

Measuring the
Engagement in
“Community-Engaged”
Research: Are We (Truly)
Empowering the
Community to Inform
Behavioral Health Equity?


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ACTRI DISC SEMINAR

JUNE 15TH, 2023





Roadmap

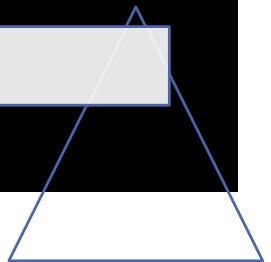
Health Equity in Implementation Science

Community-Engaged Research Principles

CERIE Overview & Aims

Measuring CE: “Advancing the Science of Engagement”

Challenges/Discussion



Health Equity in Implementation Science

An explicit and intentional integration of implementation science and equity

Community Engaged Research (CEnR) as central feature of IS from its inception

Drahota et al. (2016): recommend consensus around using the term “Community Academic Partnership” to unite research disciplines & more systematically advance the field

Holt & Chambers (2017): Community Engaged Dissemination and Implementation (CEDI) research

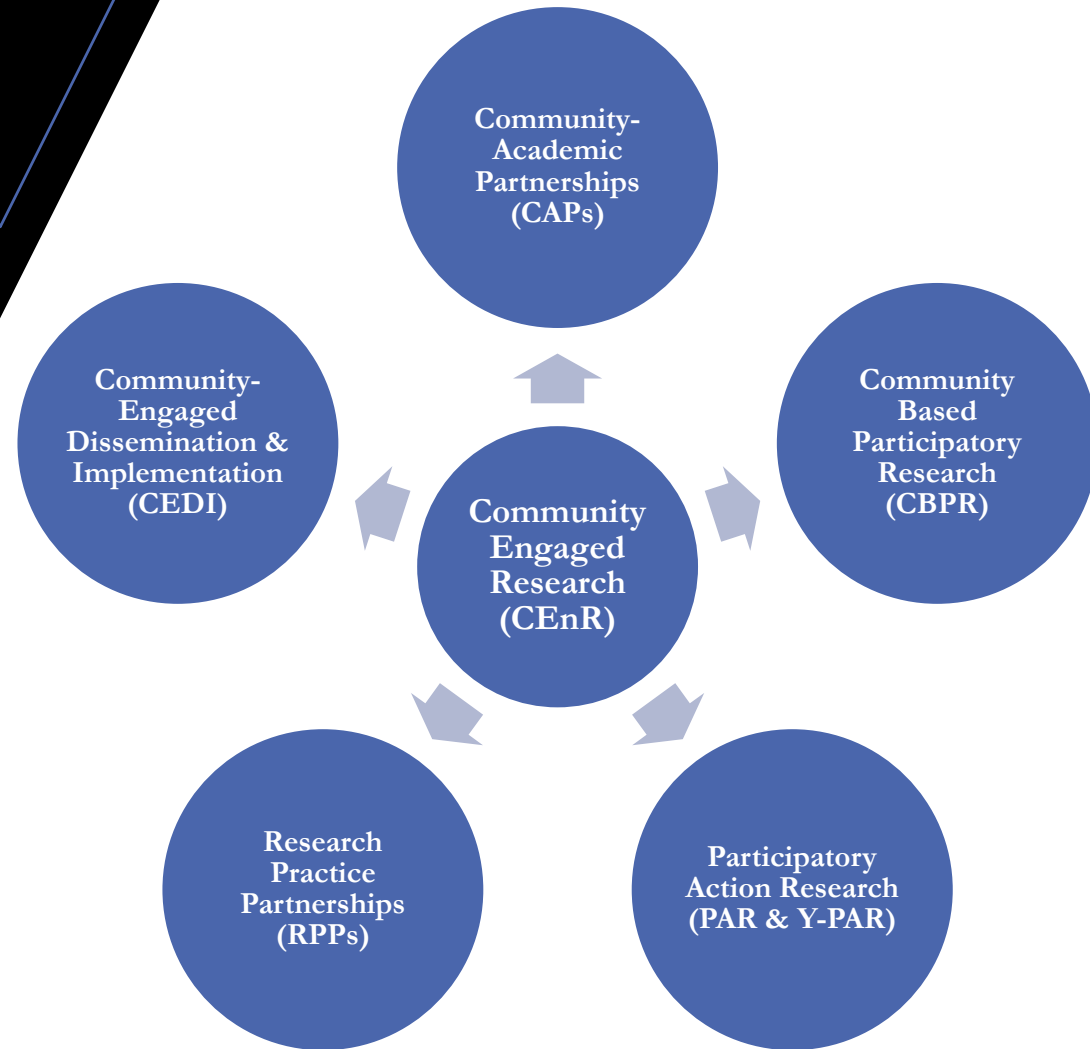
Community-Engaged Dissemination & Implementation

