

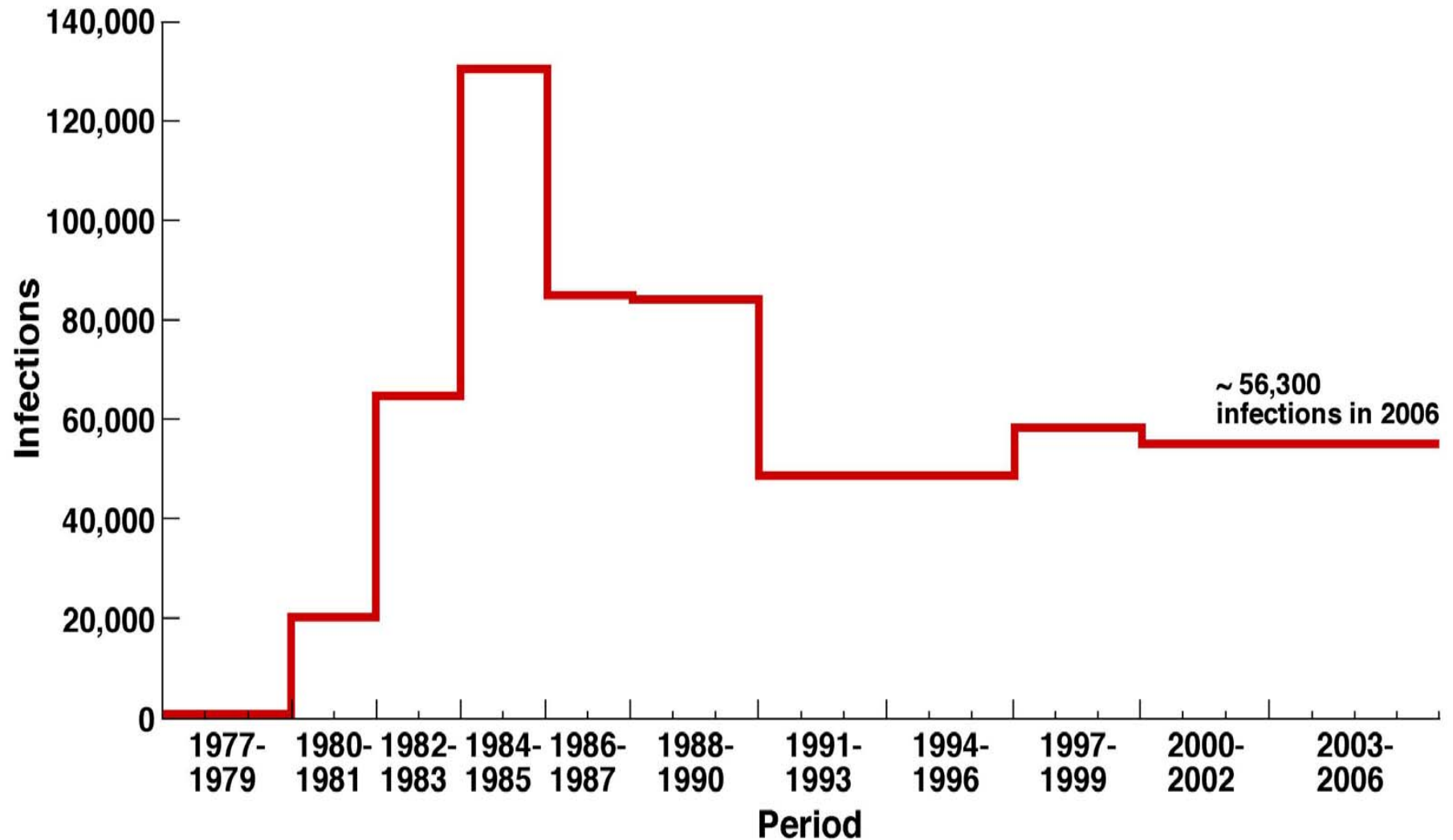
Engaging African American MSM in Research

