



National Think Tank On HIV Treatment Education, Health Literacy, and Wellness

a recap of a national think tank held in
washington, dc in april of 2013



April 2013

NMAC National Think Tank on HIV Treatment Education, Health Literacy, and Wellness – April 2013

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Executive Summary

In April 2013, as a part of an on-going HIV treatment education and mobilization initiative, the National Minority AIDS Council (NMAC) convened a national think tank in Washington, DC bringing together 45 key HIV experts to review and discuss opportunities for HIV treatment education, health literacy, and wellness.

The following report summarizes the presentations and discussions at that April think tank, reviewing current priorities and efforts in HIV treatment education and health literacy and listing the main recommendations for communities, health service providers, government, and funders.

The discussions at the think tank meeting centered around two key themes, namely:

- A new wave of HIV treatment education and health literacy work is needed to clearly communicate that HIV treatments are safe and highly effective in ensuring health and reducing risk of onward transmission.
- This new health literacy work can and should be conducted in ways that use the power of community networks to address contexts of healthcare, wellness, and social determinants.

Recommendations for follow-up actions from the April meeting included:

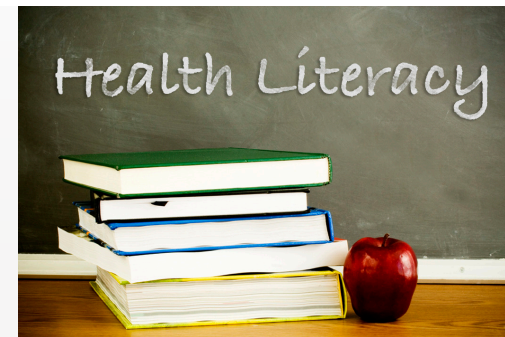
- Partnerships should be formed with coalitions engaged in HIV awareness, such as population based organizations working alongside disease specific organizations, to ensure that they include accurate information about HIV treatment in their communications.
- Multiple community organizations and training networks should be engaged to develop HIV treatment education content to ensure dissemination and delivery of information and training in a way that is aligned and coordinated.

- A broad range of coalitions can be encouraged to document and highlight HIV-positive people's knowledge and expectations about HIV treatment and healthcare, and showcase innovative practices that document and improve community-level HIV treatment literacy and expectations. These coalitions will be formed through the follow up working group activity recommended by the Think Tank.

- Funding agencies (i.e. Federal government, philanthropic organizations, private sector) should be encouraged to create and publicize new funding and training opportunities for community-based programs focused on wellness, health literacy, and people's empowerment and self-management for long-term HIV treatment.

- Emerging and established leadership among HIV-positive people should be supported to communicate the importance of HIV treatment education, health literacy, and wellness.

These recommendations will form the basis for follow-up working groups and the work of NMAC during the coming year. All of the working groups will provide critical input towards developing an "HIV Health Literacy and Wellness Blueprint" (Blueprint). The groups will be comprised of leaders in the field of HIV treatment, health literacy and patient navigation and will come from a diversity of professional backgrounds including government, community, research, and funding bodies. Combining the efforts of the working groups with the input from working group's activities during the United States Conference on AIDS (USCA) will lead to the finalization of the Blueprint.



Introduction

In the United States today, approximately 1.2 million people are living with HIV. Of those, one in five (220,000 people) are unaware of their infection. An estimated 50,000 Americans become infected with HIV each year. Although approximately 427,000 Americans are accessing HIV treatment, more than 650,000 others should be but aren't. And unfortunately, only 25% of people living with HIV (a total of 329,000 people) have successfully sustained HIV treatment to achieve a suppressed HIV viral load.

In 2010, new national commitments for health were made in the form of the National HIV/AIDS Strategy and Patient Protection and Affordable Care Act (ACA). These initiatives, along with renewed HIV advocacy and community mobilization for HIV treatment, can succeed in linking people to care and ensuring that all HIV-positive people are able to lead full and healthy lives.

