

Participatory & Community Engaged Approaches in Implementation Science

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Outline

- ▶ What are participatory and community engaged approaches?
- ▶ What are some examples of participatory/engaged frameworks and theories?
- ▶ Why and how do we use these approaches in implementation science?
- ▶ What are some examples of these approaches used in implementation science?
- ▶ What are the take-home messages?
- ▶ Where can I find resources and references?



What are
participatory &
community engaged
approaches?


DEFINING TERMINOLOGY

Defining key terminology

- ▶ **Community engaged research:** refers to research carried out “with or by” community members rather than research carried out “to, about, or for them”.
- ▶ **Community-based participatory research (CBPR):** research in which researchers and communities partner to design, implement, and disseminate research, with the primary goal of using research to affect change at the community level. Often iterative, and requires community members to set the agenda, not researchers.
- ▶ **Participatory action research (PAR):** a systematic data-gathering process involving those affected by a problem in a collaborative effort to design and conduct the research, that is then translated into action to address the root causes of the problem. Emphasizes building collective efficacy of those experiencing the problem being studied.
- ▶ **Participatory methods:** data collection activities and analysis carried out by non-researchers or with minimal prompting by researchers, with the goal of giving them a voice in problems and decisions relevant to their lives.

What they are...and are NOT

| Participatory approaches should be... | Participatory approaches should not be... |
|--|--|
| Orientation to science requiring partnership between communities & researchers | Specific to communities or community members—partners may be organizations, clinicians, leadership, etc. |
| Efforts to address inequities, decolonize research & practice by centering community needs | Driven by the needs/wants of the researcher |
| Collaborative and team-oriented | Siloed or individual-oriented |
| Sustained over a period of time | One-time or superficial events |
| Intentionally embedded into the study protocol | Unplanned |



What are some examples of participatory/engaged frameworks and methods?



THEORIES AND METHODS

CBPR and PAR

- ▶ Both frameworks that provide processes for conducting community engaged research in which community members are engaged in all aspects of the research
 - ▶ Developing the research question/area of concern and research protocols
 - ▶ Implementing the research
 - ▶ Disseminating findings and translating to solutions
- ▶ Emphasize co-learning, empowering communities
- ▶ Often iterative processes of planning, research, evidence-building
- ▶ Emphasizes physical, mental, and social well-being, and an ecological/multi-level determinants of health approach

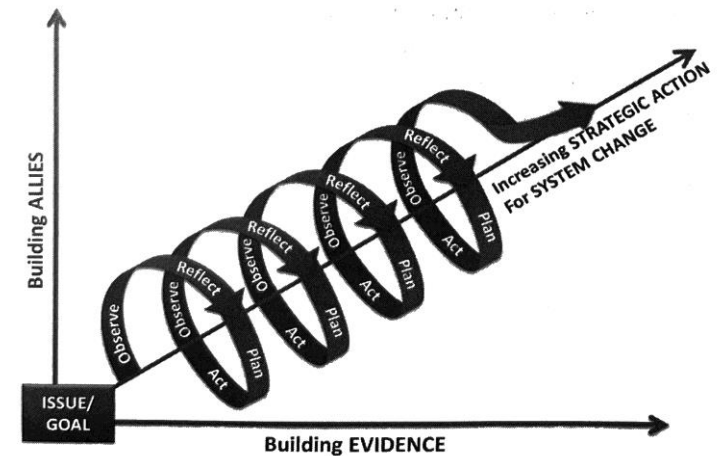


FIGURE 1.1 Participatory Action Research (PAR) spiral. Mosher and Schensul.

From Schensul & LeCompte 2016,
Ethnography in Action



Community-engaged approaches emphasizing study design and methods from the perspectives of patients/users



Partner with patients, caregivers, other users to develop research questions, recruitment, ensure the utility of the research for the users



