Strengthening community-academic partnerships in HIV implementation science:
An assessment of community-engaged research among Ending the HIV Epidemic awardees

3rd National Ending the HIV Epidemic Partnerships for Research Meeting
April 15-16, 2024 I Los Angeles, CA

Reva Datar, PhD, MPH
Postdoctoral Fellow
Johns Hopkins Bloomberg School of Public Health
rdatar1@jh.edu
Disclosures

- No conflicts of interest to disclose.
Acknowledgements

Advisory Committee

• Carl Highshaw, The AMAAD Institute
• Danielle Estes, Ladies Empowerment and Action Program Inc.
• Alejandra Grillo Roa, Entre Hermanos
• Gustavo A Morales Correa, Latino Commission on AIDS
• Crissy Irani, Institute for Community Partnerships (LLUH)
• Christopher Archiopoli, Peer Washington
• Lissette Marrero, Voces Latinas
• Krystle Culbertson, LEAP/UM
• Pedro Alonso Serrano, CQL Collaborative
• Debbie Humphries, Yale University
• David Katz, University of Washington
• Jessica Sales, Emory University
• April Pettit, Vanderbilt University
• Hina Ahmed, Vanderbilt University
• Robin Gaines Lanzi, University of Alabama Birmingham
• Audrey Harkness, University of Miami
• Jonathan Ross, Albert Einstein
• Carolyn Audet, Vanderbilt University

JHU CFAR Team

• Laura Beres, Principal Investigator
• Sheree Schwartz, Co-Investigator
• Stefan Baral, Co-Investigator
• Joseph Gregory Rosen, Co-Investigator
• Wilson Gomez, Data Analyst

This work was funded by the NIH-funded Mid-Atlantic CFAR Consortium (MACC+) Implementation Science Consultation Hub [HU CFAR P30AI094189] and Tennessee Center for AIDS Research [P30 AI110527]
Background

Since 2019, 248 EHE implementation science awards provided across the United States

The EHE initiative has an explicit goal of “strengthening research-community collaborations” among local and state health departments, communities, service providers, and research institutions.

Community engagement in research has been shown to address:
- Underlying social and structural determinants of health that contribute to health inequities
- Barriers embedded in existing healthcare systems that hinder the ability to serve HIV-affected communities

However, more information is needed to understand how to optimally design, implement and support community-academic partnerships engaging in research.

Ending the HIV Epidemic Dashboard. [https://hivmpsci.northwestern.edu/ehe-project-dashboard/](https://hivmpsci.northwestern.edu/ehe-project-dashboard/)
Study Overview

**Study objective:** To measure and describe successes and challenges in community-engaged research among academic- and community-based partners engaged in EHE activities to improve opportunities for future collaborations.

**Aim 1:** What does meaningful engagement in community-engaged research (CEnR) activities mean to awardees?

*Method:* Online survey  
*Participants:* 2021 and 2022 EHE Supplement Awardees

**Aim 2:** What are barriers and facilitators associated with meaningful engagement in community-engaged research?

*Method:* semi-structured interviews  
*Participants:* Aim 1 survey respondents

**Aim 3:** What are key priorities associated with community-engaged research in HIV implementation science among academic and community partners?

*Method:* best-worst scaling (online preferences survey)  
*Participants:* 2021 and 2022 EHE Supplement Awardees

**Timeline:**
- **July – Dec 2023**
- **Apr-May 2024**
- **May-Aug 2024**
Aim 1 Survey Measures

Level of Community Engagement

Equity Indicators:
- Power and control
- Ownership
- Decision-making
- Responsibility
- Influence
- Resource-sharing
- Mutual benefit

Contextual Factors:
- History
- Trust
- Relationship building
- Respect
- Transparency

Adapted from Key et al., 2019

Partnership Trust

- Open
- Truthful
- Communicative
- Dependability

Adapted from CDC, 2020


Survey measures (continued)

Community Involvement in Research

- Grant writing
- Analyze
- Collect Data
- Implement
- Recruit

Principles of Community Engagement

- Seek and use the input of community partners
- Foster co-learning, capacity building and co-benefit
- Facilitate collaborative, equitable partnerships
- Integrate and achieve a balance of all partners
- Involve all partners in the dissemination process
- Disseminate findings and knowledge to all partners

Adapted from Khodyakov et al., 2013

Adapted from Goodman et al., 2017

---


Aim 1 Results: Participant Characteristics

Response Rate
- Of 102 possible projects, we received completed surveys for n=54 (53%).
- Of these, n=22 (41%) projects included data from academic and community partner pairs.

