Mobilizing the House/Ball Community around Preventative and Therapeutic HIV Clinical Research

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Black and Latino MSM are a disproportionately impacted population in the domestic HIV epidemic (1), yet they are often underrepresented in HIV clinical trials (2). Identifying new and effective ways to engage these diverse populations in clinical trials can greatly benefit these populations by ensuring that research is responsive to community needs and that members of these communities have access to new and cutting-edge technologies to reduce HIV prevalence and incidence.

The House Ball Community (HBC) is a cultural community of predominately young Black (and Hispanic/Latino) MSM that is structured on belonging and cohesion ("Houses") as well as competition and performance ("balls"). "Houses" are family-like groups of peers overseen by authority figures ("House Fathers and Mothers"). Competitive "balls" are stylized modern dance or "vogue" contests between the Houses and "walkers" who are not affiliated with a particular House (2). The cultural cohesion and the existing leadership structure within the HBC suggest that this may be one resource for conducting community engagement to raise awareness and understanding of HIV clinical trials among Black and Latino MSM.

Objectives: Working with diverse members of the HBC we set out to better understand barriers, facilitators and approaches to engaging HBC members around HIV clinical research.

Approach

The 2012 House and Ball Community Change Consultation aimed to (a) initiate dialogue with the HBC, (b) identify HBC-specific barriers and facilitators for clinical trial awareness and participation, and (c) catalyze a national HBC coalition to promote HBC community engagement around HIV health and clinical research.

The Consultation was a partnership between the Adolescent Trials Network (aTN), the Office of HIV/AIDS Network Coordination's Legacy Project, clinical researchers, leaders in the field of HIV/AIDS and public health, and house and ball community leaders from around the country.

Initiating Dialogue

Selection Considerations
- Subject Matter Experts
- Researchers
- Influential Community Members & Allies
- Commitment to Process
- House Ball Leaders/Local & Regional Coalition Representation
- National House Ball Representation

Environment- Retreat Format
- Introduction Letter
- Hotel & Travel & Meals
- Participant Guided Process
- Presentations on House Ball Research and Prevention Programs

HIV Clinical Trials Awareness

During the Consultation 31 attendees completed a survey exploring their awareness of research being conducted on HIV preventive and therapeutic technologies. These include:

- HIV vaccines: is a vaccine which would either protect individuals who do not have HIV from contracting that virus, or otherwise may have a therapeutic effect for persons who have or later contract HIV/AIDS. Currently, there is no effective HIV vaccine but many research projects managing clinical trials seek to create one. There is evidence that a vaccine may be possible.
- Pre-exposure prophylaxis (PrEP): Pre-exposure prophylaxis, or PrEP, is a prevention option for people who are at high-risk of getting HIV. It’s meant to be used consistently, as a pill taken every day, and to be used with other prevention options such as condoms.
- Microbicides: Microbicides are products applied inside the vagina or rectum that are intended to protect against HIV though sex. Although microbicides are not yet available for widespread use, researchers are making significant strides in the development and clinical evaluation of both vaginal and rectal microbicide products. Microbicides that incorporate antiretroviral (ARV) drugs are showing particular promise.
- Treatment: Treatment as prevention is the use of medications for the treatment of HIV to reduce the risk that an HIV-positive person will pass the virus to their sexual partner. The strategy uses the tools of combination antiretroviral drugs known as antiretroviral therapy (ART) that HIV-positive people take to preserve life and health. ART preserves the immune system, keeps people with HIV healthy and prolongs their productive lives.

Engaging the HBC in HIV Clinical Research

In the consultation meetings and separate interviews conducted with 12 of the attendees, several themes were highlighted for promoting clinical research engagement in HBC. The 3 most common themes were:

1. Relationships:
   - Limited sustained researcher engagement in HBC activities ("helicopter research") was sited as an important barrier to members’ relationships with research sites. It was recommended that study staff attend house/alliance/federation meetings & balls.
   - Greater relationship building with researchers and HBC-leaders and gatekeepers was also deemed important.
   - Work within existing relationship structures such as CBGs.
   - Bi-directional relationships between the HBC and CBGs/Researchers that facilitate and support long-term mobilization and empowerment of the HBC sites as necessary and essential "look beyond immediate need”

2. Attitudes:
   - Negative impressions of researchers and mistrust of medical community were important barriers to engagement.
   - It was recommended that sites improve their cultural responsiveness and competence regarding HBC, and that sites increase sexual, racial, and ethnic diversity of staff.
   - They also recommended that HBC members be given opportunities to share ownership of the research process and outcomes, which would necessitate capacity building among HBC.

3. Benefits:
   - Reciprocity of the engagement process—HBC and researchers mutually benefiting from engagement—was also highlighted. Importantly, many HBC members face significant financial, employment, housing, and other hardships. In addition, conducting HBC activities and organizing the members requires substantial resources.
   - If research is to benefit from the cohesion and mobilization of HBC members, it was suggested that researchers contribute to offset the individual and community costs and burdens of participating in research or research activities.

Other notable concerns include:
- Recognize trans-community as a separate community from MSM
- Establishing and sustaining trust requires a change in the environment (medical); cultural competence/sensitivity
- Focus on community assets and resilience

Other Topics of Discussion

- Historical overview of the HBC
- Current HIV prevention research and behavioral interventions in the HBC
- Knowledge, attitudes and beliefs about HIV clinical research
- Short and long-term engagement strategies for clinical research participation
- Formation of a national coalition of House/Ball community members
- Development of a national HIV research agenda tailored specifically to the needs of the HBC
- Demographic profile of the national HBC
- Community assets and resilience

References


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