Emphasis on co-creation/co-design

Patient-centered/User-centered Research

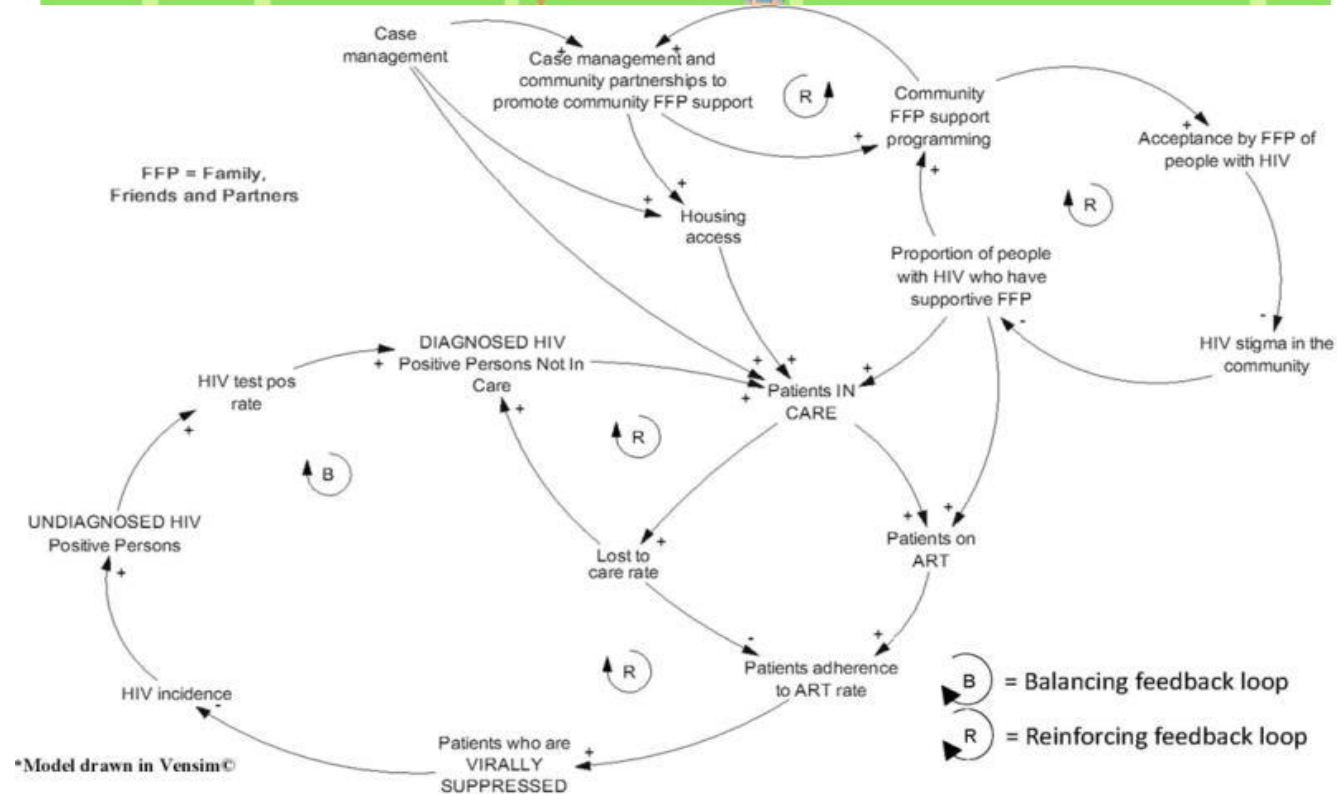
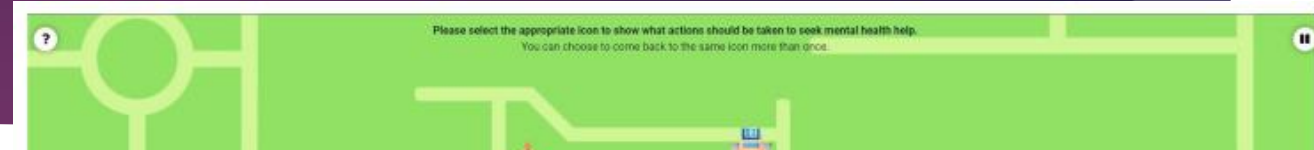
Photovoice & Other Visual Participatory Methods

- ▶ Allow individuals to create visual records of their community's strengths and challenges
- ▶ Initiates discussion and dialogue, reaching policymakers
- ▶ Includes photography, film, drawing, collage, design, theater
- ▶ Has been used with various communities, including those with disabilities that might make participation/engagement in other forms of research difficult



Participatory Process Mapping & Systems Modelling

- ▶ Process mapping creates a picture of how a pathway works, and places it doesn't
- ▶ Participatory systems dynamics modelling is like process mapping on a larger scale, usually entails multiple processes/systems interacting with each other
- ▶ Including a range of stakeholders offers different perspectives on the process or systems
- ▶ The process of developing the visuals is important, requires engagement
- ▶ Helpful for understanding process of implementing a service




Design Thinking Tools (prototyping, mind mapping, stakeholder analysis, etc.)

