Community Engaged HIV Research Involving African American Participants: Addressing Issues of Research Trust and Mistrust

Scyatta A. Wallace, Ph.D.
Associate Professor, Dept. of Psychology
St. John’s University

Fordham University
Research Ethics Training Institute (RETI)
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TRUE OR FALSE?

AFRICAN AMERICANS DON’T LIKE TO PARTICIPATE IN RESEARCH
I thought it [survey] was good. I’m glad you chose me to take the survey. I will be very interested in another one very soon, thank you.

To tell you the truth, I love it and appreciate your effort on helping us black young men. Keep up the good work.

I really think that it’s a really good survey for young black men. I really enjoyed engaging in taking this survey. I highly appreciate it.

The survey was very interesting and will be a great deal of information that will better many communities.
ANSWER:

IT DEPENDS ON HOW YOU DESIGN AND PRESENT YOUR RESEARCH
History of mistreatment in medical research
Discontent with current conditions/policy
Negative experiences with education/academia
Respect for Persons

Beneficence  Justice
Culturally Relevant Research

- Culture includes social norms, roles, beliefs, and values of a group that is passed down from one generation to the next (Triandis et al., 1980)

- Culture provides a shared system through which members interpret reality and construct their lives (Jagers, 1996)
Community Consultation

- Learn from the community what issues they are most interested in pursuing.
- Incorporate this in the research design or dissemination plan
Example of Community Consultation

- Hold town hall meeting to introduce myself and prior work
- Let attendees share interests, concerns, ideas
- Discuss my process and overall goals
  - No direct ask (e.g., no discussion of specific projects/recruitment)
- Collect contact information
- Stay in touch (listserv, fb group)
Culturally Relevant Research

- Utilize community outlets
  - Churches & mosques
  - Barber shops & Beauty salons
  - Local Businesses
Example of Community Resources Utilized for BEATS Project

- **Recruitment Sites**
  - **Fortune Society**
    - Community organization that provides previously incarcerated individuals in New York City with re-entry services

- **Resources for Study Activities**
  - Brooklyn Public Library
    - For CAB and other lab meetings
  - Shakoor’s Sweet Tooth
    - For CAB and other lab events
  - Brooklyn Community Foundation
    - Funder of community events
BEATS CAB

BEATS Community Advisory Board (CAB):

- Meet five-six times a year
- 10 members from various community organizations

Rick Brown, Senior Site Coordinator; Council for Unity
Denise Cosom, Director and Founder; Young Gents Society
Allen Frimpong, Program Manager, Living Cities- Newark, NJ's Integration Initiative
Dino Johnson, Director of School Based Initiatives; Council for Unity
Charmaine Peart HoSang, Director of Outreach and Student Services; YearUp Organization
Dr. Marie Pierre-Louis, Program Director; Haitian Centers Council, Inc.
Dr. Divine Pryor, Deputy Executive Director; the Center for NuLeadership on Urban Solutions
Xamayla Rose, Youth Policy Analyst; Brooklyn Borough President’s Office of Marty Markowitz
Ortez Taylor, IT specialist and personal chef
BEATS Yearly Qualitative Evaluation

Year 1

“Why don’t you maybe pick out some things that you think might be helpful to the board and email it to the board saying I think that these things will be helpful in our work.”

“I would like to see you guys put out a contact sheet that has all of the advisory board members names and titles, e-mails, phone numbers as a resource.”

“You all really take these diligent minutes and I would like to have an e-mail of some sort.”
BEATS Yearly Qualitative Evaluation

- We created an email listserv for CAB members to post information, events
- A CAB contact list was created and sent to CAB members
- We share the minutes from each meeting with the CAB.
### BEATS Yearly Quantitative Evaluation

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>% YES</th>
</tr>
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<tbody>
<tr>
<td>24. I have collaborated with other CAB members on a professional level outside of the BEATS Project</td>
<td>87</td>
</tr>
<tr>
<td>25. I have networked with other CAB members outside of the BEATS Project</td>
<td>89</td>
</tr>
<tr>
<td>26. I have developed friendships with other CAB members</td>
<td>89</td>
</tr>
<tr>
<td>27. I have shared information (i.e. findings, articles, job postings, events) with other CAB members</td>
<td>100</td>
</tr>
<tr>
<td>28. I have attended events of other CAB members</td>
<td>100</td>
</tr>
<tr>
<td>29. I shared information on HIV and/or the criminal justice system that I have learned while being a CAB member within your organization?</td>
<td>78</td>
</tr>
</tbody>
</table>
“I think we should have something happen within us in-between meetings. [Pause] I don’t know what it is but I think that it should be something that allows us to see each other in different ways and in different circumstances.”