Starting in 2011, the National Minority AIDS Council (NMAC) launched a new HIV treatment initiative to build community awareness, education, and mobilization. This new NMAC Division, named Treatment Education, Adherence and Mobilization (TEAM), conducted research in preparation for the 2013 National HIV Treatment Education, Health Literacy, and Wellness think tank. NMAC developed a literature review of evidence based models of treatment education programs and a qualitative research report measuring level of knowledge around HIV treatment and treatment as prevention. The review paper, titled "How to end AIDS in the United States: Community-oriented HIV service delivery, treatment education, and mobilization" provided TEAM with a better understanding of the structures that existed in support of HIV treatment education and best practices to move forward as we plan the path to end AIDS in America. The qualitative research report gave NMAC an idea of the level of literacy among African American women and Latino MSM.

From April 3-4 of 2013, NMAC convened a diverse group of HIV stakeholders ranging from researchers to community based organizations, to government, to private funders to participate in the National HIV Treatment Education, Health Literacy and Wellness Think Tank in order to create a treatment education plan for the 21st century.

The objectives of the April 2013 think tank were to:

- Review the current and potential landscape of HIV treatment education, health literacy, and wellness;
- Review challenges of social determinants of health and their impact on HIV treatment education;
- Identify HIV treatment and health literacy guidelines;
- Understand the role of patient navigation in ACA and its impact on NHAS goals; and
- Identify roles of HIV treatment education/ wellness in the public, private, and nongovernmental organization (NGO) sectors.

These initiatives, along with renewed HIV advocacy and community mobilization for HIV treatment, can succeed in linking people to care and ensuring that all HIV-positive people are able to lead full and healthy lives.

The think tank agenda included a two day format with presentations, group discussions and break out working groups. Participants represented the diversity of stakeholders in the HIV sector including government, non-government, community, funders and PLWHA.

The think tank was envisioned as the beginning of a process, providing the foundation for further action. As such, participants were asked to suggest recommendations for communities, health

service providers, government, and funders. These recommendations are presented in this report, and will form the basis for follow-up working groups and the work of NMAC during the coming year.

It remains possible to meet the 2015 goals of reduced HIV incidence and improved rates of HIV treatment and care as set out in the National HIV/AIDS Strategy. Doing so requires immediate scale-up of HIV testing, treatment, and combination prevention approaches. This is a collective effort, one that NMAC is committed to supporting.

The Landscape of HIV Treatment Education

The April 2013 think tank began with three presentations about the landscape of HIV treatment education, looking at the history, current opportunities, and key messages and components of what people need to know now. These presentations were then followed by a 90-minute discussion.

History of community HIV treatment education

Presenter: Matt Sharp, independent consultant

The earliest years of the epidemic were characterized by a community-driven response. Even prior to the identification of HIV, people shared information through word of mouth, printed flyers, doctors, and community newspapers, and then began organizing regular meetings, town halls, and hotlines. Activist groups such as ACT UP formed to push for more HIV and opportunistic infection treatment research and to demand early access to experimental treatments. Activists quickly became knowledgeable about HIV treatment research and medical recommendations. By the mid-1990's, community HIV activists began organizing structured HIV treatment education efforts, including the NMAC-sponsored North American Treatment Advocates Forum (NATAF) and other trainings sponsored by groups such as ACRIA, the Black AIDS Institute Black Treatment Advocates Network (BTAN), the California Statewide Training & Education Program

(C-STEP), Philadelphia Fight's Project TEACH, and the Treatment Action Group (TAG). In the late 1990's, HIV treatment websites such as aidsmeds.com and thebody.com were launched.

In 2012, the AIDS Treatment Activists Coalition (ATAC) surveyed 14 long-time HIV treatment educators and activists to collect perspectives about successes and failures in the history of community HIV treatment education to help provide clues about what might work best in the future. From this study, ATAC formed the following recommendations for future HIV treatment education:

- HIV treatment education needs to be updated regularly to reflect advances in science and service delivery approaches.
- HIV treatment education should include people with HIV at every stage, including design, implementation, and evaluation.
- It is critical for educators to work in collaboration across institutions, community organizations, and other disease groups.
- Sustained funding must be ensured to keep the best training programs going.
- Adult learning styles must be incorporated into HIV training.
- Peer educators are very capable, but they should not be the sole source of trainers. Peer educators need mentorship and ongoing support. Co-facilitation between professionals and community volunteers works well, and remuneration of peer educators is necessary.