Cultural domain and cultural consensus elicitation and analysis



Qualitative vignettes

Focus group discussions



Qualitative Elicitation Techniques

Quiz: Are these community-engaged/participatory?

- ▶ Scenario 1: A researcher wants to understand factors influencing maternal and child health in a community hospital where she has never worked before. She decides to conduct 2 focus groups with mothers on their experiences accessing antenatal and postnatal care, and will publish the findings in a scientific journal. 
- ▶ Scenario 2: A researcher has been working on maternal and child health with a community hospital for 2 years. At a community advisory meeting, stakeholders describe challenges with maternal mortality and morbidity. They would like to explore causes and solutions. The researcher and the stakeholders partner to design and implement the study, which includes focus group discussions and a quantitative needs assessment. The findings will be published in a scientific journal and shared at the community advisory meetings. 

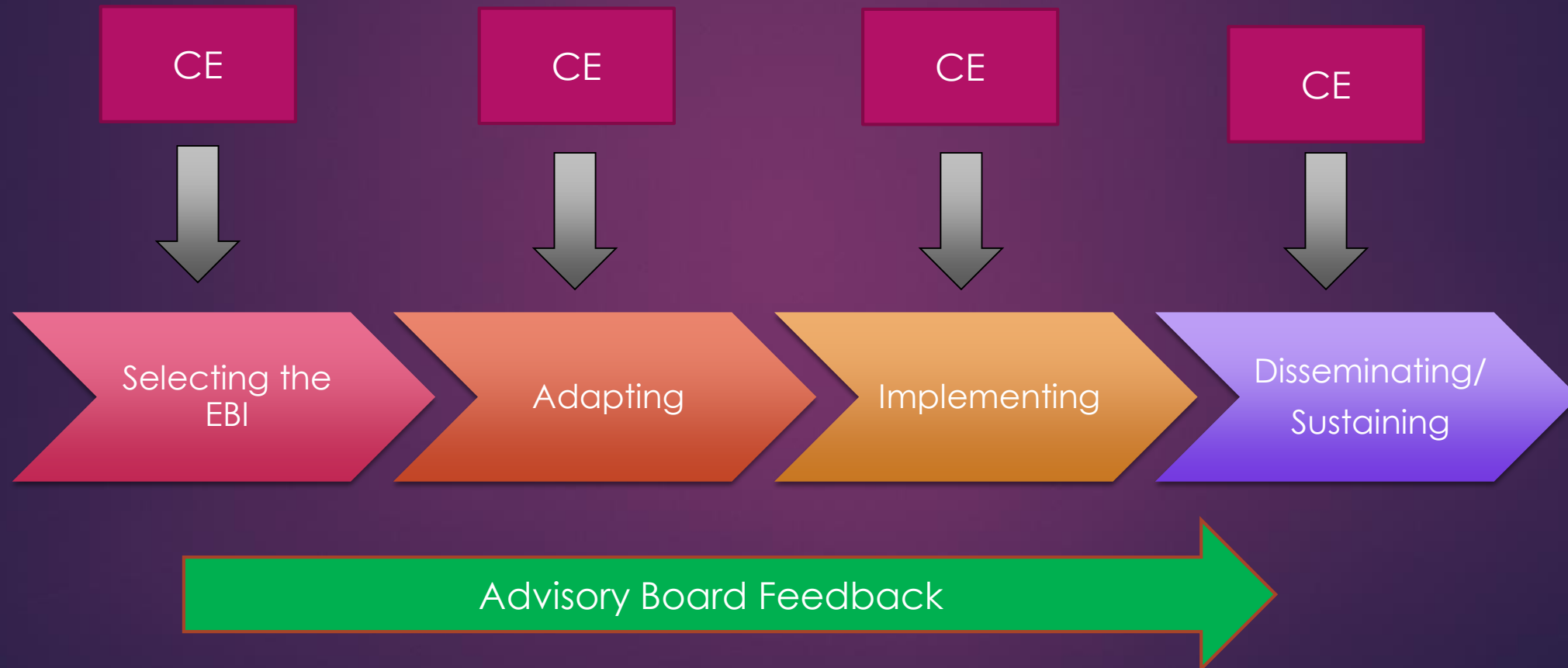
Why and how do we
use these
approaches in
implementation
science?