“Research involving dissemination or implementation of evidence-based health interventions within clinical or community-based settings using community-engaged processes or partnerships, including but not limited to community-based participatory research.”
(Holt & Chambers 2017)

Emphasizes engagement of *stakeholders* (e.g., community members, practitioners, community organizations, etc.) with diverse experiences, perspectives, and expertise to provide key knowledge re. local context, priorities, needs, and assets

Incorporating unique perspectives from communities which have been historically excluded from the research process

Types of Community Engaged Research





Community Engaged Research Principles

Before starting work with the community

- 1. Defined purposes, goals, & community
- 2. Know the community

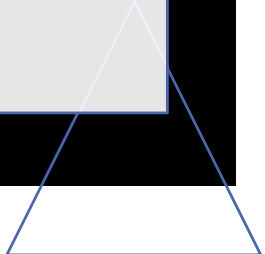
Needed for Engagement

- 3. Go to the community
 - 4. Look for collective self-determination
- 



Community Engaged Research Principles

Succeeding in the Engagement Process

- 5. Community partnerships are vital
 - 6. Respect community diversity & culture
 - 7. Mobilize community assets and develop capacity
 - 8. Maintain flexibility
 - 9. Commitment to collaboration
- 



Community
Empowered Research
to Inform Behavioral
Health Equity
(CERIE)

- Community-partnered collaboration centered on a comprehensive approach to community engagement for behavioral health equity and inclusion.
- UCSD partnership with Community Health Improvement Partners (CHIP) and the Global Action Research Center (Global ARC)
- Funded by the County of San Diego Behavioral Health Services System (BHS)
- Predicated on full community involvement at all phases of the project

Continuum of Community Engagement

Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

Outreach	Consult	Involve	Collaborate	Shared Leadership
<i>Some community involvement</i>	<i>More community involvement</i>	<i>Better community involvement</i>	<i>Community involvement</i>	<i>Strong bidirectional relationship</i>
<i>Communication flows from one to the other, to inform</i>	<i>Communication flows to the community and then back, answer seeking</i>	<i>Communication flows both ways, participatory form of communication</i>	<i>Communication flow is bidirectional</i>	
<i>Provides community with information</i>	<i>Gets information or feedback from the community</i>	<i>Involves more participation with community on issues</i>	<i>Forms partnerships with community on each aspect of project from development to solution</i>	<i>Final decision making is at community level</i>
<i>Entities coexist</i>	<i>Entities share information</i>	<i>Entities cooperate with each other</i>	<i>Entities form bidirectional communication channels.</i>	<i>Entities have formed strong partnership structures</i>
<i>Outcomes: Optimally, establishes communication channels and channels for outreach.</i>	<i>Outcomes: Develops connections</i>	<i>Outcomes: Visibility of partnership established with increased cooperation</i>	<i>Outcomes: Partnership building, trust building</i>	<i>Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.</i>

Source: Clinical and Translational Science Awards (CTSA) Consortium *Principles for Community Engagement* (2011)

CERIE AIMS



Aim 1: Develop a community engagement process rooted in approaches which promote community empowerment



Aim 2: CEnR approach to integrate community collaborators (e.g., community affected, community impacted, allies, advocates, interested parties, etc.) via a Community Partnership Council (CPC)

