

# Ethical Challenges for Research-Related HIV Testing and Counseling: Community Perspectives

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## *Overview:*

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- Focus group study exploring the opinions of active street drug users towards recruitment for and participation in drug use research involving HIV testing.



# *Background*

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- Importance of research on drug use and HIV acquisition and transmission.
- Drug users' attitudes, beliefs, and fears about HIV may discourage participation.
- Monetary incentives and free testing may be unintentionally exploitative.
- Importance of participant perspectives.



# *Acknowledgements*

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- Co-Investigators:

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*Fordham University, Bronx NY*

*Merrill Singer, G. Derrick Hodge, Greg Mirhej*  
*Hispanic Health Council, Hartford CT.*

- Sponsor: NIDA (grant # RO1 DA015649)
- Staff of Housing Works
- Staff of Hispanic Health Council
- Focus Group Participants



# *Participants*

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- Male (N=68) Female (N=32)
- Mean age 43 years, Range 22 – 70
- 36% Black (AA or Caribbean)  
43% Hispanic/Puerto Rican  
22% non-Hispanic White
- 24% MSM
- 61% unemployed
- 46% lived in shelter, community boarding or with relative
- 90% active drug users
- 50% IDUs
- 45% HIV positive
- 75% participated in substance abuse or HIV research



# *Method*

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11 focus group discussions stimulated by 3-5 minute video-taped “research vignettes”

- Ethnically diverse professional actors with interchanging roles as “investigator” and “participant”.
- English and Spanish versions.
- Female groups saw female “drug user” and male investigator: Male groups the reverse.

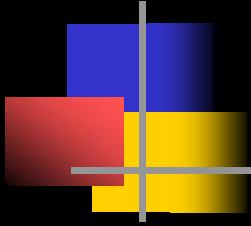


## *Video Vignette*

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**Street recruiter approaches “drug user” to participate in study involving HIV testing and answering questions about sexual behaviors and drug habits.**

- Participants will receive \$40.
- Participants will receive referrals to clinics if HIV+
- Research information confidential
- If participant chooses to seek treatment, physician would be required by law to report his or her positive HIV status to the state, although state prohibited from disclosing information.



# Facing the Fear of HIV Testing





***“I don’t want to know...”***

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*“You go crazy because you learn that you are HIV positive and sometime you even feel like you want to commit suicide.”*



"I live like I don't have it."

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- *"My wife's been HIV positive for years and never taken a medication a day in her life."*



*“They will want nothing  
to do with me”*

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*“...That’s the sad part about it...the majority of Blacks have the virus and they don’t speak about it in the churches...its like a big disease that people taboo.”*

*“The relatives are the first ones to say that you are sick, that you cannot come in...They are the first ones to say things that are hurtful to us.”*



## *“Don’t wanna leave a paper trail”*

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*“...in order to get treatment he would have to go on record as being HIV... You can’t have anonymous on your record.”*

*“You don’t want to take that chance that your kids get taken away.”*

*“At any moment the Feds or any government person want this information they will have to give it to them”*

*[If the researcher couldn’t guarantee confidentiality]*

*“I wouldn’t do it. Not even for \$1,000.”*



# *“I don’t know if I can trust them”*

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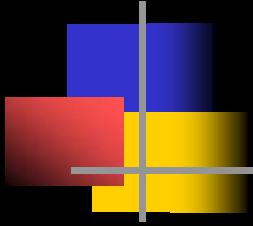
- *“You never know, they [street recruiter] could be cops...”*
- *“I don’t know if they’ll [investigator] do what they say...”*
- *“As for her privacy, she can give a false name--  
At least she'll know where her health stands.”*



# “They should do pre and post testing counseling”

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- *“[the researcher] should give counseling before they even decide to do anything like that...Some people will freak out..that might make them a lot worse than what they are.”*
- *Counseling is a good one. Because it helped me understand my addiction, and how I got HIV, what to do, what not to do.*



# “Moving Forward”



## *“You gotta be responsible”*

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- *“Once you know, then you can do something about it...then it’s a whole new door that opens”*
- *When I found out, I knew then that I had to protect myself, but most of all, I gotta protect my wife, my kids, so its (getting tested) a good thing.*
- *“I wouldn’t want to put someone else at risk...like if I was working in a deli and cutting meat.”*





# "Your help is priceless"

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*"That's how I found out I was sick, cause they offered the money and I was using dope... and I didn't care what they asked me, my name or what, the money made me take the test."*

*"If it wasn't for them offering the money, I wouldn't have found out I was sick at the time, and I'm glad."*

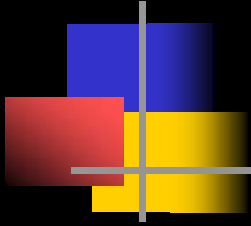
*"A good incentive is getting anything related to you improving your health."*



# "Because she promised"

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- *"I don't think there is a risk because [the researcher] said that the study would be confidential."*
- *"It is illegal to reveal any information that you don't sign a paper telling that you want to release information"*



“More focused on the drugs  
than living”



*“Most drug addicts are chameleons”*

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*“We know that we are going to use the money to get drugs.”*

I will be whatever you want me to be in order to get what I need.. So stop the nonsense. If it is the non-users that get the money, all of a sudden I am a non-user. Okay?

*“They should give us the money because you don’t know if we have bills to pay.”*



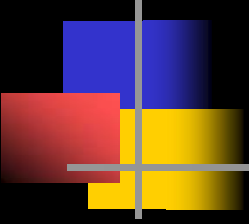
# "Research is a business"

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*"The only way they get people who are HIV is because they give \$20."*

*"Because in the long run, in every research, numbers count. And they gotta meet those quotas."*

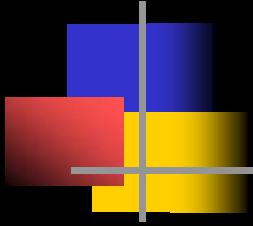
*"He has to do a blood test, they are going to do a bunch of other things, and he is going to be there for two hours. For me, I think that it is enough money [\$40] because he is getting a benefit too."*



# *“They (investigators) should be genuine”*

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- *“I appreciate the fact that he didn’t touch her or tackle her or anything. He gave her a chance and he just raised his voice a little and nothing got hurt.*
- *“People doing these things have no experience..she made it worse. She should have given him alternatives.*
- *“If your on drugs you’re in a high state of mind... [the recruiter] must make sure we are mentally ready and understand”*



# Dualities of Participant Perspectives: What can investigators do?



# Monetary Incentives:

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## *Exploitation & Equity*



Challenge investigator biases,  
ensure fair compensation, access  
understanding, and discourage  
impulsive decision-making





# Protection of Privacy

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*Trust & Trepidation*



Become sensitive to recruit context risks,  
Become familiar with & clearly inform  
recruits about legal reporting  
requirements within the framework of  
confidentiality



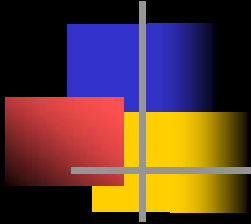
# Fear of HIV Test Results

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*Rejection & Responsibility*



Pre-test as well as post-test  
counseling and partnerships with  
referral sources



*“if you go for the test, they gonna help you. They gonna help you with the medications, how to deal with it...you know what I’m saying?”*

*They not just gonna leave you like that”*