WHY IMPLEMENTATION SCIENCE
SHOULD ENGAGE USERS

Rationale for Using Community Engagement in Implementation Science

- ▶ Implementation science is usually carried out by teams, and is multidisciplinary to begin with
 - ▶ Community engaged approaches are also team-oriented and can help build trust and collaboration
- ▶ Successful implementation requires coordination across stakeholders and (potentially) organizations
 - ▶ If stakeholders do not understand or agree with the intervention, they may be disinclined to support implementation
 - ▶ Stakeholders can offer insights into barriers/facilitators of implementation
- ▶ Evidence-based interventions may need some adaptation before implementation
 - ▶ Understanding what and how to adapt the intervention requires stakeholder insights

Community/Stakeholder Engagement Across the Implementation Process





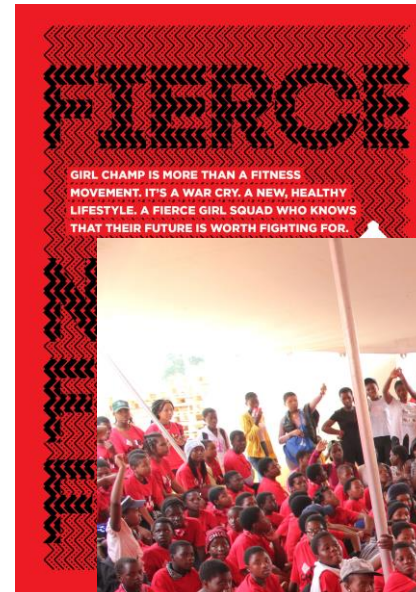
How have people
used these
approaches in
implementation
research?



