

# Optimizing Treatment and Treatment as Prevention (TasP): Qualitative Research Report

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## Background

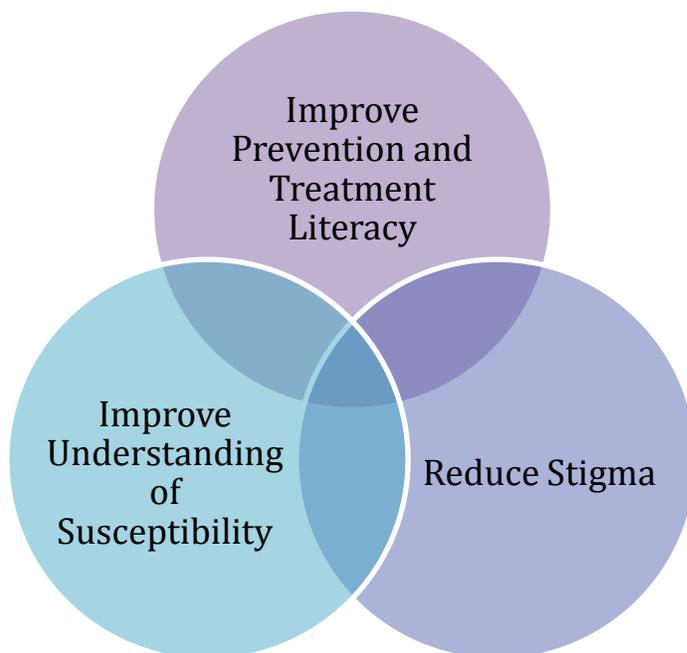
In 2011, the National Minority AIDS Council (NMAC) received support from the MAC AIDS Fund to explore knowledge, benefits, barriers, and other factors influencing HIV treatment.

As a result, NMAC conducted qualitative research, with the support of The Henne Group (THG), with black gay and bisexual men in Oakland, Atlanta, and New York.

Recommendations from this round of research included:

- Improving prevention and treatment literacy;
- Improving understanding of susceptibility; and
- Reducing stigma.

The research report stated that one recommendation could not be fully addressed without addressing the other two and the following graphic representation was used to demonstrate the inter-relatedness of each recommendation.



The Treatment Education, Adherence and Mobilization Team (TEAM) at the National Minority AIDS Council (NMAC) strives to promote leadership and enable communities of color to access HIV counseling and testing services, treatment, and quality healthcare.

In the spring of 2012, TEAM contracted with THG to extend the initial research to different target populations while focusing more specifically on one of the key recommendations from the initial

round of research; that is, improving treatment literacy (including treatment as prevention or TasP).

This new round of research was comprised of two focus groups, one in the District of Columbia (DC) with black HIV-positive women and the other one in Los Angeles (LA) with Hispanic or Latino HIV-positive gay or bisexual men.

This round of research also included two community forums, one in DC and the other one in LA, to add additional insight into information gathered during the focus groups and to better understand the beliefs, attitudes, and concerns of community leaders regarding antiretroviral (ARV) treatment, treatment literacy, and TasP.

## Research Methods – Focus Groups

### ***Focus Group Recruiting***

Respondent sample was drawn from a variety of methods, including a database of potential respondents, referrals from community-based or AIDS-service organizations, clinics, and neighborhood fliers. The recruitment strategy can be found in Appendix A. Potential respondents were all screened using a standardized questionnaire (Appendix B). Only qualified individuals were invited to participate and subsequently scheduled for the focus group discussions. Ten to 12 respondents were scheduled per group in order to ensure that there would be at least 8 respondents participating in each of the focus groups.

### ***Focus Group Process***

Upon arriving at the focus group facility, respondents were given a confidentiality form to fill out and sign. They were rescreened to make certain that they all met the qualifications for participation. They were then escorted to the focus group room and the moderator began the discussions. Melissa Shepherd moderated the focus group in DC and Dr. Octavio Vallejo moderated the focus group in LA. Ms. Shepherd and Dr. Vallejo are experienced moderators, HIV prevention and treatment experts, and health education or communication specialists. The resumes for Ms. Shepherd and Dr. Vallejo are included in Appendix E. The moderators followed a detailed discussion guide that was developed by THG and approved by NMAC (Appendix C).

### ***Characteristics of Focus Group Respondents***

Ten black HIV-positive women participated in the focus group in DC. Their demographic and other characteristics are as follows:

Age	Income	Last Grade of Education	Employment Status	Health Insurance Status	Diagnosis Date	CD4 Count / Viral Load	Date Began ARV Meds
21	< \$20K	High School	Unemployed	Public	2010	526 / Undetectable	January 2011
22	< \$20K	< High School	Unemployed	Public	November 2011	300s / 5,000	Never
25	\$20K - \$35K	Some College	Part Time (2 jobs)	Private	November 2010	659 / Undetectable	November 2010
34	< \$20K	Some College	Unemployed	Public	March 2010	103 / 136,000	October 2011
38	\$20K - \$35K	< High School	Unemployed	Public	2006	DK	Never
42	< \$20K	< High School	Unemployed	Public	June 1996	572 / 2,200	Never
44	< \$20K	< High School	Unemployed	Public	May 2009	876 / DK	Never

Age	Income	Last Grade of Education	Employment Status	Health Insurance Status	Diagnosis Date	CD4 Count / Viral Load	Date Began ARV Meds
48	\$20 - \$35K	High School	Retired / Disabled	Public	September 2010	833 / 50	2008
53	\$36K - \$50K	College Degree	Full Time	Private	June 1998	833 / 50	2008
60	< \$20K	High School	Unemployed	Public	November 1989	651 / 991	Never

Three out of 10 respondents (or 30 percent) were 25 years of age or younger. Four out of 10 respondents (or 40 percent) were 26 to 45 years of age. Three out of 10 respondents (or 30 percent) were over 45 years of age.

Two out of 10 respondents (or 20 percent) had private health insurance. The rest (or 80 percent) had no health insurance and / or public healthcare.

One of the respondents had been living with HIV for over twenty years. She had never been on medication and considered her HIV disease to be stable (her CD4 count was 651 and her viral load was 991). On the other end of the spectrum, the most recently diagnosed respondent was diagnosed only five months before the focus group discussion. Although her CD4 count was in the 300s and her viral load was 5,000, she had not yet started taking ARV medication.

Nine Hispanic/Latino gay or bisexual HIV-positive men participated in the research in Los Angeles. Their demographic and other characteristics are as follows:

Age	Income	Last Grade of Education	Employment Status	Health Insurance Status	Diagnosis Date	CD4 Count / Viral Load	Date Began ARV Meds
25	< \$20K	High School	Full Time	None	September 2008	573 / 12,000	Never
26	\$51K - \$75K	Trade School	Full Time	Public	January 2011	500s / Undetectable	March 2011
28	\$20K - \$35 K	College Degree	Full Time	Public	January 2008	520 / 800	Never
31	\$75K - \$100K	College Degree	Full Time	Private	May 2005	DK	June 2008
33	< \$20K	High School	Unemployed	None	April 2007	685 / 5,000	Never
33	\$20K - \$35K	Some College	Unemployed	None	December 2007	1000 / Undetectable	March 2008
37	\$20K - \$35K	Some College	Part Time	None	April 2011	560 / 1,300	Never

Age	Income	Last Grade of Education	Employment Status	Health Insurance Status	Diagnosis Date	CD4 Count / Viral Load	Date Began ARV Meds
43	< \$20K	High School	Part Time	Public	July 1999	300 / Undetectable	June 2009
46	\$101 - \$150K	College Degree	Full Time	Private	May 1995	540 / 75	May 1996

One out of 9 respondents (or 11 percent) was 25 years of age or younger. Seven out of 9 respondents (or 78 percent) were 26 to 45 years of age. One out of 9 respondents (or 11 percent) was over 45 years of age.

Two out of 9 respondents (or 23 percent) had private health insurance. The other 7 had no health insurance and / or relied on public healthcare.

One of the respondents had been living with HIV for over 17 years and had been on HIV medication since 1996. On the other end of the spectrum, one of the respondents was diagnosed a year before the focus group discussion was held. At the time of the group, his CD4 count was 560 with a viral load of 1,300 and he had not yet started taking ARV medication.

This group, on the whole, was more highly educated than the group in DC and had a higher income. Additionally, there were fewer unemployed respondents in LA than in DC.

## Research Methods – Community Forums

### ***Community Forum Invitations***

NMAC worked in conjunction with THG to create a sample or list of community leaders. At least three e-mails were sent to each individual on the list. In addition, recipients were asked to forward the e-mails to other community leaders who might be interested in attending the forums. Key opinion leaders in each city were also asked to forward the e-mails to their broader list of contacts. (See Appendix A for invitation strategy).

NMAC asked interested individuals to register for the forums so that the size of the groups could be determined in advance. This would ensure that adequate planning was done to accommodate each participant. Community leaders in both cities reported saturation with HIV-related meetings. Therefore, additional outreach was conducted in order to increase the chance that optimum participation would be achieved. (Note: between 10 and 20 community leaders was considered optimum).

### ***Community Forum Process***

As community leaders arrived for the forums, they were asked to sign in. THG staff called community leaders who had registered and had not yet signed in fifteen minutes prior to the start of the session so that it could be determined whether or not to expect them. This permitted the moderator to wait until all were present to begin the forum. Ms. Shepherd moderated both community forums using a discussion outline that was developed by THG and approved by NMAC (Appendix D).