The think tank was envisioned as the beginning of a process, providing the foundation for further action.

- Any HIV treatment curriculum needs to be grounded in the holistic health and rights contexts of the intended training participants.
- HIV science basics should be included in any curricula. Trainers should be well versed in science and should be able to effectively and creatively explain the science to others.

Current opportunities in HIV treatment education

Presenter: Sam Avrett, The Fremont Center

To reach the goals of the National HIV/AIDS Strategy, progress is needed to diagnose people with HIV, link them to care, initiate ART, retain them in care and maintain viral suppression. This is illustrated below in the HIV treatment cascade, published in December 2011 by the US Centers for Disease Control and Prevention (CDC, Dec 2011). A combination of interventions to improve engagement in care at each level of the cascade is needed to improve HIV health outcomes, reduce new infection rates and lower costs.

Treatment education and health literacy play a key role in engagement in care. According to a study published by the CDC, many HIV-positive people do not consider HIV treatment because they feel well (18%) or do not want to think about being HIV-positive (21%) and even after they start HIV

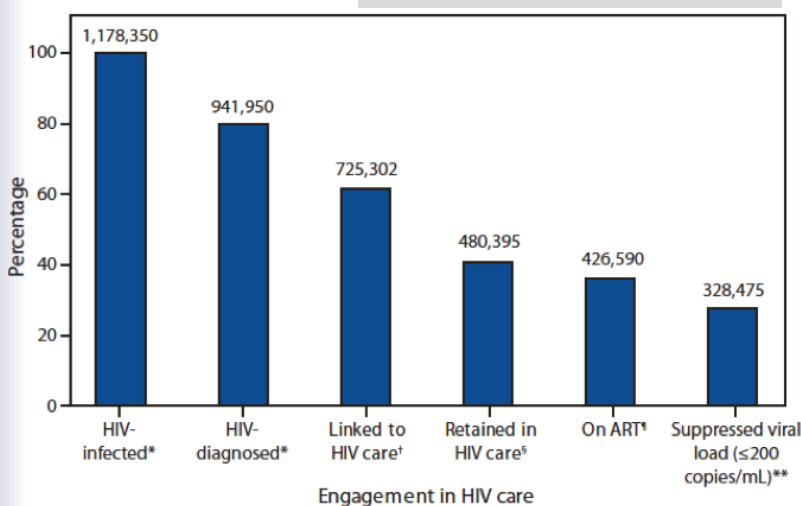
treatment, they experience challenges in getting and taking their pills because of factors such as mental health (33%), transportation (25%), and uncertain shelter and housing (15%). (CDC, Sept 2011)

Service providers also document ways that services are impeded by a lack of HIV treatment education and support. Both providers and patients need to know the risks of not treating HIV, and patients see better outcomes if they are empowered advocates for themselves in securing appointments, seeking information, knowing to complain in case of a bad provider experience, and managing their care across multiple providers and services.

Many studies about structural and social determinants of health also confirm that most people need more than an appointment and a prescription to succeed in HIV treatment. HIV affects many people who are also experiencing poverty or financial stress, alcohol or drug dependence, dislocation due to insecure housing or incarceration, and other barriers to sustained medical care.

Dozens of community-based programs have documented success in linking people to HIV testing and care, maintaining and benefitting from HIV treatment, and overcoming structural barriers to health. For example, in Birmingham, after the Alabama Project Connect program offered patient navigation support, the proportion of patients failing to enroll in HIV care decreased from 31% to 18% (Wylie 2009). In the Bronx, outreach to HIV+ drug users in single room occupancy (SROs) significantly increased engagement in medical care and HIV treatment (Cunningham et al. 2008). And in Rhode Island, with outreach and support, 82% of ex-offenders managed to stay in HIV care consistently for more than one year (Rich et al., 2001, Wohl et al., 2004).