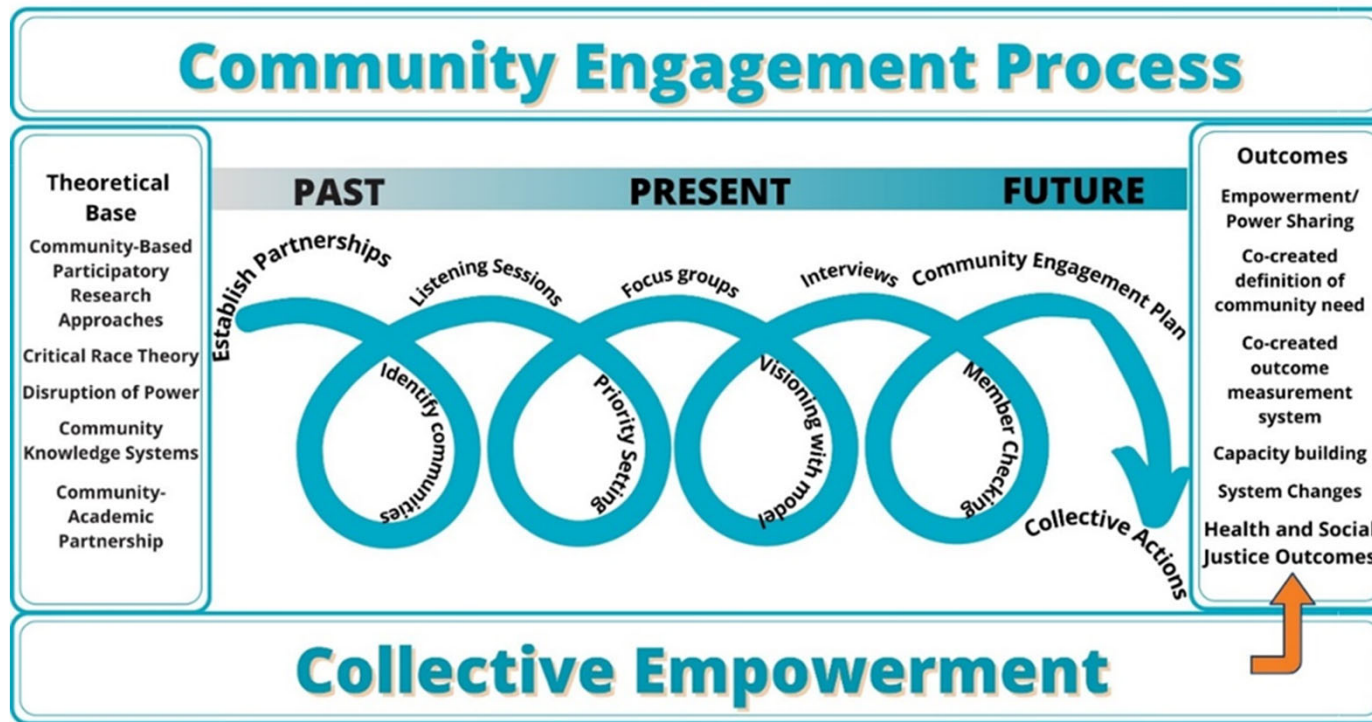


Aim 3: Conduct system-wide community engagement activities



Aim 4: Create a strategic plan to improve behavioral health service delivery for historically underrepresented populations.

Aim 1: Community Empowerment via Engagement



Adapted from Wallerstein et al (2020)

<https://engageforequity>

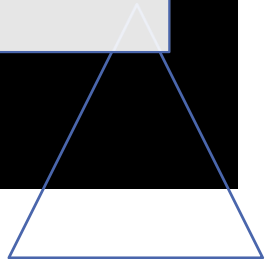


Aim 2: Develop & Implement a Community Partnership Council (CPC)

CPC will be “CAP” which will operationalize the “CEnR” approach

- Principles of cultural exchange
- Training & support for capacity building
- Collaborate on multiple, co-led approaches to determine & prioritize greatest system needs
- Undertake evaluation & feedback processes

CPC will engage in a collaborative planning process through a VMOSA (vision, mission, objectives, strategies, & action plan)





Aim 3: Systemwide Engagement

Representative of San Diego County

Priority communities (defined by state/county)

Activities include: listening sessions/forums, focus groups, interviews, & surveys






Aim 4: The Strategic Plan

Implement a Community-Engaged Approach
(Aims 2 + 3) to inform BHS program and policy
= community-driven evidence to inform BHS
decision-making



So...