EXAMPLES FROM THE LITERATURE

CE to Assess Needs & Identify the EBI

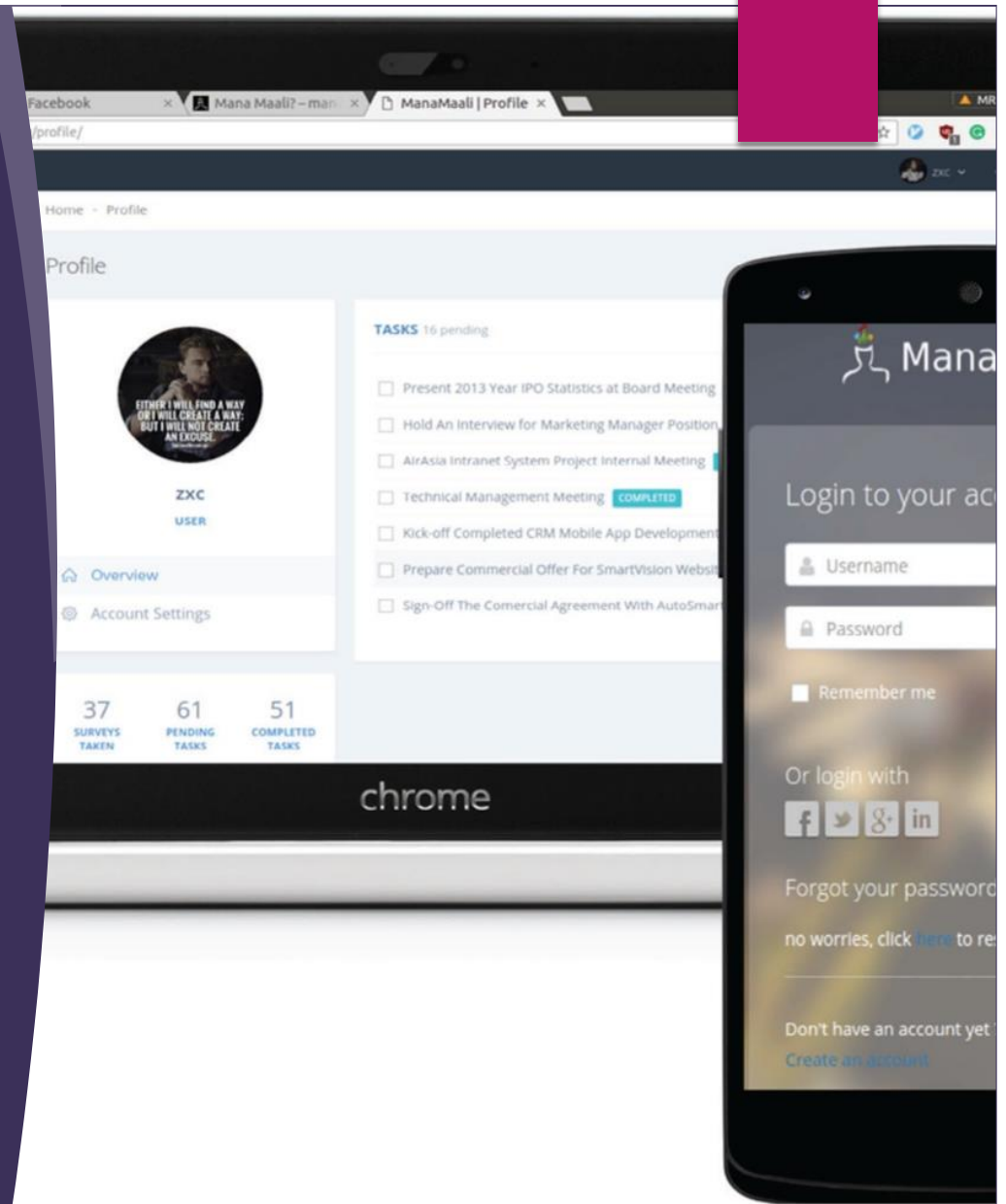
- ▶ Formative research involving CE can help with initiating research, assessing needs, and choosing the relevant EBI for implementation
- ▶ Girl Champ in eSwatini used modified photovoice activity and community advisory boards
- ▶ Identified needs for better implementation of youth-friendly services and different communication approach
- ▶ CE made the resulting program more effective by emphasizing needs of girls, working through existing community structures, and building on existing resources



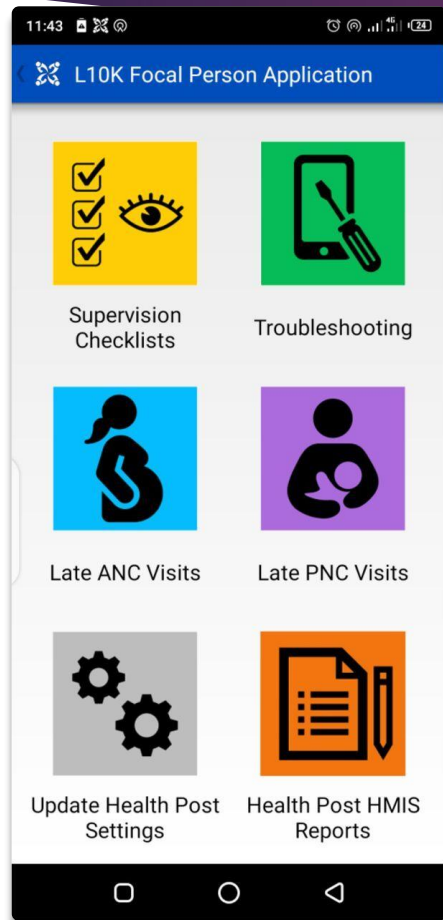
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CE to Adapt an EBI

- ▶ EBIs are often developed and tested elsewhere and require adaptations to local context
- ▶ Example: The Mana Maali digital CBT anxiety program in India
- ▶ Employed theatre testing and focus group discussions
- ▶ Participants used the program, and then discussed usability, acceptability, feasibility