### ***Characteristics of Community Forum Respondents***

Eleven community leaders participated in the forum in DC.

Name	Organization
Randall Brown	Self
James Sykes	HealthHIV
George Kerr	START
Justin Goforth	Whitman Walker
Toni Holness	Women's Collective
Paulette Sheffield	Black Leadership Coalition on AIDS
Philip Pratt	BMX – DC
Antonio Bethea	Metro Teen AIDS
Kimberly Gordon	Damien Ministries
Tanya Henderson	Damien Ministries
Michelle Moses	AMFAR

Seventeen community leaders participated in the forum in LA.

Name	Organization
Ricky Santayo	Community Outreach – Walgreens
Jonie Osborne	St. Paul ME
Dana Williams	Faith Temple
Kylie Gordon	In the Meantime
Ricky Rosales	City of LA
Kimberly Kislser	Friends Research Institute
Dahlia Ferlito	Friends Research Institute
Daniel Robison	Being Alive
Sean Martin	Being Alive
Fernando Navarro	Green Vanity
Lyle Black	Being Alive
Alex Garner	Frontiers
Anthony Gutierrez	LA Gay and Lesbian Center
Terry Smith	AIDS Project Los Angeles
Michelle Enfield	AIDS Project Los Angeles
Vance Martin	GLAD – United Ministries
John D' Amico	City of West Hollywood

## Findings

### **DC Focus Group - Black HIV-Positive Women**

#### ARV Medication

One half of the participants in DC were taking ARV treatment for their HIV. Four out of the five respondents who were taking medication said they were doing so because their physicians recommended they begin. The other woman on medication said that she demanded the medication because she had two cousins who died of HIV disease.

The vast majority (or 80 percent) of the women who were taking medication indicated that they didn't know much about the medication before taking it. Only one out of five (or 20 percent) indicated that she researched the medication online after her doctor referred her to a pharmaceutical company-sponsored web site.

None of the women on medication had concerns about side effects before beginning ARV treatment. Only one woman said that she had adverse side effects after starting ARV treatment, and her physician switched her to another medication. After switching, she no longer experienced adverse side effects.

All of the women in the focus group, whether currently taking medication or not, said that fear of side effects was not an issue for them.

*“Side effects are not something I think about.”*

#### Access to Care

All of the participants saw their doctors regularly, with most seeing them every 6 months. Of the five currently taking HIV medication, none reported trouble getting it. However there was a discussion about ADAP running out in DC and concern was expressed about whether or not they would still be able to get ARV medication in the future.

#### Decision Whether or Not To Take Medication

Eight out of 10 respondents (or 80 percent) indicated that their physician made the decision about when to begin ARV treatment. One of the women not currently on medication indicated that her doctor wanted her to begin, but she wasn't ready.

*“It is my decision, up to me. I am just not sure. I was just diagnosed recently and my doctor already wants me to start the medicine. I know a lot of people who have been able to manage their HIV without it and I want the chance to do the same.”*

Most of the other women in the group chimed in and tried to convince this respondent to listen to her doctor. Her CD4 count was in the 300s and viral load was over 5,000 when she was diagnosed. The discussion focused mainly on how doctors look at CD4 counts and viral loads to determine when to start a patient on medication.

When asked what it would take for her to get on medication, she expressed very strong feelings.

*“I guess I would begin taking it on my deathbed. Not before. I hate taking medicine. Besides someone told me HIV medicine doesn’t work.”*

When the other four respondents not currently on ARV medication were asked the same question, they each pointed to t-cell or CD4 count as the trigger for when to begin taking medicine. They each said that their doctor was watching their numbers carefully and they would not go on medication until their CD4 count reached 500. One of these four women had a CD4 count of 572 with viral load of 2,200 at the time of the focus group and the rest of the women in the group expressed that it was okay for her not to be on medication at that time.

The predominate belief among participants in this focus group was that individuals should not begin taking ARV medication before their CD4 count reached 500.

*“It’s not a good idea to go on medication until your count drops below 500. You don’t need it and it’s not good for you to start early.”*

Only one out of 10 respondents (or 10 percent) expressed a strong belief that individuals should consider starting to take ARV medication as soon as possible after being diagnosed. Her reasoning, however, had nothing to do with new Public Health Service Guidelines, as none of the respondents had heard about those. Some even questioned whether or not new guidelines existed.

*“It’s crazy to go on medication as soon as you’re diagnosed. I’m sure my doctor would have told me if that’s what experts recommend. I know for a fact that they recommend NOT starting treatment until t-cell counts reach 500. It used to be 300.”*

Most of the respondents indicated that they strongly trust their doctor to let them know when to begin taking ARV medication. One respondent, however, disagreed.

*“I think that too much power is given to the doctor. I can take steps to maintain my health. It’s about us, not about what the doctor says.”*

### Beliefs About Whether or Not It Is Possible To Manage HIV Without ARV Medication

Five out of 10 respondents (or 50 percent) expressed the belief that it is possible to manage HIV without ever taking ARV medicine.

When asked about other steps they take to control or manage their HIV, most mentioned reducing stress as the number one action they should take.

*“Stress kills people with HIV.”*

An animated discussion ensued about how to reduce stress when someone is living with HIV.

Methods that respondents used for avoiding stress included:

- Staying away from toxic relationships;
- Having a support network that can help individuals cope with life;
- Putting their life “in God’s hands.”

Other actions mentioned for managing HIV included:

- Getting plenty of rest;
- Dealing with addictions to alcohol or drugs;
- Maintaining healthy body weight;
- Paying attention to nutrition (cooking at home).

When asked about how many people respondents believe can actually manage their HIV without ever taking medication, most indicated that it is rare.

*“I don’t think it’s a huge number.”*

One woman in the focus group believed that she is controlling her HIV without medication.

*“My doctor labeled me years ago as someone who could stay healthy without medication.” (Note: This respondent was diagnosed in 1989 and her CD4 count at the time of the research was 651 and her viral load was 991).*

### Treatment as Prevention

All of the women in this focus group stated strong beliefs that individuals on medication who have undetectable viral loads can transmit HIV the same as those not on medication with detectable viral loads.

Many even became angry when the moderator suggested that there might be a prevention benefit to treatment because they simply didn’t believe it.

When asked directly if someone’s viral load is undetectable, does his or her chances of passing the virus onto others during sex increase, decrease, or stay the same, one hundred percent of the women in the focus group stated that the chances stay the same.

After much discussion, though, one woman in the group pointed to the practice of taking ARVs during pregnancy, surmising that since that has worked to bring down infection rates among infants, then perhaps there is something to the concept of treatment as prevention. Several women countered her point, stating that while more infants are being born HIV-free, it is not because mothers took ARVs during pregnancy, but because there has been an increase in cesarean births.

## Pre-Exposure Prophylaxis (PEP) and Post-Exposure Prophylaxis (PrEP)

Not a single woman in the focus group had ever heard of PEP or PrEP. During the discussion, many women stated that they should have been told about it.

*“Community groups, doctors, and the government all have a responsibility to inform people about what’s going on. People need to know all of their options, whether you agree with them or not.”*

As a whole, the women in this group were especially incensed that they didn’t know about PEP. One woman remarked --- and a few others agreed --- that the government and pharmaceutical companies don’t want people to know about PEP because they are making too much money off of people becoming infected and suffering with this disease.

## Treatment as Prevention (TasP)

Respondents were asked to imagine for a minute that everyone, or almost everyone, in a community who is living with HIV achieves undetectable viral load, and were then asked what affect could that have on the epidemic. One hundred percent of the women in the group stated that it would have no effect at all on the epidemic.

When the research foundation of TasP was explained, respondents indicated that it would definitely motivate them to begin medication if it really would help keep them from passing the virus to others. They also responded very positively to the notion that they could be a part of something bigger such as curbing the epidemic in their community. But they continued to question whether or not it was accurate that someone could reduce their chances of passing the virus onto others by achieving undetectable viral load.

## Conclusion

Almost all of the women in the focus group felt they were sufficiently informed about HIV treatment at the beginning of the group, and by the end, felt strongly that they didn’t have all the information that they needed to make informed choices. Some were quite angry with that.

This group was fairly homogenous in their attitudes and beliefs. Since only one group was conducted, it is impossible to know whether or not this is an anomaly. Additionally, it would be beneficial to conduct other groups among black HIV-positive women with higher education, higher income, and greater levels of private insurance in order to better understand whether the lack of knowledge seen among this group of women was the result of public healthcare, lower health literacy, or other factors.

## ***LA Focus Group – Hispanic and Latino HIV-Positive Gay and Bisexual Men***

### ARV Medication

Two-thirds of respondents in the LA focus group were taking ARV medication to treat their HIV disease. Although most of the six respondents taking ARV medication were doing so at their physician's recommendation, all indicated that they had good knowledge about HIV treatment before starting medication. One respondent took treatment education classes, two others stated that they did their own research (mostly through the Internet, friends, and magazines), and still another, who was in jail at the time, got treatment education in that setting. The remaining two respondents spoke about getting the majority of their information from their physicians.