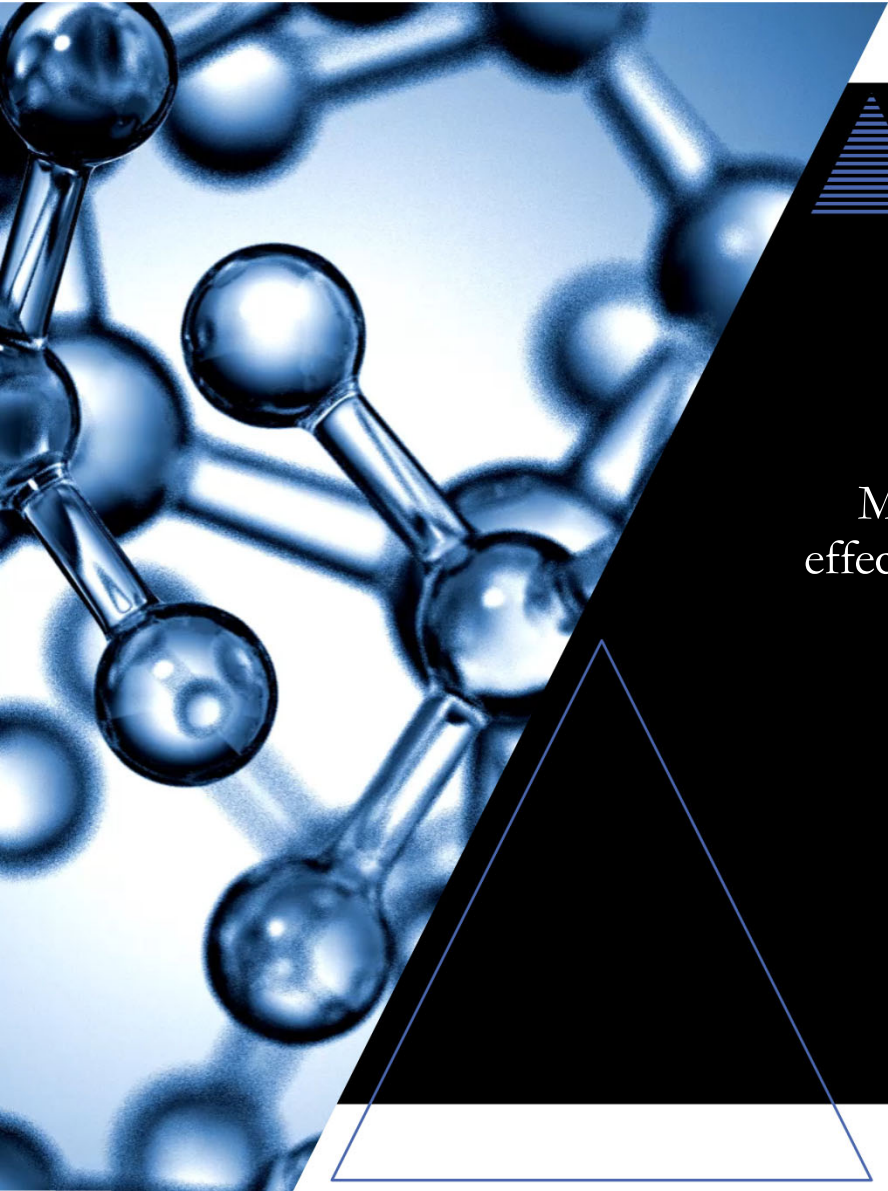
- Is CERIE effective in its approach?



“Engaging vulnerable community stakeholders in medical research is less of a controlled and predictable science than we might wish. Nevertheless, it seems curious that we invest millions of dollars in product development, clinical training, design and building of facilities, etc, but often leave vital processes of community engagement largely to trial and error.”

NEWMAN PA. (2006) TOWARDS A SCIENCE OF COMMUNITY ENGAGEMENT. LANCET.

DOI: 10.1016/S0140-6736(06)68067-7.