Evidence-based guidelines do exist to improve people's entry into and retention in care and treatment. Recommendations issued in 2012 by an IAPAC panel include:



- Offer HIV treatment education, counseling, and adherence support at one-to-one level and group level.
- Support people with strengths-based case management.
- Conduct intensive outreach for those not engaged in medical care within 6 months of learning that they are HIV-positive.
- Support peer or paraprofessional patient navigation.

HIV treatment literacy: What people need to know now

Presenter: David Evans, Project Inform

HIV treatments have improved dramatically during the past decades. So have the core messages and components of what people need to know:

- For most people, HIV treatment is relatively simple, effective, tolerable and safe, and for people with HIV who are taking treatment and achieving viral suppression, expected life spans for many are now near normal.
- Untreated HIV causes inflammation and may cause long-term damage.
- HIV treatment is also prevention, in that antiretroviral drugs taken by an HIV-positive

person can reduce risk of onward transmission (“Treatment as Prevention” or TasP). Antiretroviral drugs taken by an HIV-negative person (Pre-exposure prophylaxis or PrEP) can also prevent HIV acquisition.

- Safety issues and side effects associated with ART are no greater than those for many other drugs. HIV medicines have about the same efficacy and safety levels as statins (used for lowering cholesterol).
- A person’s decisions about use of any medicine should be made with medical advice and should be based on one’s health, health risks, and life circumstances. This is the same with use of antiretrovirals (ARVs) for HIV treatment and prevention.

Treatment literacy defines what clinicians and patients should know when they talk about HIV treatment decisions, including understanding CD4 and viral load levels, side effects, drug resistance and the need for adherence and the risks of HIV transmission. Further research is needed to better understand how patients understand, retain and utilize this knowledge to make and follow through on treatment decisions.

Information about the preventative impact of treatment is still relatively new. But this information presents possibilities for profound changes in the ways in which HIV prevention and treatment services are provided. One key piece of necessary work is to educate people about this new information. Treatment will now be considered not only to benefit the individual’s health but also to protect others from transmission. This alters the process to determining when to initiate treatment and, therefore, alters the scope of work of treatment educators, sexual health counselors, HIV testing counselors and health care providers. How best to incorporate information for patients about the earlier use of treatment for prevention purposes is a key research question.



Ultimately all of these treatment options compel a reexamination of our expectations and practices for both the provider and the patient. HIV treatment is different now and approaches to treatment literacy need to change, especially in thinking about education from a wellness and health management perspective. As HIV becomes a chronic illness requiring life-long treatment and prevention efforts, much can be learned from the ways that illness and treatment are explained in other chronic conditions, such as diabetes or high cholesterol.

Discussion

After the presentations, the participants discussed the following themes:

Be clear and informative

“Early HIV treatment prevents immune system damage and preserves health. If people are HIV-positive and do not start treatment, they risk an early death. Messages have to be clear and simple to be understood.”

- In supporting campaigns to increase demand for HIV testing and treatment, both the New York City Health Department and CDC learned that messages must be simple and clear in order for people to understand and respond to them.
- Health providers must convey information correctly. Whether it’s HIV, heart disease or hypertension, information must be presented to patients in ways that make them with diagnostic and treatment options and procedures. If the provider is not well informed and comfortable with the information, they will not convey information to patients properly.
- Information should not be oversimplified. Where evidence is mixed and guidelines are not straightforward, people should be given the details in order to consider their options. An example is prostate cancer, where patients who test positive for an elevated prostate-specific antigen are

informed about the potential costs and risks of biopsies or surgery as well as the potential benefits. Responsibility is shared with the patient. In the 1983 Denver Principles, now 30 years old, people living with HIV took on the mandate to understand and have power over their treatment decisions. Going forward, HIV treatment education should aim to reinforce people’s capacity and autonomy in their health decisions.

