Community-Led Research: The Role of Communities in Successful Biomedical HIV Research

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Outline

• Definitions: what is community-led research?
• Why is community engagement essential for HIV biomedical research?
• When/how should a partnership be developed?
• What are the roles of researchers & community stakeholders?
• What issues need to be addressed at the beginning of this partnership?
Language matters

- Community-led research
- Community-based research
- Community-informed research
- Community-engaged research
- Community-based participatory research/practice

Community-led research does not just mean “research done in community settings” or “community based interventions”
Community Engaged Research

“The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”

- Centers for Disease Control and Prevention
SHORT GUIDE TO COMMUNITY BASED PARTICIPATORY ACTION RESEARCH
Adapted from Wilder Foundation  https://www.wilder.org/articles/using-framework-community-engaged-research
<table>
<thead>
<tr>
<th></th>
<th>TRADITIONAL</th>
<th>COMMUNITY ENGAGED</th>
<th>CBPR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection of Research Topic</td>
<td>Based on epi data &amp; funding opportunities</td>
<td>Community identifies relevant issues</td>
<td>Community identifies important issues</td>
</tr>
<tr>
<td>Study Design</td>
<td>Based on scientific rigor &amp; feasibility</td>
<td>Community ensures acceptability</td>
<td>Community intimately involved with design</td>
</tr>
<tr>
<td>Recruitment &amp; Retention</td>
<td>Based on literature &amp; “best guesses”</td>
<td>Community consulted on strategies</td>
<td>Community guides and aids recruitment</td>
</tr>
<tr>
<td>Instrument Design</td>
<td>Instruments adopted/adapted from other studies.</td>
<td>Instruments adopted &amp; tested/adapted to fit local populations</td>
<td>Community developed instruments</td>
</tr>
<tr>
<td>Data Collection</td>
<td>Conducted by academics</td>
<td>Community involved in some data collection</td>
<td>Conducted by community, if feasible; focus on capacity building</td>
</tr>
<tr>
<td>Analysis &amp; Interpretation</td>
<td>Researchers own the data, analyze &amp; interpret findings, publish in peer review journals</td>
<td>Results shared with community for interpretation; dissemination includes community venues</td>
<td>Data shared; community &amp; researchers interpret; wider community dissemination</td>
</tr>
</tbody>
</table>
Transgender People and HIV

- Data gaps for almost all low and middle income countries
- Trans people can also be prisoners, sex workers, PWID...

- **25 million** transgender adults worldwide
- Estimated global HIV prevalence of **19%** among transgender women
- Transgender women are **49 times** more likely to live with HIV
- Transgender women sex workers have a **12 times** higher risk of HIV acquisition

**Prisoners**
- **5-10%** TW have been incarcerated (USA)
- **38%** TW prisoners have been sexually assaulted in prison (USA)

**Sex Workers**
- **50%** TW have been sex workers (USA)

**MSM**
- **20-30%** transgender men have sex with cis men (USTS 2015)
- Often excluded from MSM programming or programs don’t include reproductive health concerns/cancer screening

**PWID**
- High rates of substance use, few data on # trans PWID
- Needle sharing for silicone/hormones – data gap

Sources: WHO; UNAIDS; Baral S, 2013; Winter S, 2016
HIV and Transgender People in the US

Prevalence

• USA (all adults): 0.39%

• Transgender women 14.1% (8.7%, 22.2%)*
  • Black 44.2%
  • Hispanic 25.8%
  • White 6.7%

• Transgender men 3.2% (1.4%, 7.1%)*

* Lab confirmed

Trans People & Engagement in Research

Individual Factors:
- Knowledge
- Fear of Side Effects
- Impact on Hormones
- Medical/Research Mistrust

Research Team:
- Trans-Identified Staff
- Trusted Facility
- Cultural Humility
- Community Partners

Research Topics:
- Community Priority
- Accessible to Community

Structural Factors:
- Forms/ID
- Logistics/Time
- Transportation
- Housing
- Compensation

What are the Benefits of Community-engagement for Researchers?

• Helps to identify community priorities
• Input into study design help to make tools and interventions culturally appropriate
• Builds trust between researchers & communities & future collaborations
• Improves communication, address community concerns
• Increases participation and retention
• Improves dissemination of results to communities
Protests at the International AIDS Conference 2004 about early PrEP trials
- Community involvement must happen at all stages of research
- Power of advocacy
- Importance of transparent communication
What are Benefits for Community Stakeholders?