<table>
<thead>
<tr>
<th>Race</th>
<th>Academic (n=53)</th>
<th>Community (n=29)</th>
<th>Total (n=82)</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian or Alaska Native</td>
<td>3%</td>
<td>9%</td>
<td>3%</td>
</tr>
<tr>
<td>Asian</td>
<td>15%</td>
<td>13%</td>
<td>15%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>White</td>
<td>1%</td>
<td>0%</td>
<td>1%</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islander</td>
<td>3%</td>
<td>0%</td>
<td>3%</td>
</tr>
<tr>
<td>Multiple Races</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Not Reported</td>
<td>58%</td>
<td>15%</td>
<td>73%</td>
</tr>
</tbody>
</table>

Participant Demographics: Gender
- Female: 57%
- Male: 3%
- Non-binary: 1%
- Transgender man: 3%
- Transgender woman: 0%
- Not Reported: 3%

Number of community-academic partnerships (CAPs) prior to EHE award

<table>
<thead>
<tr>
<th>Number of CAPs (Median; [IQR])</th>
<th>Academic (n=53)</th>
<th>Community (n=29)</th>
<th>Total (n=82)</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 [2, 12]</td>
<td>4 [1, 7]</td>
<td>7 [2, 12]</td>
<td></td>
</tr>
</tbody>
</table>
Level of Community Engagement: Anticipated vs. Actual (n=81)

41/53 (77%) academics reported expecting higher engagement than they actually experienced.

20/28 (71%) community partners reported expecting lower levels of engagement than they actually experienced.
Principles of Community Engagement: Average Quality Scores

### Total Sample (n=80)

- **Disseminate Findings and Knowledge Gained to All Partners**: Poor (3.1), Excellent (4.18)
- **Involve All Partners in the Dissemination Process**: Poor (2.92), Excellent (4.18)
- **Integrate and Achieve a Balance of All Partners**: Poor (3.8), Excellent (4.18)
- **Facilitate Collaborative, Equitable Partners**: Poor (3.8), Excellent (4.18)
- **Foster Co-Learning, Capacity Building, and Co-Benefit for All Partners**: Poor (3.83), Excellent (4.18)
- **Seek and Use the Input of Community Partners**: Poor (3.96), Excellent (4.18)

### Community (n=52) vs. Academic (n=52)

- **Disseminate Findings and Knowledge Gained to All Partners**: Community: Poor (3.4), Excellent (3.6); Academic: Poor (2.9), Excellent (3.7)
- **Involve All Partners in the Dissemination Process**: Community: Poor (3.5), Excellent (4.0); Academic: Poor (2.6), Excellent (4.3)
- **Integrate and Achieve a Balance of All Partners**: Community: Poor (4.3), Excellent (4.1); Academic: Poor (4.1), Excellent (3.7)
- **Facilitate Collaborative, Equitable Partners**: Community: Poor (4.0), Excellent (3.7); Academic: Poor (3.7), Excellent (4.0)
- **Foster Co-Learning, Capacity Building, and Co-Benefit for All Partners**: Community: Poor (4.2), Excellent (3.7); Academic: Poor (3.7), Excellent (4.3)
- **Seek and Use the Input of Community Partners**: Community: Poor (4.0), Excellent (3.9); Academic: Poor (3.9), Excellent (4.2)
Community Involvement in Research Activities

High community engagement reported for recruitment and primary data collection, and intervention implementation activities.

Low engagement reported in early stages of research process including grant writing, background research, choosing research methods.
Partnership Trust

While receiving overall high scores, “trust” components including power sharing, dependability, and clear communication received lower scores.
Other components of meaningful engagement: Qualitative findings

- Sociocultural responsiveness
  “Our project involves staff at CBOs… many of them share the intersecting identities we are addressing in our project: Latinx, immigrants, limited English proficiency, LGBTQ, HIV positive, underpaid/overworked. It was very important to acknowledge this and make space for our different identities and needs.” -- Academic Partner

- Intentionality
  “One of the keys to a successful partnership is being intentional at the beginning of the project about defining roles, responsibilities, expectations, and goals. Just saying "we want you to be equitable partners" doesn't necessarily result in a change in approach…” -- Community Partner

- Study feasibility
  “Academic partners often design unrealistic studies, that somehow pass Center/NIH review… Community partners are often burdened with fixing these studies and/or implementing a study they could have said from the outset would not be feasible. Due to rushed timelines for supplement submissions, there is little time for this kind of constructive criticism to be provided at the design phase, leaving community members feeling obligated to participate in burdensome and difficult research projects.” -- Community Partner

- Finance and administrative barriers (e.g., IRB barriers)
Implications

• EHE IS awards have largely resulted in active, trustworthy community collaborations and decision-making that includes both academic and community partner perspectives.

• Challenges persist in aligning expectations of community engagement with implementation.

• Differing interpretations of terms commonly used in community engagement may pose a challenge to measuring level of engagement (e.g., community involvement vs. community participation). More work is needed to establish consistency in defining/interpreting CEnR-related terms.
Implications

• Further research is needed to understand **how** community partners want to be involved in the research process and **what kinds of changes** can be made to facilitate improved meaningful engagement in projects funded through EHE awards.

• Strategies are needed to **improve equity** in power sharing, clear communication, and dependability among community-academic partnerships.

• **Structural changes** within the systems that facilitate partnerships are needed (e.g., feasible submission timelines, administrative support to facilitate grant funds) to more fairly recognize the important contributions of community partners and prevent placing additional burden on these organizations.