As a whole, this group of respondents was well informed about treatment. When asked about questions they may still have about treatment, information about side effects for specific medications was mentioned most frequently. Other questions included:

- Will I need to take medication for the rest of my life, or can I eventually get off of it?
- What have they seen in clinical trials?
- Whether my genotype is compatible?
- How ARV medication will affect my Hepatitis C?

### Access to Care

Eight out of 9 respondents (or 89 percent) said that they saw their physicians regularly. Only one respondent spoke about challenges with both seeing his doctor and taking medications. These challenges stemmed from the fact that his boss didn't know that he was HIV-positive and his work schedule made it difficult to see his doctor as often as he needed to.

Although most of the respondents were employed either full or part-time, only two out of 9 (or 22 percent) had private health insurance. The rest had no health insurance and / or received public healthcare. None of the respondents who were taking ARV medication expressed difficulty getting the medicine.

### Decision Whether or Not To Take Medication

Three out of four respondents (or 75 percent) in the group not taking ARV medication mentioned side effects as one of the key reasons they had decided not to take the medicine yet.

*"I don't want to risk the side effects if I don't need to."*

*"I'm afraid to damage my liver and kidneys."*

All four mentioned that they didn't need to take the medication yet, pointing to their CD4 counts as the primary reason for not taking it.

*“I’ll take it when I need to. When I reach 400, I’ll consider it.”*

*“When my t-cells drop below 500, I’ll consider it.”*

CD4 counts and viral load counts for the four respondents not taking medication were:

- 520 / 800;
- 560 / 1,300;
- 573 / 12,000;
- 685 / 5,000.

One of the respondents not taking ARV medication also indicated that he was waiting for his insurance to become active so that he could afford medication. In the mean time, he planned to just watch his CD4 count and unless it changed, he would continue to delay taking medication.

One of the respondents not taking ARV medication expressed the concern that others could find out he is HIV-positive once he started taking medication.

*“Not too many people know now that I’m HIV-positive and I don’t want to risk others finding out so I’ve decided not to take it just yet. Once the count gets lower, I’ll consider it.”*

All four respondents not taking ARV medication had talked with their doctor about when to start. All indicated that they trust their doctor when he or she tells them that they don’t yet need to take ARV medication.

The moderator asked the 6 respondents taking ARV medication what they would tell the respondents not taking meds about their experience.

All expressed the belief that one shouldn’t tell them they need to start taking medication, but instead should try to provide information that might help them decide.

*“For me personally, before I started taking medication, I was very afraid of side effects. That was my major concern. Everybody seems to be pretty concerned. But I ended up not experiencing any side effects. People need to know that a lot of people don’t have that problem.”*

A few respondents spoke about how much better the medications are now when compared to the older ARVs.

*“I liken it to MACS. Technology just gets better and better. I could be very happy with my blackberry; but once I try the iPhone, I realize that technology just exceeded my imagination. It just depends on when you want to jump on the bandwagon. You can’t be afraid to try new things. Most people feel so much better on medication because they feel empowered, secure, and healthier.”*

### Beliefs About Whether or Not It Is Possible To Manage HIV Without ARV Medication

Most of the respondents in this focus group believed that it would be rare for someone to be able to manage HIV without ever having to take ARV medication. However, one of the four respondents expressed his belief that he is likely one of the ones who can manage HIV without ARV medication.

*“I think I could be able to. My t-cells have always been high.” (Note: this respondent’s CD4 count at the time of the focus group was 685, and he was diagnosed in 2007. His viral load was 5,000).*

### PEP and PrEP

All of the respondents in the focus group knew about both PEP and PrEP.

Three respondents had recommended PEP to a sex partner. Although even among this highly educated group, there were still questions about PEP. One man said that he was aware of PEP and even tried to get it at one point before he became infected. He said he went to the ER and told them that he had been exposed. The doctor there told him that PEP should not be prescribed because if he became infected, he would risk developing resistance and then the medications wouldn’t work when he needed them.

Another respondent echoed that concern, believing that when someone takes PEP, if they do become infected, the drugs won’t work for them.

Several of the respondents said that PEP was a well-kept secret.

*“It’s very hush-hush.”*

Eight out of 9 respondents (or 89 percent) believed that PEP should be more widely available. The other respondent believed that more research was necessary.

*“We need serious research that demonstrates without a shadow of a doubt that it works.”*

All of the respondents agreed that more education about PEP is needed.

Five out of 9 respondents (or 56 percent) had heard about PrEP. Only one had recommended PrEP to a sex partner.

Two respondents (or 22 percent) believed PrEP to be a viable alternative to using condoms.

*“I think it’s a better alternative to condoms than not doing anything. I have a hard time with condoms.”*

One respondent believed that no one should take ARV medication if they are HIV-negative.

*“I don’t understand why someone would take it. Why someone would take something that is toxic.”*

### Treatment as Prevention (TasP)

All of the respondents in this focus group had heard about TasP.

*“Someone on meds is much less likely to pass the virus on.”*

TasP was mentioned even before the moderator brought it up, with one respondent stating that it was important to bring down viral load for one’s own health and for prevention.

Many of the respondents mentioned that it was still important to use condoms, even if viral load was undetectable.

Respondents spoke about the fact that even if viral load was undetectable, it could spike without the person realizing it. Reasons mentioned for this included:

- Non compliance taking medication;
- Reinfection;
- Development of resistance;
- Stress;
- Taking diet pills.

Of the five respondents taking ARV medication, three (or 60 percent) had achieved undetectable viral load. All expressed confidence that their viral load will stay undetectable.

*“I eat healthy by trying to cook my own food, I have stopped smoking, I don’t take any drugs, and drink very little alcohol. I am the healthiest now that I have ever been. I am confident my viral load will remain undetectable.”*

The primary concern about TasP expressed by this group of men was that it might increase unsafe behavior.

*“It would cause a situation where people would just get crazy and end up making the epidemic worse.”*

*“The next generation might feel it is not necessary to be cautious because they wouldn’t be afraid.”*

## Conclusion

Almost all of the respondents in this focus group were very well informed about treatment and, for the most part, treatment as prevention. PEP and PrEP appeared to be topics about which they could use additional information, even though they understood the basics.

Additionally, this group was fairly homogeneous in their treatment related attitudes and beliefs. Since only one group was conducted, it is impossible to know whether or not this is an anomaly. Since this group was fairly well educated with higher incomes, it might be useful to conduct at least one more group of Hispanic or Latino gay or bisexual men in LA who are not so well educated, and who have lower incomes. This would permit a comparison in knowledge, attitudes, beliefs, and behaviors that might prove helpful.

Concerns about side effects appeared to be particularly prevalent among this group of men in LA. The moderator explored this at the end of the group, and some indicated that there has been a fairly high profile campaign about ARV-related side effects in LA that has informed their thinking and increased their fears. Additional research about this could be very useful in understanding and documenting why some groups of people are more aware and fearful of potential side effects than others.

## ***DC Community Forum***

### When HIV-Positive Individuals Should Begin Treatment with ARV Medication

There was some initial discussion about how recommendations have changed over the years. Several community leaders expressed that at one time the guidance was to begin treatment with ARV medication when CD4 counts reached 300, then 500; but now the guidance is that one should begin treatment immediately following diagnosis.

A few community leaders stressed that it has now been scientifically demonstrated that HIV begins to damage the immune system immediately. Therefore, according to these leaders, CD4 counts should now only be regarded as indicating the level of urgency for treatment, not a target for starting treatment.

That being said, the group then focused the discussion on the conditions necessary for a community to recommend immediate ARV treatment. The conditions discussed are as follows:

- ARV medications had to get easy enough for individuals to commit to taking them forever;
- There had to be enough medicine available; and
- It had to be demonstrated that ARV meds could be preventative.

While the group unanimously agreed about the benefits of treatment immediately following diagnosis, there followed a discussion of why it might not be best to start until other concerns have been addressed.

The discussion followed two paths – obstacles to effective treatment, on the one hand, and necessary conditions for a person’s readiness on the other.

The first obstacle to effective treatment discussed by community leaders in DC was housing. All community leaders agreed that there is virtually no housing available for HIV positive individuals in DC. (One community leader stated that there were over 900 HIV-positive individuals on housing waiting lists in the District). There has been some success with drop-in centers, or places where medications can be stored and accessed 7 days a week (Whitman Walker currently provides such a service, but it was acknowledged that many more sites are necessary).

The second obstacle discussed was stigma. A community leader representing young, black gay men said that his demographic simply wouldn’t chance going into even an unidentified storefront drop-in center for medication because of the risk of being seen.

The third obstacle discussed was the prevalence of mental health issues among some HIV-positive individuals; which, along with anger and fear, can lead to self-destructiveness.

The fourth obstacle discussed was that some people have had very bad experiences with public health, feeling both stigmatized and denigrated by the process of accessing services.

The last obstacle brought up by community leaders in DC was cost. It was stated that even for those with private insurance, for some people the 20 percent copay is too much.

The discussion then turned to readiness for treatment. As a whole, the group felt strongly that it was necessary for individual’s to have access to a strong system of support --- including peers and loved ones --- who can help them believe in the value of their life and have the aspiration to get and / or stay healthy.

*“Physicians universally think that pill burden is the biggest barrier to readiness for treatment. When, in fact, far more complicated factors can interfere with adhering to drug regimens. Support is critical to getting past many of these factors.”*

### PEP and PrEP

All of the community leaders were well educated about PEP, but they were quite concerned that others in their communities were not as well informed.