Measuring CERIE
effectiveness: Advancing
the Science of
Engagement

- While CEnR is increasingly accepted as essential to improving research quality & health outcomes – across scientific disciplines – the science of engagement effectiveness lags practice
- And, effective methods for engaging & facilitating inclusion of historically underrepresented communities as study partners presents a further knowledge gap
- How to understand power-sharing practices that create pathways toward health equity outcomes

Patient-Centered Outcomes Research Institute (PCORI)



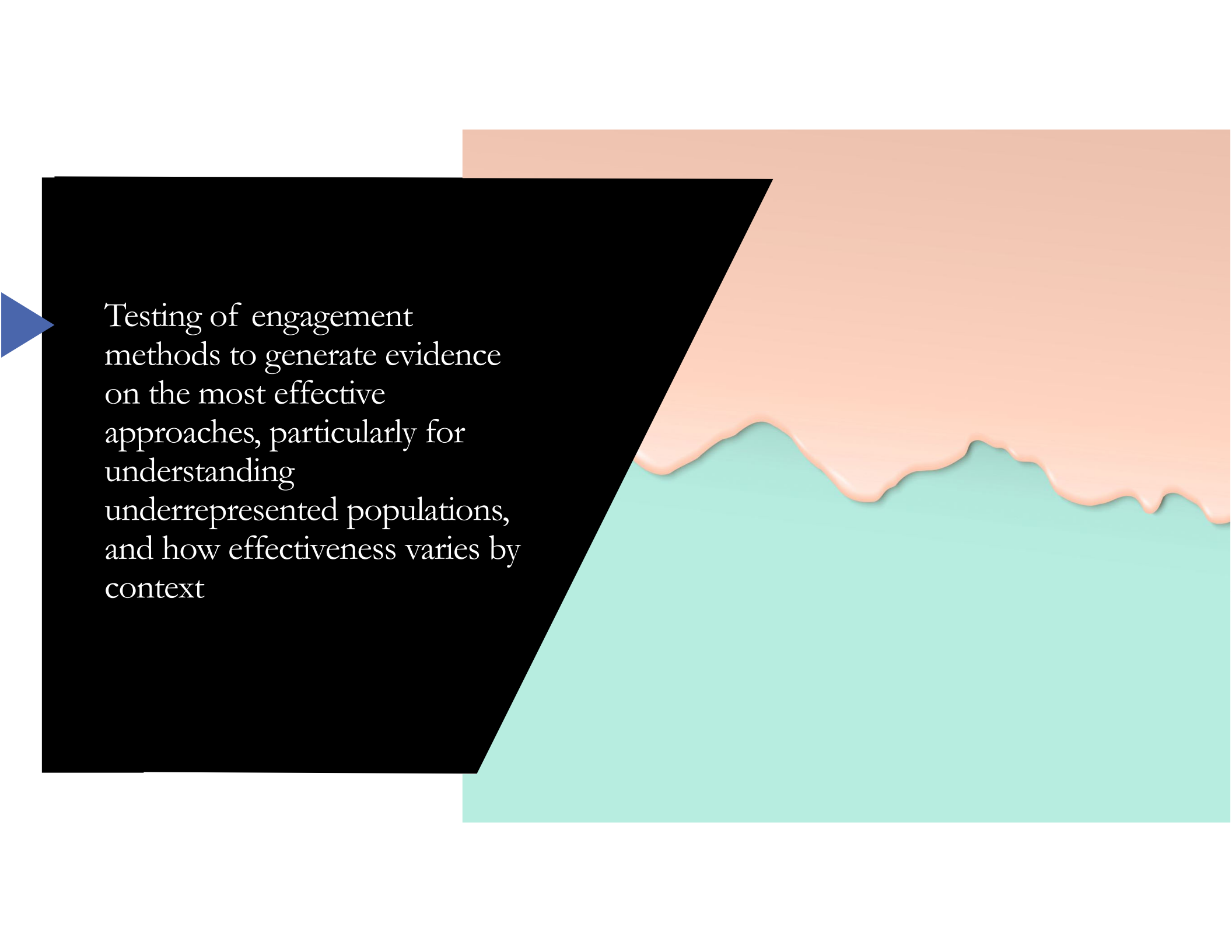
Funding Announcement to Advance the Science of Engagement (SoE): Address high-priority gaps in the SoE, focused on the evaluation of engagement methods