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

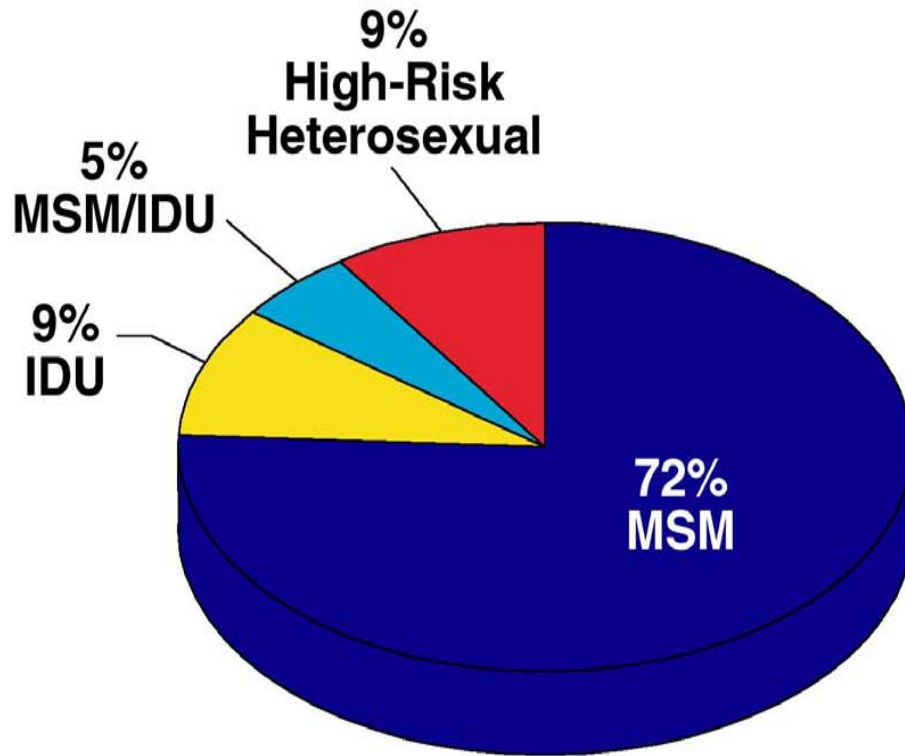
- Overview of the Legacy Project
- Defining Engagement
- Barriers that Prevent African American MSM from Participating in Clinical Research
- Lessons Learned
- Recommended Strategies

Estimated Number of New HIV Infections Among Adults/Adolescents, USA, 1977-2006

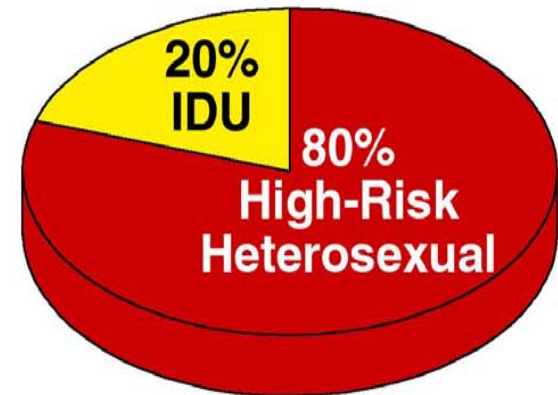


Source: CDC/JAMA 300:520, 2008. Extended-back-calculation model, 50 US states and the District of Columbia.