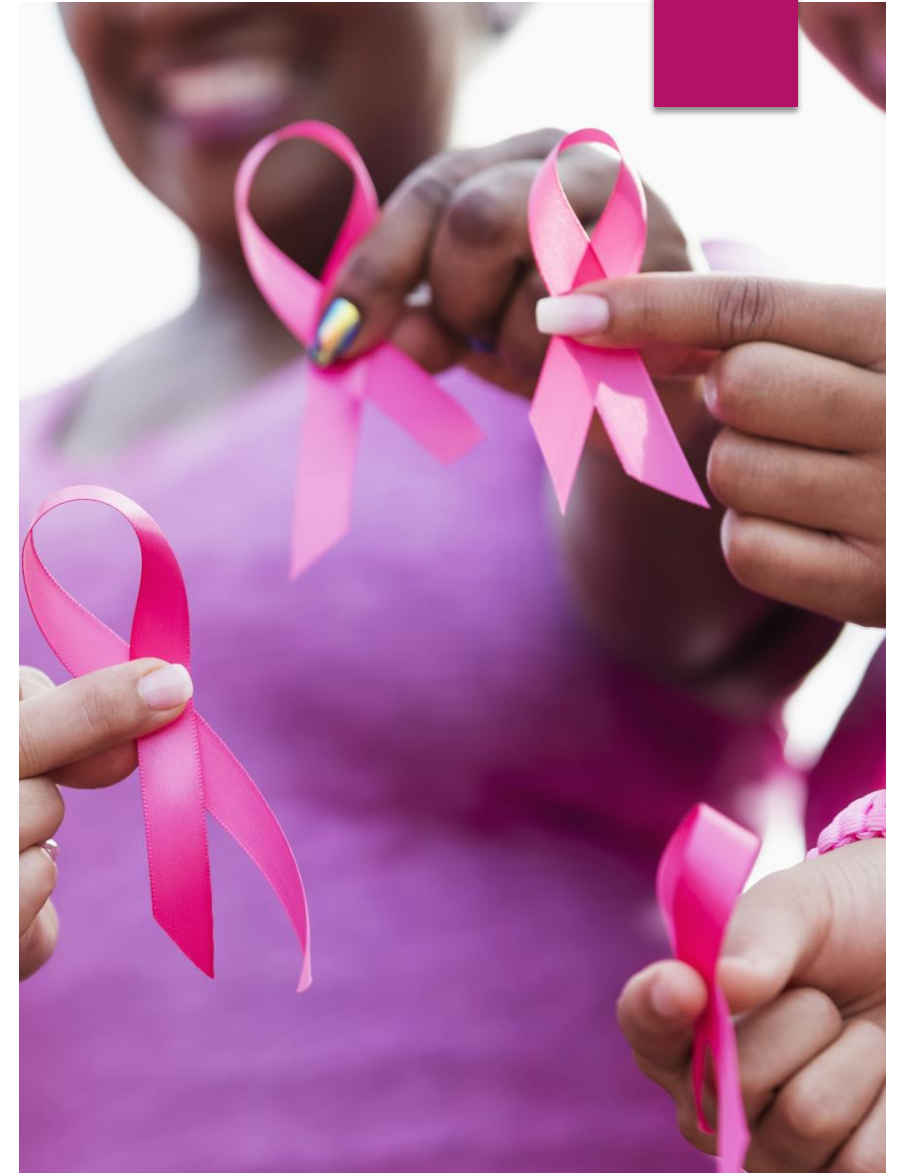
CE during Implementation of the EBI



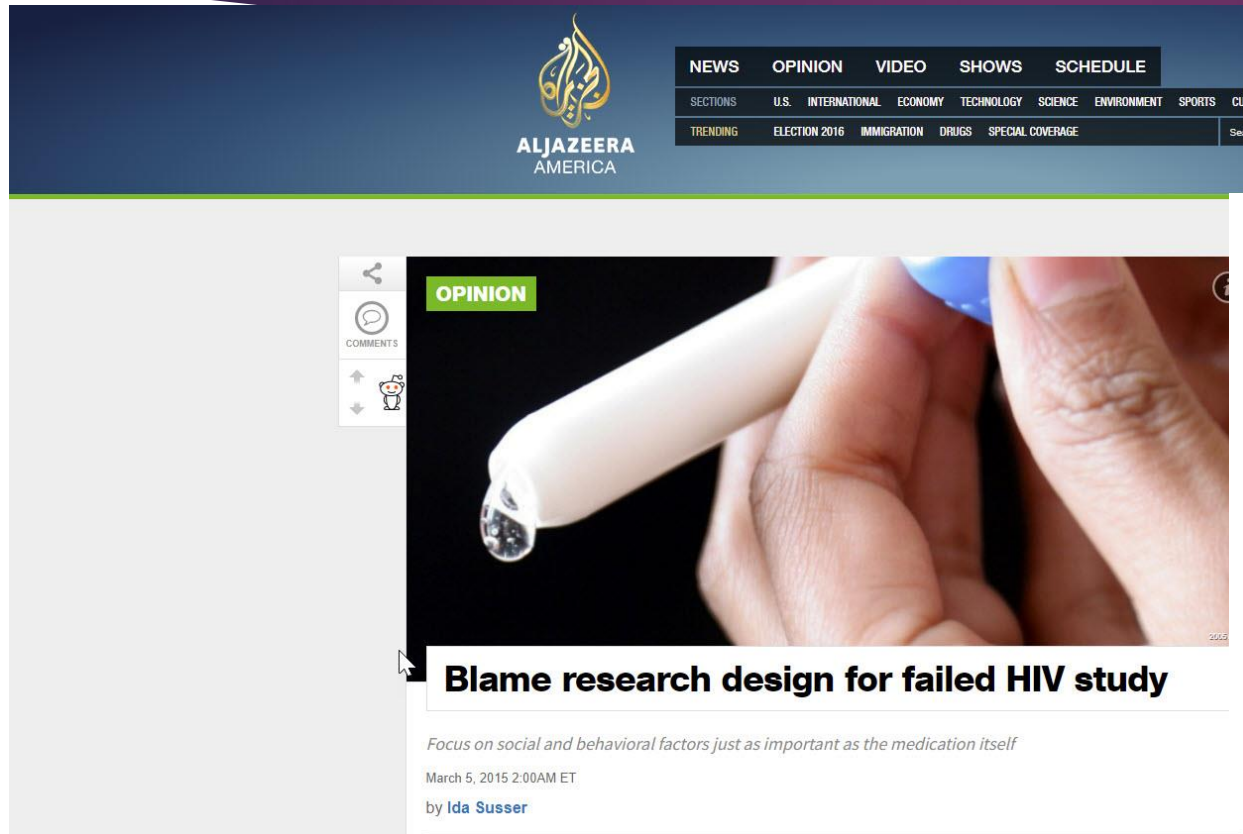
- ▶ Over the course of implementation, CE can occur through advisory boards
- ▶ Community/stakeholders may have a significant role in implementing and may be responding to implementation data collection instruments
- ▶ Example: The Last Ten Kilometers 2020 Project (L10K 2020) in Ethiopia to improve the timeliness and quality of maternal and neonatal primary care
- ▶ Used stakeholder engagement across the healthcare system, throughout the study, to ID implementation barriers and facilitators

CE for Dissemination & Sustainment

- ▶ Need plans for maintaining implementer and stakeholder buy-in
- ▶ Sustaining EBIs may require shifting to community/stakeholder-led implementation
- ▶ Example: The Peace of Mind Program (PMP) in Texas to improve mammography adherence
- ▶ 3 key stakeholder groups were ID'ed at each site: decision-makers, program champions, and patient navigators
- ▶ CE was integrated into all stages including sustainment, with regular meetings
- ▶ Stakeholders were supported by research team to build efficacy to continue implementation



Failures in CE Contribute to Failures in Science