*“Few people know what it is or that it is very effective. Those who do know tend to be white and well educated.”*

One participant stressed that availability to PEP was dependent on which doctor individuals saw for their healthcare. The group agreed and offered insight into why women may not be as well informed about PEP.

*“Some gay activist physicians who stay up to date on the latest research and treatment make sure that their clientele is aware of things like PEP, while most other individuals’ healthcare providers are unlikely to distribute this information. This is a factor, for sure, in fewer women being aware of PEP and / or choosing to take PEP.”*

The group then began to discuss access to PEP, and most community leaders in this group agreed that there is very limited access to PEP in DC. Community leaders stated that while Medicaid, Medicare, and private insurance will pay for PEP, only one clinic in DC (Whitman Walker) actually prescribes it. There was unanimous concern expressed about this lack of access.

All of the community leaders were well educated about PrEP, but many expressed unease with it. Primary on the list of concerns was that there were still unanswered questions, such as whether or not regimens other than the regimen from the iPrEx trial could work. Discussion about this particular concern led to questions about how long before sex one has to take PrEP for it to be effective. It was pointed out, and many agreed, that until these questions are answered, it is difficult to promote PrEP.

Community leaders were unanimous in their concern that, even if all the questions were answered, those who most need PrEP will be least likely to have access to it.

There was discussion about how to educate people about PrEP. The AIDS Healthcare Foundation's very visible campaign against PrEP was discussed and most community leaders expressed strong concerns that this campaign was making PrEP so controversial that it made education about PrEP difficult.

*"It is so controversial in some circles that it makes us worried about not saying something the right way so we don't say anything at all."*

As a whole the group believed that there should be education about PrEP. Although many felt uncomfortable about it, every community leader in the group expressed strong opinions that it should not be up to them --- or up to public health --- to purposefully keep information from people.

*"Accurate information should be out there. We need to trust people with information. To do anything less would be just wrong and we can clearly see the results of what happens when we wring out hands and say nothing. We have created an information vacuum so organizations with an agenda, like AHF, can spread inaccurate information without challenge."*

## Treatment as Prevention (TasP)

The group, as a whole, was very knowledgeable about TasP and there didn't appear to be anyone in the group who didn't believe that reducing community-level viral load would bring down infection rates in a community.

There was discussion about being very careful about how TasP is implemented because of fears that HIV-positive individuals would be made to take ARV medication before they were ready for it. Criminalization was also mentioned briefly as a fear --- that at some point in the future, behaviors such as not taking meds could be criminalized.

Even with these concerns, most of the community leaders expressed dismay that so little is known about TasP in their communities. They all agreed that more education is clearly needed.

Community leaders cautioned that outreach and engagement on complex topics such as TasP requires cultural knowledge and sensitivity. Most agreed that it would be important to partner with organizations in the community who can reach individuals, speak their language, and engender trust.

All agreed that any such an outreach effort has to be direct and ongoing. There was strong consensus that one should stay away from campaigns that just say, "ask your doctor" or "talk about it."

*"Particularly since so much education is needed in some populations, such as women, it is really bad to get their attention and not deliver actual information that could help them."*

## Conclusion

This group of community leaders in DC was very well educated about treatment and TasP, including PEP and PrEP. Even though they were well educated, many of them expressed some concerns about how and by whom other individuals in their communities will be educated. Some of the community leaders seemed almost paralyzed by the controversies and complexities and, therefore, didn't seem empowered to take on the education role. At the same time, they cautioned about the importance and necessity of direct education coming from within communities.

It will be important to increase the self-efficacy of community leaders by providing specific training in communicating about complex and sometimes controversial topics such as TasP, PEP, and PrEP.

## ***LA Community Forum***

### When HIV-Positive Individuals Should Begin Treatment with ARV Medication

Most of the community leaders indicated that they believe individuals should begin taking ARV medication right after being diagnosed.

*“I have a doctor who thinks people should start as soon as they find out.”*

The discussion about when individuals should begin taking ARV medication led very quickly to a discussion about adverse side effects. Some of the community leaders expressed caution about advocating for beginning ARV medication early because of the strength of the medicines.

*“These are really strong medicines that can affect your liver, and your overall health in general. They can make you weak. It might not be worth taking them until you really need them.”*

The discussion about side effects evolved into a discussion about an AHF campaign that focused on side effects of ARV medication. The community leaders questioned whether or not that campaign could be adversely affecting people’s decisions about treatment. They shared perspectives that the campaign and AHF had effectively silenced discussion among community leaders. Many participants spoke about the animosity that has been created, pitting leaders against other leaders, resulting in polarization inside the HIV/AIDS community in LA.

### PEP and PrEP

As a whole, community leaders felt strongly about the value of PEP and believed that it should be more widely accessible. They talked about pilot programs where emergency rooms could give five Truvada pills over the weekend to tide individuals over until they could get a full prescription from their doctors or a local clinic. But these programs were not well funded so were not widely available. There was also great concern expressed that more people don’t know about PEP.

The discussion about PrEP focused on controversy surrounding the FDA review of Truvada for PrEP and the AHF *No Magic Pill* campaign. Some community leaders indicated that they were not really supportive of PrEP until more research could be done. But they were still very concerned about the “stifling of discussion” and there was strong consensus that individuals at risk for HIV should be educated about iPrEx and their options related to PrEP.

### TasP

Most of the community leaders understood the research behind TasP.

*“It reduces the risk of infection by 96 percent.”*

There was an animated yet respectful discussion about the benefits of TasP to individual as well as community health. Most were very encouraged by the promise of TasP, but, at the same time, expressed caution.

*“I think fundamentally the individual and their doctor should decide when it’s best for them to go on medication --- and it should be for their own individual health, not to prevent transmission.”*

Many community leaders expressed concern that individuals who need ARV medication for their own health are not able to get it. The AIDS Drug Assistance Program (ADAP) waiting lists were

given as examples of the challenges many communities face in getting medication to all who need it. Statements were made about ensuring that all who need ARV medication for their own health should get it before we begin giving ARVs for PrEP or TasP.

There was also discussion about individual readiness for medication, and ensuring that in the rush to “put people on meds,” a community doesn’t end up creating more problems such as developing more resistance. Many community leaders in LA indicated that adherence to medication is difficult even in the best of circumstances, and if individuals are not ready, they may not be compliant.

The recent change in the Public Health Service Guidelines about starting ARV medication was discussed. Some in the group had heard about the change, while others had not.

*“Theoretically the new guidelines state that everyone goes on medication as soon as they are diagnosed, regardless of CD4 count.”*

Many community leaders expressed concerns about advocating for starting medication too soon after diagnosis.

*“I think there’s always a month or two of going crazy in your head, and getting things together, and also getting the facts straight from your doctor, getting education, and getting the resources you will need. You can’t rush all of that.”*

### Conclusion

As with the LA focus group respondents, the community forum participants were extremely well informed about ARV treatment, PEP, PrEP, and TasP. However, there wasn’t consensus regarding implementation, particularly for some of the more complex strategies such as TasP and PrEP.

Many of the community leaders remarked how productive it was to have a discussion about these topics, though. It was clear that creating more opportunities for open and direct discussion would be useful as communities grapple with the complexities and controversies surrounding TasP.

## Recommendations

1. Forums and other opportunities for community leaders to discuss issues related to TasP should continue to be supported by NMAC and others.
2. Basic information about HIV treatment and TasP should be provided to all HIV-positive individuals through treatment education and health literacy programs at the community-level. Information provided should include the proven benefits of ARV treatment to both individuals and communities.
3. Community leaders should be given training and nuanced language to assist them in providing education about complex topics such as ARV treatment, TasP, PEP, and PrEP. Particular focus on language is critical to ensure that HIV-positive individuals come to understand they have options without sparking unintended consequences like undermining condoms or other HIV prevention methods.
4. Information targeting women about reducing the risk of mother-to-child transmission should be provided to all HIV-positive women as part of a broader education program about ARV treatment, viral load suppression, and TasP. Better understanding about the mechanics of reducing the risk of transmission from mother-to-child could help women better understand TasP.
5. Treatment education and health literacy programs for HIV-positive individuals should include information about current expert guidance and the fact that it is not necessary (or, in some instances, advisable) to wait for CD4 counts to reach a certain level before starting to take ARV medication. ARV treatment should be considered as soon as possible after being diagnosed with HIV, but the focus should be on considering treatment, weighing options, and assessing readiness --- so that individuals understand the research and expert guidance but also understand that they have a choice about how and when to begin treatment.

## Appendix A

### Recruitment Strategy – Focus Groups

#### Strategy for Recruiting Black HIV-Positive Women in DC and Hispanic or Latino Gay or Bisexual HIV-Positive Men in LA

##### Recruitment Goal:

THG will recruit 10 – 12 black HIV-positive women in DC and 10 – 12 Hispanic or Latino gay and bisexual HIV-positive men in LA. It is anticipated that at least 8 – 10 respondents per city will ultimately participate in the research.

##### General Recruitment Strategy:

###### Phase One

- Contact potential participants from the THG database.
- Fax fliers to HIV prevention and treatment CBOs and ASOs, Sexual Health Clinics, HIV Support Groups, and Hospitals that serve black women and Hispanic or Latino gay or bisexual men. Conduct follow up calls to ensure that the fliers were received and posted.
- Post fliers in neighborhoods frequented by black women or Hispanic/Latino gay or bisexual men.