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



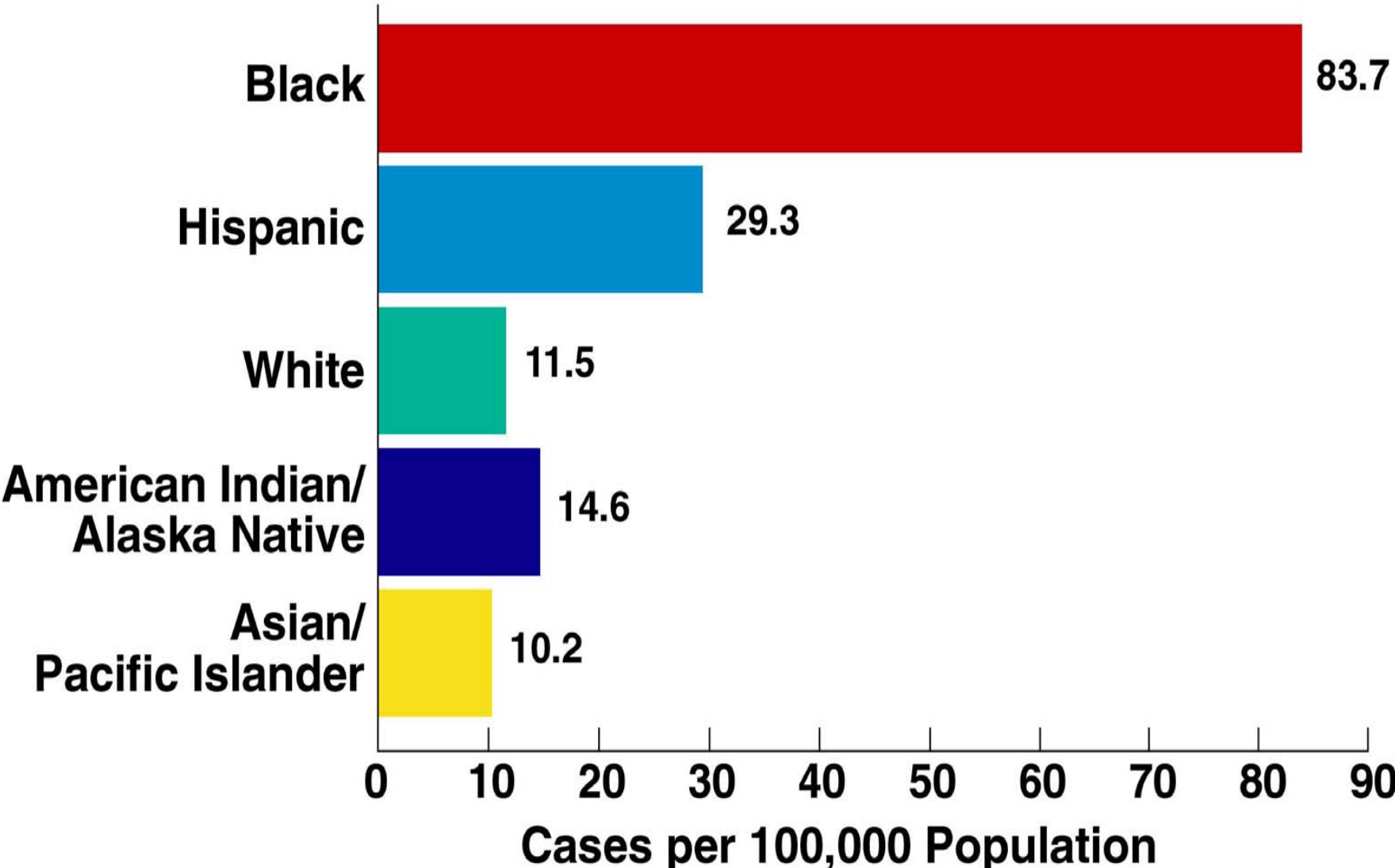
Men
73%



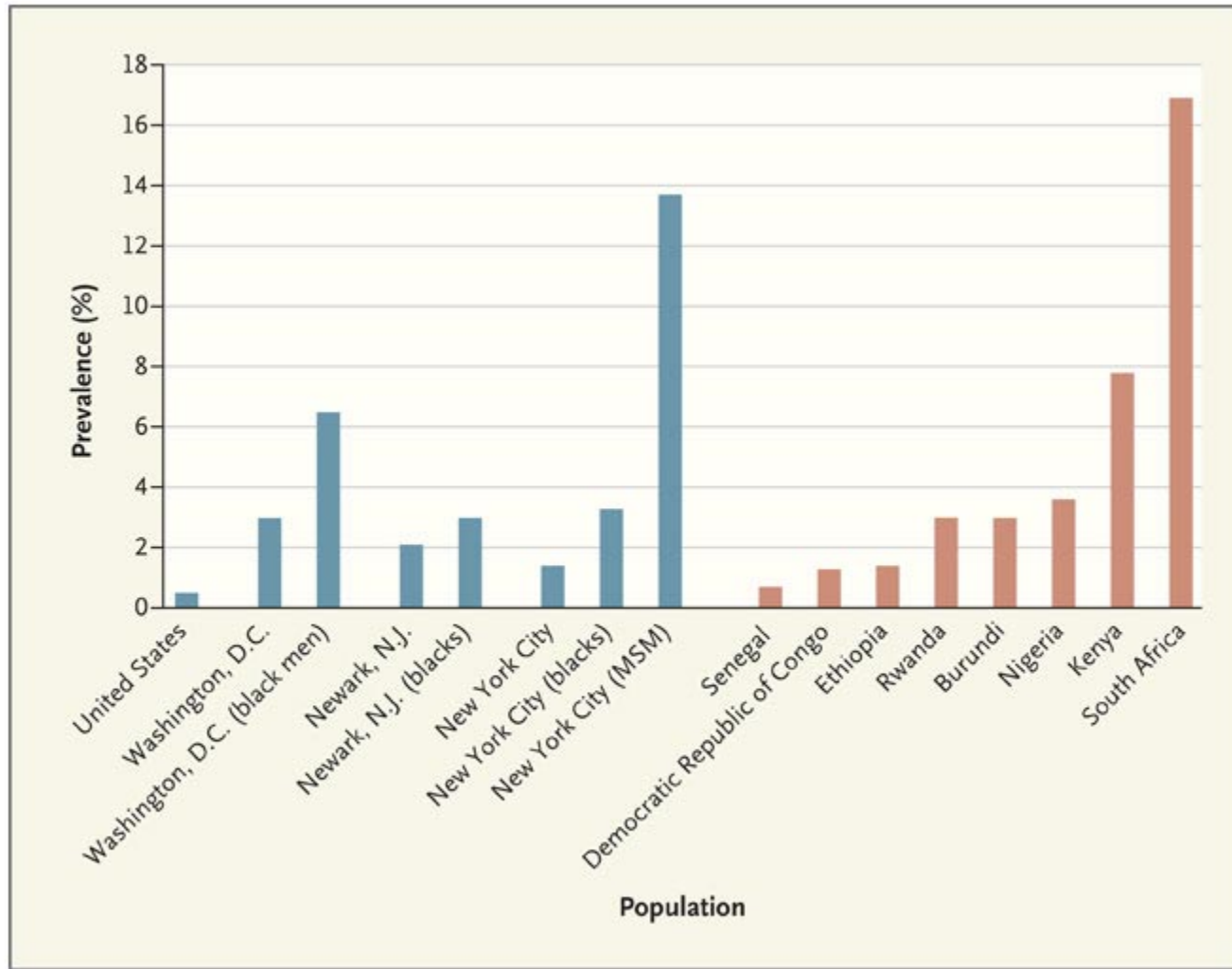
Women
27%

N = 56,300

Estimated Rates of New HIV Infections by Race/Ethnicity, United States, 2006



HIV Prevalence in Adults from Selected Countries in Sub-Saharan Africa and Subpopulations in the United States



El-Sadr W et al. N Engl J Med 2010;10.1056/NEJMp1000069

Are HIV/AIDS Conspiracy Beliefs a Barrier to HIV Prevention Among African Americans?"