No consensus exists on how to measure the variety of aspects that constitute engagement, and little systematic study has examined what engagement methods are most effective



The long-term goal of the SoE initiative is to build an actionable evidence base that clearly identifies the methods & approaches that lead to effective engagement; how they should be modified & resourced for different contexts, settings, and communities to ensure equity in engagement and research; & how engagement supports patient-centered outcomes research



Testing of engagement methods to generate evidence on the most effective approaches, particularly for understanding underrepresented populations, and how effectiveness varies by context



SoE Study Aims

01


Define activities and behaviors that encompass a CERIE approach

02

Design a (comparative effectiveness) approach to understand which components predict engagement success and the mechanisms which underly them

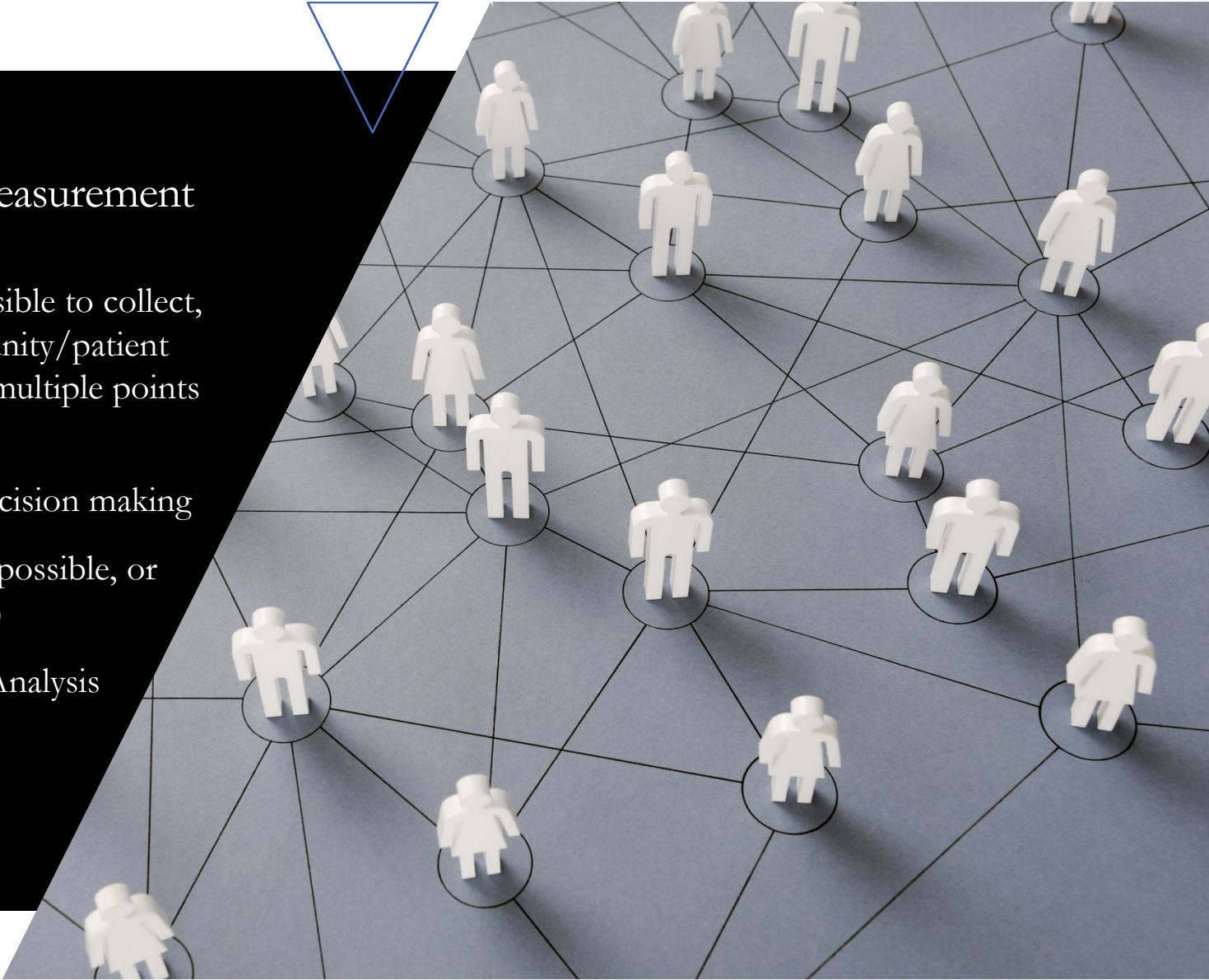
03

Demonstrate the effectiveness of CERIE components via a robust mixed-method approach





Aim 3: Evaluation/Measurement

- Metrics should be easy/feasible to collect, sensitive to change, community/patient centered, and measured at multiple points in time
 - Must support real-world decision making
 - Validated measures (where possible, or propose validation strategy)
 - Consider: Social Network Analysis
- 

Range of potential outcomes

Quality of engagement (e.g., engagement experience, partnership functioning, group dynamics)

Outcomes of engagement (e.g., trust among community members & researchers)

Impact of engagement methods on research process (e.g., collaborative decision-making)

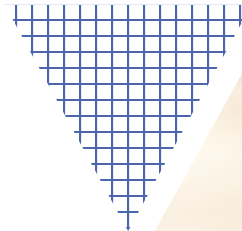
Near-term outcomes (e.g., timely completion of projects, representative participants)

How is BHS being responsive to needs identified by CE activities?



Who are participants?

What is design?





Potential Implementation Approach: 3-Phase Diffusion Model

01


Create the CPC

02

CPC becomes in-vivo implementation coaches for additional CPC waves in identified communities, until full diffusion is achieved

03

CPC shifts to maintenance function: ensuring system-wide, authentic community input in BHS program planning & policy





Challenges/ Discussion