###### Phase 2 (if necessary)

- Contact previous recruiters to offer them referral fees.
- Offer referral fees to HIV prevention and treatment CBOs and ASOs and Sexual Health Clinics.

### Invitation Strategy – Community Forums

#### Strategy for Inviting Community Leaders in DC and LA to Participate in Community Forums

##### Invitation Goal:

It is anticipated that between 15 and 20 community leaders will participate in each of the forums.

##### General Invitation Strategy:

THG will send out e-mail invitations to a list of HIV prevention and treatment community leaders in DC and LA. THG will develop the invitation list in conjunction with NMAC. At least three e-mails will be sent to the list, and recipients will be asked to forward the e-mails to other community leaders who may be interested in attending the forums. Additionally, key opinion leaders in each city will be asked to forward the e-mails to their contacts.

## Appendix B

### Screening Questionnaire – Focus Groups

THG1206 – NMAC Optimizing Treatment and TasP

3/8/2012

Hello, my name is \_\_\_\_\_ and I work for The Henne Group, a Marketing Research firm. We are conducting a research project and would like to see if you qualify.

The study involves a two hour focus group at a facility in **[name of city]** on **[date]** from 6-8pm. If you qualify, you will discuss a topic in a group with a moderator and be compensated \$85 by cash for your time.

**DC: Wednesday, April 11<sup>th</sup>**

**LA: Monday, April 16<sup>th</sup>**

The screening process will take approximately 5 minutes. It is your choice to answer these questions. Your answers will be kept private and we will never link your name with any of your responses. May I ask you a few questions now to see if this study would be appropriate for you?

- Yes
- No → **make note in database**

Name: \_\_\_\_\_ → **double check spelling**

Phone: \_\_\_\_\_ → **mark type**

Cell

Home

Work

Other: \_\_\_\_\_

Recruitment source: \_\_\_\_\_ → **refer to database**

Past studies: \_\_\_\_\_ → **refer to database**

1. In what city do you live?

\_\_\_\_\_  
**Must be near either District of Columbia (DC) or LA**

2. How old are you?

\_\_\_\_\_ years old

**Must be between 18 and 60 years of age**  
**Recruit a mix**

3. What is your gender?

Male → **LA only**

Female → **DC only**

Transgender → **Terminate (Disqualified)**

4. Which of the following best describes your ethnicity?

- White / Caucasian
- African American / Black
- Hispanic / Latino
- Other: \_\_\_\_\_

**LA – must identify as full or partial Hispanic / Latino**

**DC – must identify as full or partial African American / Black**

5. Who do you have sex with?

- Men
- Women
- Both
- Other: \_\_\_\_\_

**LA - must be MSM**

**DC - must be women who have sex with men**

6. What is the yearly income for your household?

- Less than \$20,000
- \$20,000 - \$35,000
- \$36,000 - \$50,000
- \$51,000 - \$75,000
- \$76,000 - \$100,000
- \$101,000 - \$150,000
- \$151,000 - \$200,000
- Greater than \$200,000

**Recruit a mix**

7. What is your employment status?

- Full-time
- Part-time
- Unemployed
- Disabled
- Student
- Retired
- Homemaker

**Record profession:** \_\_\_\_\_

8. What type of health insurance do you have?

- Private (Blue Shield, Aetna, HMO etc)
- Public (Medi-Cal, ADAP, Ryan White etc)
- None → How do you pay when you see a doctor?

**Recruit a mix**

9. Do you or does someone in your household work in marketing or advertising?

- Yes → **continue but check with client**
  - No
- Who:** \_\_\_\_\_

10. What is the highest level of education you have completed?

- Less than high school
- GED
- High school diploma
- Some college → **continue to Q12**
- Associate's degree (2 year college) → **continue to Q12**
- Bachelor's degree (4 year college) → **continue to Q12**
- Some grad school → **continue to Q12**
- Graduate degree or higher → **continue to Q12**

11. What was the name of the last book, newspaper, or magazine you read?

- Literate
- Illiterate → **discontinue**

12. What recreational drugs, including weed, have you used in the last month?

- None → **continue to Q14**
- Weed
- Cocaine
- Meth
- Heroin
- Ecstasy
- Other: \_\_\_\_\_

13. How often have you used [this/these] [drug/drugs] in the last month?

- Weed = \_\_\_\_\_ / month
- Cocaine = \_\_\_\_\_ / month
- Meth = \_\_\_\_\_ / month
- Heroin = \_\_\_\_\_ / month
- Ecstasy = \_\_\_\_\_ / month
- Other: \_\_\_\_\_ = \_\_\_\_\_ / month

14. Have you been diagnosed as being HIV-positive?

- Yes
- No → **Terminate (Disqualified)**

15. When were you diagnosed with HIV?

Month: \_\_\_\_\_

Year: \_\_\_\_\_

**Recruit a mix**

16. What are your most recent T-cell/CD4 and viral load counts?

T-cell/CD4: \_\_\_\_\_

Viral Load: \_\_\_\_\_

- Doesn't know

17. Do you currently work for or volunteer your time with an organization or program that is involved in HIV/AIDS education, prevention, advocacy, or treatment?

- Yes
- No → **continue to Q19**

18. What do you do at this organization?

**If currently active within HIV/AIDS outreach/prevention or AIDS Service Organization →  
Terminate (Disqualified)**

19. Have you seen a healthcare professional to discuss your HIV or to get an HIV lab test in the past 12 months?

- Yes  
 No

20. Do you take prescription medication for your HIV? If so, when did you begin taking medication for your HIV?

Month: \_\_\_\_\_

Year: \_\_\_\_\_

- Never

**Recruit a mix of treatment experienced and treatment naive**

### Disqualified

Thank you for taking the time to answer my questions. Unfortunately, you are not eligible for this particular study. May we continue to contact you for future studies?

- Yes

No → **make note in database**

**Update change in database (ex: treatment experienced, date discrepancy, scammer etc)**

### Qualified Hold

Thank you for answering our questions. You may be eligible for our upcoming study. I will review your answers with my supervisor, and if we choose to include you in our study, you will receive a call.

Name: \_\_\_\_\_

Phone #1: \_\_\_\_\_

- Cell

Home

Work

Other: \_\_\_\_\_

Phone #2: \_\_\_\_\_ → **ask for an additional number**

- Cell

Home

Work

Other: \_\_\_\_\_

Email: \_\_\_\_\_

Notes: \_\_\_\_\_

## Scheduling

- If participant arrives 15 minutes early for sign-in then he/she gets a \$10 Starbucks gift card
- Give participant facility location and facility phone number for directions
- Give participant direct line (415.348.2925) in case of questions
- Ask for email (if not provided earlier) or street address for confirmation letter

Street address: \_\_\_\_\_

- Ask for additional number (if not provided earlier) for reminder call
- Participants must bring ID

- Disqualified** because \_\_\_\_\_
- Qualified Hold**
- Scheduled** and put on spec sheet
- Confirmation email or letter** sent
- Reminder call** made

## Appendix C

### Focus Group Discussion Guide

Discussion Guide for “Optimizing Treatment and TasP (Treatment as Prevention)”

Focus Groups

April 11, 2012 – District of Columbia

April 16, 2012 – Los Angeles

Final Draft – April 10, 2012

Goal – 120 Minutes (including Check-in With Back Room) - Estimated Length of  
Current Guide: 115 Minutes

#### 1. Introduction – 5 Minutes

Thanks for coming today. Go over ground rules:

- Interview will last between an hour and a half and two hours;
- Independent moderator;
- No right or wrong answers;
- Confidentiality;
- Topic: First of all, everyone in this room has indicated to us that they are HIV positive. Some are taking antiretroviral prescription medication for your HIV and others are not. We’re going to talk today about what optimum HIV treatment is – what it means to you – what it means to your health – and then we’re going to talk about new directions for antiretroviral HIV treatment.

#### 2. Background Info – 10 Minutes

**OK, now let’s go around the room and let you introduce yourselves. Tell us your first name, a sentence or so about yourself and when (what year) you were diagnosed with HIV. Okay? Let’s start to my right and just go around the table.**

**Okay, let’s get more specific now. I’d like you to tell us what your viral loads and CD4 counts are and whether or not you are currently taking antiretroviral medication for HIV. Let’s go around the table once again starting on my right.** What is your viral load and CD4 count?

Are you taking prescription antiretroviral medication for your HIV? What are you taking?

Those of you taking ARV medication for your HIV, how much would you say you knew about the medication before you started taking it? Would you say you knew a lot, a little, or somewhere in between?

(IF LITTLE OR SOMEWHERE IN BETWEEN) Some people have told us that they didn't want to know much about the medication they would be taking before they started. Did you want to know more or was it a conscious decision NOT to know?

(IF CONSCIOUS DECISION) Help me understand that. Why was that? For those of you who wanted information about the medication you would be taking, where did you go for information about the medication?

### **3. Access to care – 10 minutes**

**Now I'd like to focus on access to healthcare for your HIV.**

How many people see a doctor regularly? Let's say at least 3 to 4 times a year. Are there challenges associated with that? (IF YES) What are they?

How do you pay when you see a doctor? Do you have private insurance, public insurance such as Medicaid, or what?