The screenshot shows the Al Jazeera America website header with navigation menus for NEWS, OPINION, VIDEO, SHOWS, and SCHEDULE. Below the header is a large image of a hand holding a white pill with a blue cap, with a single drop of liquid falling from the pill. The article is categorized as 'OPINION' and has a sub-header 'Blame research design for failed HIV study'. The byline reads 'Focus on social and behavioral factors just as important as the medication itself' by Ida Susser, dated March 5, 2015 2:00AM ET.

OPINION

Blame research design for failed HIV study

Focus on social and behavioral factors just as important as the medication itself

March 5, 2015 2:00AM ET
by [Ida Susser](#)

The VOICE study appeared to lack sufficient community involvement. CAPRISA 004 focused on women in Durban (as did VOICE) and in Vulindlela, a rural area outside Durban. First securing the support of local Zulu chiefs, CAPRISA developed widespread community engagements in Vulindlela. Doctors attended local council events, and the clinic provided AIDS treatment. It is significant that CAPRISA 004's results were much better in Vulindlela than they were in Durban. Women in rural areas have historically been more constricted by patriarchal relations, more suspicious of drugs dubbed toxic by traditional leaders and, therefore, less likely to adhere to preventive measures than urban-based women. The data suggest that the long-term, substantive community engagement in Vulindlela boosted women's cooperation. Rather than build on these important successes, VOICE apparently did not adequately consider the social situations of the women in its study.