- Thoughts on measurement? How to intersect validated measures with community co-creation?
- Possible diffusion model of CPC approach
- Community-led research and IS: Centering equity and generating community-driven evidence = implications for IS?



Thank You!



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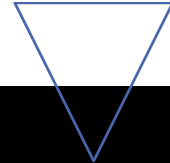
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CERIE: Year 1

- Goal: Creating a definition of community engagement according to the community
- What does community engagement mean to the community partners?



Overarching theme of CE: Building Trust

Transparent communication

Inclusivity

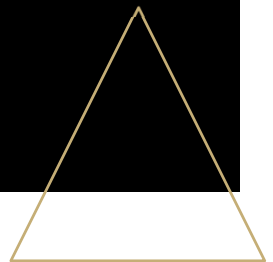
Credibility



How is CE effective (according to community)?

- Holding engagement activities in neighborhood/community spaces
- Participating in existing community meetings to connect with people “where they are” (i.e., shift research mentality – don’t expect community members to “go to” externally held engagement events)

“We just have to meet them where they are, and speak their language, as opposed to inviting them into our space.”

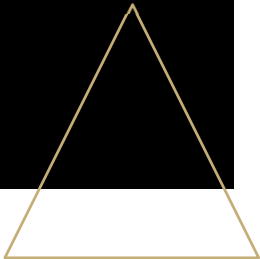





How is CE effective (according to community)?

- Holding engagement activities in neighborhood/community spaces
- Participating in existing community meetings to connect with people “where they are” (i.e., shift research mentality – don’t expect community members to “go to” externally held engagement events)
- How is input being used in program planning & decision-making
- Bidirectional communication! Feedback to the community that is clear & easy to understand

“We just have to meet them where they are, and speak their language, as opposed to inviting them into our space.”





“You know, what community engagement really, where the power is... is inviting people into a conversation or more, you'd hope, craving the opportunity to be invited into their conversation. You know, I think that that really is, you know, because ... the example for years, you know, creating a seat at the table for people, but the reality is, rather than creating a seat for them, let's give them a table. And, and hope they give us a seat at their table. Because we're gonna find out so much more about what works and what doesn't work.”