For those on medication for your HIV, Is it challenging to pay for your medication? How do you pay for it?

### **4. Discussion with those not taking HIV medication – 15 minutes**

**Now I'd like to focus for just a minute on those of you who are not taking HIV medication. If the rest of you could listen carefully --- I'll pull you all into the discussion shortly.**

Why haven't you started taking HIV medications yet? When do you think you will start taking medications for your HIV?

On a ten-point scale, how ready would you say you are to begin taking medication for HIV, with 1 meaning you are not at all ready and 10 meaning you're totally ready?

**(FOR THOSE OF YOU NOT CURRENTLY READY TO BEGIN MEDICATION)**

**Talk to me about what it would take for you to be totally ready to take HIV medication.**

(PROBE): What would have to happen for you to be ready?

Have you talked with your doctor about starting?

(PROBE): What does your doctor tell you?

Do you trust the information you have been told by your doctor about HIV medication? Why? Why not?

(PROBE): Do you trust your doctor overall?

How about Community Based Organizations or AIDS Service Organizations? Do you trust them for information about HIV medication? Why or why not?

(PROBE): Do you trust them overall?

**Let's talk about HIV medications in general.** How often do you think someone has to take HIV medication?  
Does HIV medication generally have to be taken with food?  
How many pills does someone need to take at one time?

**Let's talk for a minute about how familiar you may or may not be with specific HIV medications.** Are you familiar with any specific HIV medications?

**I have just a few more questions for those of you not currently taking HIV medication.**

Where would you say you have learned the information you currently have about HIV medications?

What kinds of information do you think you would need to know about any HIV medication before starting to take it?

**This is the last question for those of you not currently taking HIV medication.** Would you say that you are afraid of potential side effects? What have you heard about side effects? Which ones, if any, frighten you the most?

**5. Discussion with whole group – What constitutes success with HIV treatment? – 20 Minutes**

**Now, I'd like to speak with the whole group and have you focus on what success looks like in HIV treatment.**

How does someone know if his or her HIV medication regimen is successful?  
What should treatment goals look like? Please note, you don't have to be currently taking medication to answer this question).

You mentioned undetectable viral load / what about undetectable viral load. Can you tell me what that means?

How many people in this room think they have undetectable viral load right now?

I'm curious, once your viral load is undetectable, does it always stay that way?

(PROBE): What are some of the reasons that viral load may increase after it was once undetectable? Those of you who have undetectable viral load, does it worry you that it might not stay that way?

What are some of the things that you do to try and keep your viral load undetectable?

(PROBE): How confident are you that these things will work over time?

## **6. Discussion about HIV medication between those currently taking medication and those not currently taking HIV medication - 23 Minutes**

**I'd like you to think back to the earlier discussion with those individuals in this room who are not currently taking HIV medication.**

Those who are taking medication, knowing what you know today, what would you tell \_\_\_\_\_ about your personal experience. What do you think they should know?

Are you concerned for them because they are not on medication?

(PROBE): Why or why not?

I'm curious. How many people in this room believe that it is possible to control HIV WITHOUT ever taking HIV medication? If so, for how long?

Have you ever heard the term "elite controllers?"

"Elite controllers" is the name scientists have given a group of individuals who seem to be able to control their HIV infection over the long term without HIV medication.

Do any of you who are not on medication suspect that you could be an "elite controller?" (IF YES) Why do you think that?

Do you have any idea how many elite controllers scientists believe there are in the world?

## 7. Treatment as Prevention – 10 Minutes

**(IF MENTIONED PREVIOUSLY) Some of you may have mentioned earlier that effective HIV treatment can help reduce the risk of transmitting HIV to others.**

**I'd like to switch the focus of our discussion to keeping your sex partners safe from HIV.**

First question. Do you think HIV treatment affects transmission? That is, does HIV treatment affect whether or not someone will pass the virus on to his or her sex partner?

(PROBE): Tell me about that.

If someone's viral load is undetectable, do his/her chances of passing the virus onto others during sex increase, decrease, or stay the same?

If someone's viral load is undetectable, is it okay not to use condoms with his / her sex partner? (IF YES) Why? How do others feel about that?

## 8. Discussion about PEP and PrEP – 10 minutes

Has anyone ever heard of HIV negative people taking antiretroviral medication to keep from becoming infected with HIV? Please tell me what you've heard.

**PEP, is called Post-exposure Prophylaxis, and is when someone who is HIV negative takes ARV for a regimen of 28 days after they might have been exposed to HIV ---- as a measure to try and interrupt transmission.** Show of hands, how many of you have heard of PEP?

Another show of hands, did any of you ever do a regimen of PEP before becoming infected with HIV?

(IF YES) Can you tell me about that experience?

Have any of you recommended PEP to a sex partner?

How available do you think PEP is in your community?

How available do you think it should be?

Do most people know that PEP is available or do you think more education is necessary?

(IF MORE EDUCATION IS NECESSARY) Tell me about that.

**PrEP, is called Pre-Exposure Prophylaxis, and is when someone who is HIV negative takes ARVs every day to try and prevent HIV infection.**

Show of hands, how many of you have heard of PrEP?

Another show of hands, did any of you ever take PrEP before becoming infected with HIV?  
(IF YES) Can you tell me about that experience?

Have any of you recommended PrEP to a sex partner?  
How available do you think PrEP is in your community? How available do you think it should be?

Do most people know about PrEP or do you think more education is necessary?  
(IF MORE EDUCATION IS NECESSARY) Tell me about that.

**Let's imagine for a minute that everyone, or almost every one, in a community who is living with HIV achieves an undetectable viral load.**

What affect could that have on the community as a whole?

What if almost everyone in the whole country who is living with HIV could achieve an undetectable viral load? What would that mean?

## **9. Discussion about whether or not it is possible to End the Epidemic? – 5 minutes**

**I have one final set of questions.**

Do you think it's possible to end the HIV epidemic?

(IF YES) What would it take to end the epidemic?

(IF NECESSARY) Have you read or heard anyone say that it is possible to end the HIV epidemic if almost everyone who is living with HIV is on HIV medication and achieves an undetectable viral load? Tell me about that.

(PROBE): Do you believe that is true or not?

## **10. Check in with back room – 5 Minutes**

## **11. Thank You and Goodbye – 2 Minutes**

## Appendix D

### Community Forum Discussion Outline

Discussion Outline for “Optimizing Treatment and TasP (Treatment as Prevention)”

Community Forum

April 12, 2012 – District of Columbia

April 17, 2012 – Los Angeles

Final Draft – April 12, 2012

Goal – 120 Minutes - Estimated Length of Current Guide: 122 Minutes

#### 1. Introduction – 5 Minutes

Thanks for coming today. Go over ground rules:

- Discussion will last between an hour and a half and two hours;
- Explain process;
- Taking Notes;
- No right or wrong answers; looking for your opinions;
- Topic: We’re going to talk today about what optimum HIV treatment is – what it means to you – what it means to individual health and to health of whole communities – and then we’re going to talk about new directions for HIV treatment. NMAC is using these community forums to better understand the needs of communities for HIV treatment education and advocacy.

#### 2. Background Info – 15 Minutes

**OK, now let’s go around the room and introduce ourselves. Tell us your first name, why you’re here, if you work or volunteer in HIV -- who you work for or volunteer with, and how long you’ve been involved with HIV work.**

#### 3. Discussion about those not taking HIV medication – 10 minutes

**Now I’d like to focus for just a minute on HIV-positive individuals in your communities who are not taking HIV medication.**

First of all, when do you think someone should start taking antiretroviral medications for HIV?

(PROBE): Is there an ideal time? (IF YES) Tell me about that.

**Talk to me about what you think it takes for someone to be totally ready to take antiretroviral HIV medication.**

(PROBE): What has to happen for someone to be ready?

Where would you say most people living with HIV learned the information they currently have about medications to treat HIV?

What kinds of information do you think someone would need to know about any medication to treat HIV before starting to take it?

**4. What constitutes success with HIV treatment? – 20 Minutes**

**Now, I'd like to have you focus on what success looks like in HIV treatment.**

How does someone know if his or her HIV medication regimen is successful?

What should treatment goals look like?

You mentioned undetectable viral load / what about undetectable viral load?  
Can you tell me what that means?

I'm curious, once someone's viral load is undetectable, does it always stay that way?

(PROBE): What are some of the reasons that viral load may increase after it was once undetectable?

Do you think individuals in your community with an undetectable viral load worry that it might not stay that way?

What are some of the things that someone can do to try and keep their viral load undetectable? Do you think most people taking HIV medication know this?

(PROBE): How confident do you think people are that these things will work over time?

**5. Discussion about PEP and PrEP – 10 minutes**

Has anyone ever heard of HIV negative people taking antiretroviral medication to keep from acquiring HIV? Please tell me what you've heard.

**PEP is called Post-exposure Prophylaxis, and is when someone who is HIV negative takes ARV for a regimen of 28 days after they might have been exposed to HIV ---- as a measure to try and interrupt infection.** Show of hands, how many of you have heard of PEP?

How available do you think PEP is in your community?

How available do you think it should be? Does anything about PEP concern you?

Do most people know about PEP or do you think more education is necessary?  
(IF MORE EDUCATION IS NECESSARY) Tell me about that.

**PrEP, is called Pre-Exposure Prophylaxis, and is when someone who is HIV negative takes ARVs every day to try and prevent acquisition of HIV infection.**

Show of hands, how many of you have heard of PrEP?