Group: (people agreeing)

“We have resources around here- we don’t even know what we have and we’re not utilizing it and we have to find a way to do that.”

“How about if we put together an event utilizing solely the resources at this table.”

“That’s a good idea. It’s good”
BEATS Project IMPACT
IMPROVING HIV AWARENESS & TESTING AMONG YOUNG INCARCERATED MALES

September 26th 2013

SPEAKERS
Dr. Robert Fullilove
Professor, Mailman School of Public Health
BEATS Senior Consultant

Mr. Sean "Dino" Johnson
Director of Program Marketing,
Council for Unity/BEATS CAB Member

Ms. Alison O. Jordan, LCSW
Executive Director, Transitional Health
Care Coordination for NYC DOH

Ms. Vivian Siu
Film Producer, President Diversity Films Inc.

Mr. Escott Solomon
HIV Counselor/ Advocate

Dr. Jeri Dyson
Adolescent Medicine Physician
GET IN THE KNOW/Medical Advisor
BET Rap It Up Campaign

FILM SCREENING AND Q&A
WITH PRODUCER

WHY US?:
LEFT BEHIND AND DYING

RAP-IT-UP

ST. JOHN’S UNIVERSITY
Consider potentially stigmatizing findings

- High level of concurrent sexual relationships, descriptions of criminal behavior
  - Engage with community stakeholders about how to disseminate information in a factual manner while respecting concerns
  - Think of potential issues ahead of time, particularly questions during presentations (e.g., sex while in prison stereotype)
Help Community Understand Benefits of Research
Disseminate findings to community outlets

Black girls are using drugs to feel good cause they don’t feel good about themselves
By Dr. Scyatta A. Wallace

—Black girls will steal your boyfriend— Black girls are loud and have an attitude—

These are among the statements highlighted in my research which was recently published in the article “Gold Diggers, Video Vixens, and Jezebels: Stereotype Images and Substance Use Among Urban African American Girls” in the Journal of Women’s Health. The federally funded study included African American adolescent girls (ages 10-15). I was very alarmed by the findings and felt a scientific article buried in the halls of academia was not doing justice to the important information found in the report.

Almost half of the girls agreed with statements such as:

- Straightened hair looks better than natural hair
- Black girls are loud and have an attitude
- Having long hair gives you a better appearance
- Black girls are mad and ready to fight

Almost a quarter of the girls agreed with statements like:

- Black girls are gold-diggers
- Black girls use sex to get what they want
- It’s important to have good hair

Findings from the study showed that girls who agreed with these types of statements were more likely to use drugs. Teens that use drugs at such an early age are at risk for many other issues including school dropout, early sexual activity, violent behavior, STDs/HIV and involvement in the criminal justice system.

The findings are a call for us to pay attention. It shows us that some of our girls are buying into the negative stereotypes they may be seeing in the media/popular culture or their surroundings about Black girls/women. It underscores that Black girls are getting a message that what they look like counts and for some of them this means believing having darker skin and/or kinky hair counts less.

We need to ask ourselves as a community, where are our girls hearing or seeing these messages? In what ways are those messages being validated and reinforced? Are we doing a good job of helping them navigate the messages they are observing? Are we speaking up about the need for more balanced images?

So what can we do? Here are several tips to help Black girls through these difficult issues:
Girls Matter!
A webinar series addressing adolescent girls' behavioral health

WOMEN'S ADDICTION SERVICES LEADERSHIP INSTITUTE
Create lay friendly workshops about research
- Present to recruitment sites
- Present to potential participants
- Present at community events
Why do Research?

- Usually starts with a research question
  - E.g., Does eating fast food contribute to Type II diabetes in children ages 9-12?
Share your expertise with the community
Study: Childhood trauma, fibroids linked

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Scyatta A. Wallace, Ph.D.
Associate Professor
Dept of Psychology
St. John’s University
wallaces@stjohns.edu
(718) 990-2398
www.y-heart.org
Discussion Questions

- What are some cultural factors that might be important to consider when framing your research/questions and design?
- What are some contextual factors (historic/contemporary) that you should keep in mind that might impact research with your specific population?
- What about your research findings might unintentionally stigmatize your population? What could you do to help prevent/decrease stigmatization?
- What are some culturally relevant strategies you can put in place to disseminate the results of your study?