Engaging African American MSM in Research

Damon L. Humes, MHS
Legacy Project Director
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At a Glance

• Overview of the Legacy Project
• Defining Engagement
• Barriers that Prevent African American MSM from Participating in Clinical Research
• Lessons Learned
• Recommended Strategies
Estimated Number of New HIV Infections Among Adults/Adolescents, USA, 1977-2006

Estimated HIV Incidence by Gender and Risk Category, United States - 2006

- **Men**: 73%
  - 72% MSM
  - 5% MSM/IDU
  - 9% IDU
  - 9% High-Risk Heterosexual

- **Women**: 27%
  - 80% High-Risk Heterosexual
  - 20% IDU

N = 56,300
Estimated Rates of New HIV Infections by Race/Ethnicity, United States, 2006

- Black: 83.7 cases per 100,000 population
- Hispanic: 29.3 cases per 100,000 population
- White: 11.5 cases per 100,000 population
- American Indian/Alaska Native: 14.6 cases per 100,000 population
- Asian/Pacific Islander: 10.2 cases per 100,000 population
HIV Prevalence in Adults from Selected Countries in Sub-Saharan Africa and Subpopulations in the United States
Are HIV/AIDS Conspiracy Beliefs a Barrier to HIV Prevention Among African Americans?"  
(source: Bogart LM, Thorburn S. *JAIDS 2005; 38*)

<table>
<thead>
<tr>
<th>HIV/AIDS Conspiracy Belief</th>
<th>Overall</th>
<th>Men</th>
<th>Women</th>
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<tbody>
<tr>
<td>Medicines to treat HIV are saving lives in the black community</td>
<td>38.4</td>
<td>42.0</td>
<td>36.5</td>
</tr>
<tr>
<td>A lot of information about AIDS is being held back from the public</td>
<td>58.8</td>
<td>62.6</td>
<td>56.8</td>
</tr>
<tr>
<td>AIDS has a cure, but it is being withheld from the poor</td>
<td>53.4</td>
<td>55.2</td>
<td>52.5</td>
</tr>
<tr>
<td>Government is telling the truth about AIDS</td>
<td>37.0</td>
<td>31.6</td>
<td>39.9</td>
</tr>
</tbody>
</table>
Study participation that reflects demographics of the epidemic would be optimal

- **US HVTN trials 2004-06 (incl STEP all US sites)**
  - 37% Female
  - 63% Male
  - 60% White
  - 26% Black
  - 9% Hispanic/Latino
  - 5% Asian/Pacific Islander
  - Native American, multiracial and other

- **New infections, 2006 †**
  - 27% Female
  - 73% Male
  - 35% White (11.5 †)
  - 44% Black (84 †)
  - 17% Hispanic/Latino (29 †)
  - 2% Asian/Pacific Islander
  - 1% Native American
  - 1% other

† Source: “Estimation of HIV Incidence in the United States.” *JAMA*, August 6, 2008;300:520
The Response...

The HVTN Legacy Project:

• Pilot Projects (Philadelphia, Rochester, Birmingham, NYC)

• Racial and Ethnic Minorities Research and Mentorship Program (RAMP)

• Social Marketing Campaign
HANC Legacy Project: NIAID HIV/AIDS Clinical Trials Networks

- ACTG: AIDS Clinical Trials Group
- IMPAACT: International Maternal Pediatric Adolescent AIDS Clinical Trials Group
- MTN: Microbicide Trials Network
- HN: HIV Prevention Trials Network
- INSIGHT: International Network for Strategic Initiatives in Global HIV Trials
- HIV Vaccine Trials Network
HANC Legacy Project

Mission: The Legacy Project works to increase the participation of historically underrepresented communities most impacted by the domestic HIV epidemic into HIV prevention and treatment clinical research.

Focus Areas:
• Research
• Capacity Building & Technical Assistance
• Engagement & Collaboration
The Legacy Project’s Definition of Engagement

**Community engagement** focuses on the development and maintenance of partnerships and quality relationships with a variety of stakeholders to develop trust and engage those partners in a shared vision. Community engagement requires commitment to a process of shared principles and values for the mutual benefit of all parties.
Barriers to African American MSM Participating in Clinical Research

• **Mistrust** (Overcoming conspiracy theories about science, research and/or government)
• **Language/Research Literacy** (Do the participants understand the study?)
• **Safety** (Have their safety concerns been addressed?)
• **Awareness of the study** (Outreach and recruitment strategies)
• **Social Marketing Campaigns** (Do they have real-life images of the target population?)
• **Staff** (Do the researchers, community educators and site staff represent the target population?)
• **Ineligibility** (Are there other opportunities to get involved? What’s next?)
Lessons Learned: Down *The Yellow Brick Road*

Dorothy

Scarecrow

Tin Man

Cowardly Lion

Clinical Research OZ
Recommended Strategies

- Host Community Events (Have open discussion about mistrust, conspiracy and withheld cures/information)
- Hire staff that represent the target population
- Recruit Spokespersons (People who will discuss their positive experience with others)
- Recruit Models (Real-life people from the target community and sub-communities)
- Offer options for persons who are Ineligible (Discuss other studies, volunteer opportunities and ways to become involved?)
Recommended Strategies continues...

• Review Outreach Plan with the target population (Think beyond your local CAB)
• Partner with local organizations and groups
• Have your outreach materials at non-HIV community events
• Use language that your target audience can understand
• Make clear the research process from beginning to end
• Address safety concerns openly and frequently
• Be appreciative of your participants time and find ways to celebrate them (Give awards, press/praise and incentives to show gratitude.)
Conclusion

• Scarecrow (a brain)
• Tin Man (a heart)
• Cowardly Lion (courage)
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Thank YOU!

For more information:

Damon L. Humes, MHS
Legacy Project Director
Office of HIV/AIDS Network Coordination
dlhumes@fhcrc.org
206.667.7139
www.fhcrc.org