(source: Bogart LM, Thorburn S. *JAIDS* 2005; 38)

HIV/AIDS Conspiracy Belief	Overall	Men	Women
Medicines to treat HIV are saving lives in the black community	38.4	42.0	36.5
A lot of information about AIDS is being held back from the public	58.8	62.6	56.8
AIDS has a cure, but it is being withheld from the poor	53.4	55.2	52.5
Government is telling the truth about AIDS	37.0	31.6	39.9

Study participation that reflects demographics of the epidemic would be optimal

- | | |
|--|--|
| ▪ US HVTN trials 2004-06
(incl STEP all US sites) | ▪ New infections, 2006 † |
| – 37% Female
63% Male | – 27% Female
73% Male |
| – 60% White
26% Black
9% Hispanic/Latino
5% Asian/Pacific Islander
Native American,
multiracial and other | – 35% White (11.5*)
44% Black (84*)
17% Hispanic/Latino (29*)
2% Asian/Pacific Islander
1% Native American
1% other |

*rate per 100,000

† 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



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



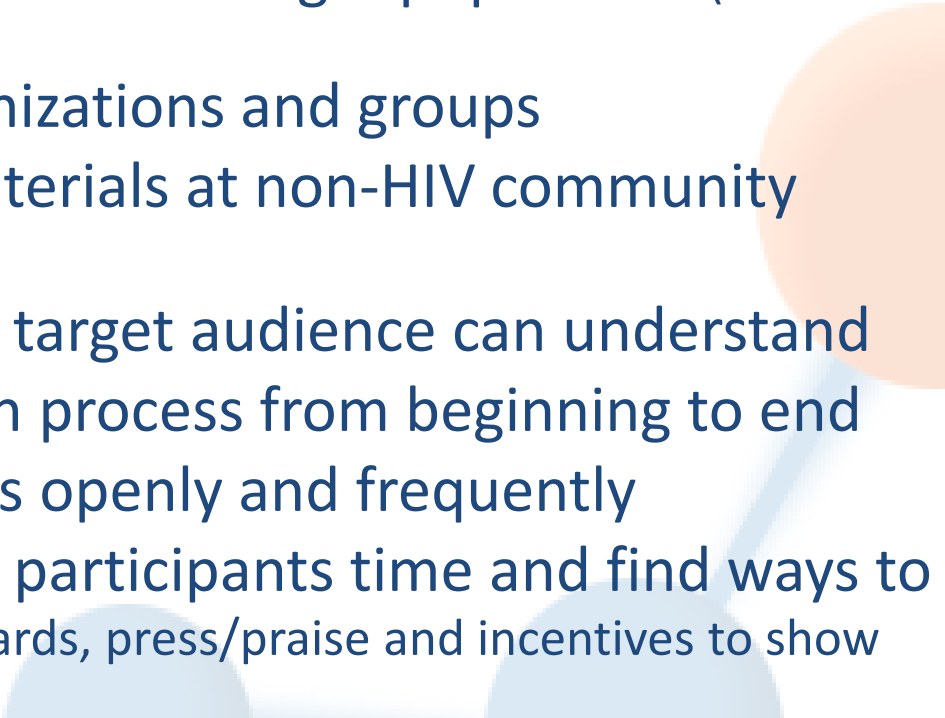
Clinical Research **OZ**



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.)
- 
- A decorative graphic in the bottom right corner of the slide. It features a large, semi-transparent orange circle at the top right. Below it, a light blue line extends downwards and to the left, connecting to a semi-transparent blue circle. From this circle, a horizontal line extends to the left, connecting to another semi-transparent blue circle. A final line extends downwards and to the left from the second blue circle, connecting to a third semi-transparent blue circle at the bottom right.

Conclusion

- Scarecrow (a brain)
- Tin Man (a heart)
- Cowardly Lion (courage)



Acknowledgements

- Jeffrey Schouten, MD, JD, & the HANC Team
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- Legacy Project's Women's HIV Research Collaborative



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