• Address important disparities in the community
• Ensure research conducted is culturally relevant
• Create/protect jobs
• Build research infrastructure
• Reduce power imbalance
• Identify risk associated with participation and help develop appropriate ways to protect participants
  – ethical, political, and logistical concerns
• Research may be more likely to lead to improvements in community health
How to Build Authentic Community-Researcher Partnerships

- Respect
- Mutual Understanding
- Transparency
- Community Stakeholder Accountability
- Integrity
- Accountability
Considerations for Community Stakeholders

- Who are the researchers? Can we work with them?
- Have they previously worked with our communities?
- Is there a commitment/experience to community engagement?
- What will be our level of participation?
- How will it benefit us?
- How will we be compensated for our contributions?
- Do we have the bandwidth?
- What resources (time, money, space) are needed?
- What about the research burden on our community?
- How will people provide input?
- Can we maintain commitment?
Considerations for Researchers

• Why do you think your research is aligned with community needs?
• What are your research interests & why do you do this work?
• What experience do you have working with community stakeholders?
• How will stakeholders involved? Study design? Recruitment? Publications?
• Can you cope with the realities of working with community stakeholders? Conflicts of commitment, institutional capacity, Community research expertise, grassroots activism
• Are you committed to capacity building and sustainability?
• How will you value community contributions (budget)
• How will you allocate for CAB development and management?
Decide on level of participation

- How much/little do stakeholders want to be involved?
  - Research question
  - Research design
  - Data collection
  - Analysis
  - Dissemination
Purpose of stakeholder engagement by clinical research stage
Expect Difficulties

- There are different cultures & priorities (community vs. academia)
- Anticipate & address power imbalances (where to meet)
- There will be trust issues, work on buy-in at all levels
- Anticipate training needs
  - Research methods, Human subjects training, analyses
- Different languages, timeline
- Budgets
LEGACY: Transgender cohort study of gender affirmation and HIV-related health

• Aim: to evaluate medical gender affirmation delivered in primary care as an intervention to reduce disparities in HIV-related outcomes

• “first community-based cohort of trans people”

• 4,500 transgender adults ages 18+
  – Gender affirmation
  – HIV viral suppression
  – PrEP uptake
  – STIs
  – HIV incidence
LEGACY: Transgender cohort study of gender affirmation and HIV-related health

- Community-based, community-informed research
- 4 Focus groups (N=28) to identify research priorities and concerns with study design
- Community advisory board
- Stakeholder advisory group
- Research team: predominately trans/gender diverse
Focus Groups

1. Study design
2. Sampling
3. Recruitment and screening
4. Study implementation
5. Survey measures
5. Dissemination
Importance of Representation

“In terms of research priorities of being in research studies I feel like it’s a priority to have trans people and not just one token trans person but trans people as integral part of the research team designing it from the beginning. “

“I’ve done a few research things, and something I always appreciate is when they’re run by trans people...”
Recruitment

Participants spoke of needing to be inclusive of patients who are questioning or who do not identify as “transgender”

“I think maybe questioning folks may also not feel like they’re included...under the study premises even if they would be.”
Study Implementation

Participants wanted informed consent processes specific to use of biospecimens and separate from survey-related informed consent process

“at the very least say... ‘we will come back to you and ask for that specific consent,’ to say, ‘this is specifically what we’re going to do,’ instead of being like, ‘take my DNA.’ ”
Add resiliency measures to surveys, not just disparities and deficits

“there’s like a scale for depression...I fill out this thing when I come into my PCP... there’s no inverse of that, you know what I mean? There’s no elation.”
Dissemination of Results

“people put in all these informations, and at the same time, you almost feel like it never reaches, like, people, so they can see us in a different light... So I feel like that’s maybe one of the reasons why they don’t want to participate.”

“you’re left wondering, ‘what were the results of that study?’ “
Final Message

- Early and diversified stakeholder engagement has been key to advancing HIV biomedical research
- Engaging multiple stakeholders can be complicated
- Conflicts during research are inevitable
Many rewards for engaging communities
- Better quality data
- Long term relationships
- Generating data for real change
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