- IMPACT ON COMMUNITY
- PARTICIPANT FOLLOW-UP



COMMUNITY SCIENTIST TRAINING



TOPICS

ORIENTATION

RESEARCH 101

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

FOCUS GROUP

Purpose

Project-specific
guidance to inform
research at any stage

Qualitative data
collection

Community Role

Consultant, sharing
expertise based on
“lived experience

Research subjects,
consented for study with
inclusion/exclusion
criteria

Facilitator
and Framework

Member of Community
Scientist Program team
Flexible Facilitator
Guide

Member of research
team
IRB-approved script

Preparation

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

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



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



- 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



- 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



RESEARCHER

COMMUNITY SCIENTIST PROGRAM COMMUNITY ENGAGED RESEARCH ASSISTANCE

Do you want to get input on your research idea?

What is the purpose of the Community Scientist Feedback (CSF) sessions?

The CSF sessions allow researchers to gain feedback from his or her community of interest or patient groups on the following:

- Design
- Implementation
- Recruitment
- Retention
- Potential barriers to participation

What are the benefits of a CSF session?

- Engage stakeholders and patients through a timely, efficient and cost-effective process
- Improve research practices and dissemination
- Empower community members to provide meaningful insight into all phases of research



What can I expect from a CSF session?

Community Scientists are a diverse group of community members who provide valuable insights to researchers by sharing lived experiences with cancer or a chronic illness. They include:

- Cancer survivors
- Those living with a chronic illness such as asthma, diabetes or high blood pressure
- Caregivers to a cancer survivor or person with a chronic illness
- Interest in learning about and supporting community research

All feedback sessions take place virtually. Sessions are one hour. There is no cost to conduct a session.

To schedule a feedback session:

<https://redcap.mdanderson.org/surveys/?s=WPH7T4LYY3>



COMMUNITY



BE A VOICE FOR YOUR COMMUNITY!

JOIN THE COMMUNITY SCIENTIST PROGRAM

Community scientists are people like you, who provide valuable insights to researchers by sharing their experiences with cancer or a chronic illness. You will learn to be an advocate for research in your community and become a trained community scientist.

Before participating in the Community Scientist program, you must attend a full-day training that covers the basic principles of research and how to effectively communicate with researchers.

There will be one meeting held virtually each month and compensation is provided.

If you are active in your community and meet one of the following criteria, contact us to participate:

- I am a cancer survivor.
- I currently have a chronic illness like asthma, diabetes or high blood pressure.
- I am a caregiver to a cancer survivor or person with a chronic illness.
- I am interested in learning more about and supporting community research.

SUBMIT AN ONLINE APPLICATION TO:

<https://redcap.mdanderson.org/surveys/?s=EA8N7DK4KL>.



Video



How MD Anderson's Community Scientist Program maximizes research impact

Watch later Share

Watch on YouTube

Spread the word!

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