How available do you think PrEP is in your community? How available do you think it should be? Does anything about PrEP concern you?

Do most people know about PrEP or do you think more education is necessary?  
(IF MORE EDUCATION IS NECESSARY) Tell me about that.

## **6. Discussion about antiretroviral HIV medication - 10 Minutes**

Are you concerned when HIV-positive individuals are not on ARV medication? (PROBE)  
Why or why not?

I'm curious. How many people in this room believe that it is possible to control HIV WITHOUT ever taking HIV medication? (IF YES) For how long?

Do you know anyone who is able to control their HIV without medication?  
(IF YES) Why do you think that?

Do you have any idea how many people in the world scientists believe are able to control their HIV infection without medication?

## 7. Treatment as Prevention – 20 Minutes

**I'd like to switch the focus of our discussion to HIV prevention or reducing HIV transmission during sex.**

First question. Does HIV treatment affect transmission? That is, can effective HIV treatment affect whether or not someone will pass the virus on to his or her sex partner?

If someone's viral load is undetectable, do his/her chances of passing the virus onto others during sex increase, decrease, or stay the same?

If someone's viral load is undetectable, is it okay for them NOT to use condoms with his / her sex partner? (IF YES) Why? How do others feel about that?

**Let's imagine for a minute that everyone, or almost every one, in a community who is living with HIV achieves an undetectable viral load.**

What affect could that have on the community as a whole?

What if almost everyone in the whole country who is living with HIV could achieve an undetectable viral load? What would that mean?

Do you think it's possible to end the HIV epidemic?

(IF YES) What would it take to end the epidemic?

(IF NECESSARY) Have you read or heard anyone say that it is possible to end the HIV epidemic if almost everyone who is living with HIV is on HIV medication and achieves an undetectable viral load? Tell me about that.

(PROBE): Do you believe that is possible or not?

(PROBE): How does that make you feel?

## 8. Focus Group Highlights – 30 minutes

We asked many of these same questions of respondents in a focus group last night. I'd like to share with you a little bit about what we heard and ask you what you think about their responses.

**Focus Group with 10 Black Women who are living with HIV; 5 currently taking ARV medication; 5 not on ARV medication.**

**Have done other focus groups with Black gay and bisexual men in Atlanta, New York, and Oakland.**

**Will be doing groups next week in Los Angeles with Hispanic gay and bisexual men.**

**Group last night was consistent with other groups in the following way:**

- **The women were very focused on CD4 count as an indication of when they should begin taking ARV medication. We've seen that previously -- and it is not surprising. However, these particular women had a much stronger belief that individuals SHOULD NOT begin taking ARVs BEFORE that time. Only one person in the group believed that individuals should consider beginning taking ARVs as soon as possible after being diagnosed.**
- **One woman said that she heard a radio ad that stated, "get tested, get treated." She is not currently taking ARV medication and she said that it made her wonder if they were saying that one should begin treatment immediately following testing positive. But she wasn't sure about that.**

**TOPLINE CONCLUSION: The women in our focus group are receiving messages from their doctors loud and clear; and they are taking the information literally. When a physician says, you don't need to begin taking meds until your counts reach 500, they believe that means that they shouldn't begin taking them until then. They are basically not receiving alternative messages about when treatment can begin. There is a strong need for treatment education to include information that is nuanced in the same manner as the U.S. Treatment Guidelines.**

- **The women last night were very knowledgeable about viral load – and understood what undetectable viral load is about. Several had achieved undetectable viral load and maintained it by: never missing their medication, keeping their stress levels low, reducing or eliminating recreational drug and alcohol use, and maintaining a healthy weight. All of the women who had achieved undetectable viral load were extremely confident they would maintain it over the long term ("1,000 percent confident" said one woman).**
- **None of the women in the group believed that treatment had anything to do with transmission. When the question was first asked, there was a resounding chorus of "undetectable doesn't mean that you can't**

transmit the virus.” When asked whether it makes the chances of passing the virus on to others during sex increase, decrease, or stay the same, it was unanimous that the chances stay the same.

- One woman, though, began to talk about the role of ARVs in preventing mother to child HIV transmission and wondered if the same principle could work in sexual transmission. Most of the group argued with her stating, “mother to child transmission was reduced mostly because of cesarean births;” not the result of the mother taking ARVs during pregnancy.

**TOPLINE CONCLUSION:** The women in our focus group did not fully understand ARV use during pregnancy (although many had used it during pregnancy). Treatment education needs to focus on that aspect of ARV use --- as well as TasP.

- Not a single woman in the focus group had ever heard of PEP or PrEP. During the discussion, many women stated that, “they should have told us.” CBOs, our doctors, and the government have a responsibility to inform the public about what’s going on. People need to have all of their options, whether you agree with them or not. The women were especially interested in PEP.

**TOPLINE CONCLUSION:** There needs to be education regarding PEP and PrEP. Education needs to focus on the risks and benefits ---- and explain some of the complexities regarding the study results of PrEP among gay and bisexual men as well as women.

- When asked, “Let’s imagine for a minute that everyone, or almost everyone, in a community who is living with HIV achieves an undetectable viral load, what affect could that have on the epidemic?” Resounding that it would have “no effect at all on the epidemic.”

**TOPLINE CONCLUSION:** Basic information about the potential benefits of TasP needs to be communicated. It is important to communicate this in a way that it doesn’t undermine other prevention methods; but it is critical that individuals understand the research. Individuals indicated that it would definitely be a motivating factor to begin medication if they were a “part of something bigger” and if it really would help keep them from passing the virus on to others.

**OVERALL CONCLUSION:** Almost all of the women in this group felt they were sufficiently informed about HIV treatment at the beginning of the group, and by the end, felt strongly that they didn’t have all the information that they needed in order to make informed choices. Some

were quite angry with that, stating that people need to know what's going on. They need to understand what is possible.

All of the women in this group would benefit from strategic treatment education.

**9. Thank You and Goodbye – 2 Minutes**

## Appendix E

### Resume for Melissa Shepherd

#### SUMMARY OF EXPERIENCE

Ms. Shepherd has over 30 years of experience translating research into strategic communications. She excels in the design, implementation, and evaluation of public relations, social marketing, issues management, stakeholder relationship management, and risk communications. Ms. Shepherd is a skilled writer and editor targeting highly segmented audiences, stakeholders, opinion leaders, and the general public.

#### PROFESSIONAL EXPERIENCE

*Sr. Vice President, Strategic Communications, **The Henne Group**, San Francisco, CA, January 2011-June 2012*

Ms. Shepherd directed research and strategic communications for private and public sector clients. Focusing on public health and healthcare, her experience at THG included the following types of projects: science translation, business competitive intelligence, issues management, stakeholder opinion research, consumer and provider research, and issue analysis.

*Associate Director for Communications, Division of HIV/AIDS Prevention (DHAP), National Center for HIV, Hepatitis, STD, and TB Prevention (NCHHSTP), **Centers for Disease Control and Prevention (CDC)**, Atlanta, GA, 2009-2011*

Ms. Shepherd was responsible for issues management, enterprise communications, and stakeholder relationship management for the HIV/AIDS Division at the CDC. As part of the senior management team, Ms. Shepherd helped oversee and implement HIV prevention policies, programs, and research for a division with an annual budget of over \$700 million dollars.

*Chief, Prevention Communications Branch, Division of HIV/AIDS (DHAP), NCHHSTP, **CDC**, Atlanta, GA, 2007-2009*

Ms. Shepherd directed a branch of over 40 employees with a budget of more than \$12M annually. In this position, she was responsible for all social marketing for HIV/AIDS, including national campaigns, campaigns targeting physicians, and other behavior change and harm reduction communications efforts. She also directed all online work for DHAP, including web sites, banner advertisements, and social media. Ms. Shepherd was responsible for formative research, planning, implementation, and evaluation of all of the work she directed. Ms. Shepherd worked closely with the White House as the chief architect of the Act Against AIDS Campaign, launched in 2009.

*Senior Advisor to the Director, National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), CDC, Atlanta, GA, 2002-2007*

Ms. Shepherd served on the senior leadership team, reporting directly to the Director of NCHHSTP. In this capacity, she was responsible for strategic planning of partnership and communication activities throughout the Center.

Ms. Shepherd also served as a liaison to the *Behavioral Science and Health Education Department at Rollins School of Public Health at Emory University*. In this capacity, Ms. Shepherd helped to advise and mentor students interested in health and risk communications. She was the co-director of the Center of Health Communications. As an adjunct instructor, she taught masters level courses in health and risk communications and she served on the inter-departmental task force for public health preparedness.

*Associate Director for Communications, NCHHSTP, CDC, Atlanta, GA, 1995-2002*

Ms. Shepherd served as the senior communications scientist at NCHHSTP, overseeing the development, implementation, and evaluation of social marketing, issues management, and strategic communications approaches.

*Chief, Marketing and Communications Branch, National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), CDC, Atlanta, GA, 1990-2002*

Ms. Shepherd planned and directed social marketing campaigns for the CDC. She directed a branch of over 20 employees and a budget of approximately \$23M.

*Program Manager, America Responds to AIDS Campaign, National AIDS Information and Education Program, Office of the Director, CDC, Atlanta, GA 1987-1990*

Ms. Shepherd planned, implemented, and oversaw the evaluation of *America Responds to AIDS*, one of the first large, multi-level government sponsored social marketing campaigns in the history of public health.

