

Building Partnerships and Stakeholder Relationships for HIV Prevention: Longitudinal Cohort Study Focuses on Community Engagement

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What Is the Purpose of This Study?

- HIV Prevention Trials Network 064 assessed HIV incidence among 2,099 women living in 10 communities with high prevalence of HIV and poverty.
- Women were recruited from community locations using venue-based sampling and followed in the study for 6 to 12 months.
- Community engagement activities were designed to build rapport and establish mutual respect between researchers and community stakeholders.
- The recruitment and engagement approach aligned with the National Institutes of Health (NIH) Director's Council of Public Representatives Community Engagement Framework's five core principles: meaningful community involvement, mutual respect, authentic community-academic partnerships, community stakeholder capacity building, and effective results dissemination.
- The purpose of the manuscript is to describe the strategies used to engage community partners by the HPTN 064, a large NIH-funded, multisite trial, to successfully recruit and retain women at increased risk of HIV acquisition in the United States.
- We describe the methods used throughout all phases of the research process to engage and sustain community partnerships and stakeholder relationships.

What Is the Problem?

- African American women bear a disproportionate burden of HIV in the United States, yet are under-represented in clinical research.
- For African American women, the HIV incidence rate is 20 times higher than that of White women, and nearly five times higher than that of Hispanic/Latina women, yet African American women are under-represented in clinical research.
- African American communities in the United States may mistrust research.
- One effective strategy to decrease public mistrust and increase participation of African American communities in HIV prevention clinical research is community engagement.
- Although there is a growing body of literature which supports the role of community engagement in HIV prevention research and potential frameworks for doing so, few studies describe detailed methods applied by research teams in field settings.

What Are the Findings?

- We enrolled 2,099 women (88% African American) in only 14 months; final retention was 94%.
- Community engagement activities spanned all phases of the research process and were designed to build community rapport and establish mutual respect between researchers and community stakeholders.
- Study success, as evidenced by rapid recruitment and high retention, was grounded in the strong emphasis on meaningful community engagement throughout the research process.
- HPTN 064 found that our pre-implementation work was pivotal to the success and laid the foundation for community engagement.
- Applying the core principles of the Council of Public Representatives' model ensured inclusiveness and participation of African American women impacted by HIV from study inception to results dissemination, and supported recruitment and retention efforts.