Bottom-up research design may improve results, but this takes time, costs money and disrupts accepted hierarchies. Because funders and donors may not recognize the need to build in the costs of community engagement, studies are more likely to focus on pharmaceutical methods than on strong investment in local participation. But as we have learned from decades of AIDS research and recently with Ebola, without ongoing community involvement, it is not possible to effectively address an epidemic.

What are the take-home messages?

CONCLUSIONS

Conclusions

- ▶ If communities will not use or
- ▶ Funding agencies are engaging
- ▶ There are many matching the
- ▶ Community engagement research

ut-community-research-not-possible-community-engagement-tb-research

Syllabi from Gender... R Home - Anthro 344... HA On Racism: A New... Introduction to Imp... Online Certificate in... W Implementation Sci... Preventing COVID-... The Well-Being Ind...

Without Community, Research is Not Possible: Community Engagement in TB Research

When TB Alliance was formed, there had been no late-stage tuberculosis (TB) research trials conducted to modern standards. In addition to meeting modern regulatory standards, a feature of clinical trials that emerged since previous TB drugs were developed was community engagement (CE) in research. In spearheading the next generation of TB drug development, [TB Alliance built global capacity for modern TB research](#), including pioneering and standardizing CE as a critical component of TB drug clinical trials.

CE consists of a variety of programs and tactics to ensure TB affected community stakeholders—where research is taking place—are sufficiently informed about the research and are empowered to engage in the research process. CE enables open and consistent dialogue between researchers and the community and helps to strengthen relationships between researchers and the communities they involve in clinical trials. TB Alliance established its CE program around [the REMox TB trial](#), drawing on experiences from the HIV/AIDS research space, and working with partners across both the HIV and TB research field to ensure consistency and shared expectations. Since then, TB Alliance CE programs have expanded geographically and in scope, cementing CE as an integral part of TB treatment research.



Engaging Communities to Improve TB Research
from TB Alliance

05:41 vimeo

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Where can I find
references and
resources to help
me?

A STARTER LIST

Literature and Online Resources

- ▶ IM-ADAPT: <https://www.imadapt.org/#/>
- ▶ www.Photovoice.org
- ▶ www.participatorymethods.org
- ▶ [www. https://www.rapidresearchandevaluation.com/](https://www.rapidresearchandevaluation.com/)
- ▶ Schensul and LeCompte, *The Ethnographer's Toolkit, Second Edition* book series
- ▶ Wang and Burris, 1997, *Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment*
- ▶ Schlecter, et al. 2021, *Application of community-engaged dissemination and implementation science to improve health equity*
- ▶ Meissner, et al. 2020, *Engagement science: The core of dissemination, implementation, and translational research science*
- ▶ Polidano, et al. 2022, *Community engagement in Cutaneous Leishmaniasis Research in Brazil, Ethiopia, and Sri Lanka: A Decolonial Approach for Global Health*

Literature and Resources, Continued

- ▶ McKay, et al. 2020, Implementation science in global health settings: Collaborating with governmental & community partners in Uganda
- ▶ Ramanadhan, et al. 2018, Participatory implementation science to increase the impact of evidence-based cancer prevention and control
- ▶ Le, et al. 2022, Barriers and facilitators to implementation of evidence-based task-sharing mental health interventions in low- and middle-income countries: a systematic review using implementation science frameworks
- ▶ Last, et al. 2021, A pilot study of participatory and rapid implementation approaches to increase depression screening in primary care
- ▶ Mlambo, et al. 2019, Experiences from a community advisory board in the implementation of early access to ART for all in Eswatini: a qualitative study
- ▶ Fort, et al. 2019, Stakeholder engagement in the translation of a hypertension control program to Guatemala's public health care system: lessons learned, challenges, and opportunities
- ▶ Mugo, et al. 2020, From research to international scale-up: stakeholder engagement is essential in successful design, evaluation and implementation of paediatric HIV testing intervention