*Director of Education, AID Atlanta, Atlanta, GA, 1986-1987*

*Data Collection & Field Research Manager, Research & Decisions Corporation, San Francisco, CA, 1983-1986*

*Assistant Manager, AT&T Customer Service Attitude Measurement Program, Atlanta, GA, 1979-1983*

*Director of Qualitative Research Services, Marketing and Research Counselors, Inc., Atlanta, GA, 1978-1979*

*Qualitative Research Manager, Burke Marketing Research, Inc., Cincinnati, OH, 1976-1978*

## PROFESSIONAL MEMBERSHIPS AND INVOLVEMENT

Member, Issues Management Council

## EDUCATION

B.A., Journalism/Marketing. **University of Georgia College of Mass Communications**, Athens, GA, 1976.

Graduate of Marketing Research Management Certificate Program. **The Burke Institute, University of Cincinnati**, Cincinnati, OH, 1976-1977.

## HONORS

- 1993 CDC Award for Communications Excellence
- 1994 Federal Employee of the Year Nominee and Finalist
- 1995 CDC Award for Communications Excellence
- 1997 DHHS Secretary's Award for Distinguished Service
- 2002 CDC Supervisor of the Year Award, NCHHSTP

## Awards

- 1988 Silver Anvil Award, Public Relations Society of America for National Mailing, *Understanding AIDS*
- 1989 Multiple Cleo Awards for Excellence in Public Service Advertising
- 1990 Multiple Cleo Awards for Excellence in Public Service Advertising
- 1991 Multiple Cleo Awards for Excellence in Public Service Advertising
- 1992 Emmy Nomination for Television Documentary *Smart Sex*
- 1995 Silver Anvil Award, Public Relations Society of America for *Condom Advocacy Campaign*

## SELECT PUBLICATIONS

Middlestadt, Susan, **Shepherd, Melissa**, The Use of Theory Based Semi-Structured Elicitation Questionnaire: Formative Research for CDC's Prevention Marketing Initiative, *Public Health Reports* 1996.

**Shepherd, Melissa**, Preventing the Sexual Transmission of HIV and other STDs Among Young Adults: A Media Advocacy Strategy, *Conference on the Role of Advertising and Social Marketing, Society for Consumer Psychology* 1995, Oral Presentation and Book Chapter.

Janssen, Rob, Gayle, Helene, Holtgrave, David, Valdiserri, Ron, Buehler, Jim, **Shepherd, Melissa**, Sero Status Approach to Fighting the HIV Epidemic: Prevention Strategies for Persons Living with HIV in the United States, *American Journal of Public Health* 2001.

## Appendix E

### Resume for Octavio Vallejo, M.D., M.P.H., CHES

## PROFESSIONAL EXPERIENCE

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### AIDS PROJECT LOS ANGELES

2011 - PRESENT

#### *Treatment education specialist for the Care and Access Network Program (CAN).*

Functional responsibility in the planning, implementation and coordination of the Care and Access Network Los Angeles- a special research project funded by AIDS United Fund. Assisting in the capacity development of CAN Los Angeles community partners. Development of internal processes and support external evaluation and monitoring.

### GILEAD SCIENCES

2005 – 2011

#### *Associate Director Government Affairs- Regional Lead HIV FOCUS (HIV on the Frontline of Communities in the U.S.) Testing and Linkage to Care Initiative– Los Angeles, California*

- Generate input and ultimately buy-in from all relevant parties necessary to operationalize the specific Plan of Action (POA)
- Provide assessment of current political and policy environment in regard to HIV/AIDS testing and prevention efforts
- Develop and maintain strategic network of relationships in the region to help inform and guide local strategy
- Manage performance based POA to strict timeline and deliverables
- Project management of funded initiatives
- Perform administrative functions required of a field position, such as reporting metrics, budgeting and independent responsibility for the solution of local problems, general management and contacts with key stakeholders
- Establish strong working links with other relevant Gilead departments
- Ensure compliance by interface with legal affairs

#### *Associate Director Medical Scientist- Medical Affairs/Community– Los Angeles, California*

- Respond to scientific inquiries from health care practitioners and community health educators related to HIV treatment and management
- Identify, develop, train, and evaluate community and professional opinion leaders
- Identify, develop, train, and evaluate community and professional speakers
- Present scientific information to internal (eg, community liaisons personnel training) and external audiences (eg, community audiences, health care professional and allied health professionals)
- Support local clinical research (eg, identify education opportunities, assist with recruitment initiatives, communicate feedback from sites)

UCLA CENTER FOR HEALTH PROMOTION & DISEASE PREVENTION **1994 - 2005**  
PACIFIC AIDS EDUCATION AND TRAINING CENTERS  
MENTAL HEALTH CARE PROVIDER EDUCATION, HIV/AIDS PROGRAM  
TARGETED PROVIDER EDUCATION DEMONSTRATION GRANT PROGRAM  
***HIV/AIDS Faculty/Trainer – Los Angeles, California***

Chosen by programs promoting professional training, education and information services to serve as training specialist for AIDS Education and training programs by providing education and consulting services to care providers and educators on a wide range of issues related to HIV infection. Additional responsibilities include assisting with marketing efforts and to secure continued funding.

LATINO BUREAU FOR AIDS COMMUNITY-BASED ORGANIZATIONS **1994 - 2004**  
***Community Speaker (Volunteer Position) – Los Angeles, California***

Promote success of agencies including Bienestar Latino AIDS Project, Avance Human Services, Clinica Para Las Americas, L.A. Shanti, Clinica Monsenor Romero, Being Alive and Altamed by serving as speaker for educational events for the community at large and facilitating HIV support groups as well as providing on-site training for new agency personnel.

LOS ANGELES COUNTY HIV/AIDS STRATEGIC PLANNING AND OVERSIGHT GROUP **1999 - 2000**  
***Member – Los Angeles, California***

Selected to join group comprised of nationally recognized experts on HIV prevention, patient care and treatment to contribute to the planning of guidelines for delivery of HIV services in Los Angeles County that serve as the catalyst for nationally accepted policies and procedures.

LATINO AIDS CONFERENCE **1999 - 2000**  
***Co-Chairman, 7<sup>th</sup> Latino Aids Conference – Los Angeles, California***

Directed the planning of conference with responsibility for fundraising activities, program development and promotion of event.

BIENESTAR-EXTRA **1995 - 1998**  
***Editor – Los Angeles, California***

Responsible for selection of HIV educational material, format and layout for Spanish newsletter published for Bienestar Latino AIDS Project.

NATIONAL INSTITUTE OF HEALTH/MEXICAN SYSTEM OF INVESTIGATORS **1992 - 1996**  
***Associated Investigator, Category A – Mexico City, Mexico***

Served in the field of Public Health and Epidemiology for institutions of the Mexican health care system, regularly publishing material in peer-reviewed journals.

HOSPITAL INFANTIL DE MEXICO “FEDERICO GOMEZ” **1992 - 1994**  
***Counselor, Immunodeficiency Clinic – Mexico City, Mexico***

Provided counseling and support services for families with children infected with HIV.

SECRETARY OF HEALTH MEXICO **1992 - 1994**

***Associate Director of Research and Evaluation, General Directorate of Statistics, Evaluation and Demographic Data – Mexico City, Mexico***

Analyzed national health data to generate reports for the Secretary of Health. Provided support and guidance to the development of national public health policies.

DIRECTORATE OF EPIDEMIOLOGY, SECRETARY OF HEALTH MEXICO **1987 - 1989**

***Head of Department of Diarrheal Diseases – Mexico City, Mexico***

Collected and analyzed national epidemiological data of infectious disease affecting the gastrointestinal system. Studied epidemic outbreaks to establish epidemiological surveillance systems to control outbreaks of Salmonella, Shigella and Vibrio Cholera.

NATIONAL INSTITUTE OF HEALTH, SECRETARY OF HEALTH MEXICO **1984 - 1986**

***Head of Laboratory of Helminths and Protozoa Parasite Lab of Parasitology – Mexico City, Mexico***

Managed all diagnostic services provided by laboratory. Additionally, developed field strategies to control parasite diseases among children in rural areas.

**EDUCATION**

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AUTONOMOUS UNIVERSITY OF PUEBLA

*Puebla, Pue. Mexico*

***Doctor of Medicine (M.D.)***

UNIVERSITY OF MIAMI, SCHOOL OF MEDICINE DEPARTMENT OF EPIDEMIOLOGY

*Miami, Florida*

***Master of Public Health***

UNIVERSITY OF CALIFORNIA LOS ANGELES

*Los Angeles, California*

***Fellowship on Public Health and AIDS***

NATIONAL INSTITUTE OF EPIDEMIOLOGY, DIAGNOSIS AND REFERENCE

*Mexico City, Mexico*

***Specialty on Infectology in Public Health, Secretariat of Health Mexico***

CENTERS FOR DISEASE CONTROL

*Secretariat of Health Mexico; Atlanta, Georgia*

***Specialty on Epidemiology***

NATIONAL COMMISSION FOR HEALTH EDUCATION CREDENTIALING

*Certification test LA, CA*

***Certified Health Education Specialist CHES Number 19390***

For questions or comments about this report, please contact:

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