Update HIV information and education

“The risks of not treating HIV far outweigh the risks of treatment. HIV treatment is very effective and safe, and the benefits outweigh the risks. These messages need to be communicated!”

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“If we accept that treatment is effective as prevention, that represents a revolution in our thinking, and it is the biggest change in the HIV response since 1996. How does this affect every aspect of our work? We need to think about what this means.”

- Much of current HIV treatment education still carries relics from the 1990s, reflecting a time when HIV treatment was difficult to take and there were many more short- and long-term side effects. Misperceptions about side effects and long-term toxicities keep people from testing or initiating HIV treatment. Side effects are still important, but they no longer need to be the first message that people hear.
- Government agencies and HIV service providers continue to structurally separate treatment from prevention and HIV from other health and wellness activities, even as evidence and best practice require greater integration. HRSA and the CDC have yet to

remove organizational barriers and better integrate funding structures for prevention, treatment and care. Hospitals with designated AIDS centers are still learning how best to treat HIV as a chronic condition and integrate HIV testing and treatment counseling into routine primary care and wellness care. Many community HIV organizations are still learning how to broaden their missions and messaging to address HIV within a context of healthcare, wellness, and broader public health and welfare.

Understand what people want



“There’s no problem talking about Viagra in television ads. The same level of marketing is not being done with HIV. The HIV-negative population doesn’t know about use of antiretrovirals for prevention and they’re not sensitized to the issue. I want to see primetime HIV treatment advertising on television.”

“Why do we still ask people if they want to know if they have HIV? Why not do the opt-out testing regularly? The HIV test should be like any other test, like getting your weight taken in a physical check-up. Why do we still treat it differently?”

- If HIV is going to be successfully treated as a chronic condition, then education about HIV treatment could be conducted in the same way as education about other conditions and medicines. Examples such as the “Got Sugar?” educational campaign about diabetes or the campaigns for erectile dysfunction drugs were cited during the discussion as models for HIV campaigns.

- One approach to reducing the stigma and exceptionalism of HIV is to mainstream HIV screening and treatment education as a normal part of routine primary healthcare, as is already done with asthma, diabetes, and hypertension. In some circumstances, people appreciate getting all health-related services and information in one place at one time.

- One concern about mainstreaming HIV into general healthcare is the loss of the expertise for specialized HIV services developed over the past 20 years. Designated AIDS centers and comprehensive health and social services funded under the Ryan White HIV/AIDS Program predated the “patient-centered medical home” model by more than a decade. HIV service organizations have built up decades of experience and trust with the people whom they serve. They fear the loss of a system that they perceive to be working well in meeting people’s needs for both medical and social services, such as mental health counseling, nutritional support, and housing.

- Mainstreaming HIV can also overlook the specific needs of HIV-positive populations and the very real stigma that is still attached to HIV. Merging an HIV-positive adolescent program into a general family health practice can erase the unique relationships, approaches, and services that those teens could previously access related to sexuality, mental health, substance use, and social or economic marginalization. Offering HIV testing and HIV treatment counseling in a mainstream settings can alienate those most vulnerable to HIV because of their concerns about confidentiality and their specialized needs for counseling and support services.

Consider the many influences in people’s lives

“If I’m worried about HIV and live in the Deep South, there are lots of factors that impact whether I will look for healthcare and whether I can get it. A huge factor is the community around me - my family, my friends, my church, and what I hear

every day from people around me. We've got to work with communities to talk about HIV, talk about HIV treatment, and support health literacy and wellness."

- HIV treatment literacy and wellness programs need to account for the factors that keep many populations from seeking and accessing health care. Young men do not access care as regularly as young women, and may need special efforts to get them engaged in care. People just out of prison fall out of care at very high rates.

- Geography also matters. In New York, Illinois, and California, HIV-related treatment and wellness are supported by laws and state funding, while in the Deep South and much of the rest of the rural U.S. people face increasing criminalization, a lack of knowledgeable HIV providers, conservative communities, and poorly-funded health services.

Use community networks to engage people in health

"Coughing and sneezing into the elbow became a widespread practice during the past decade, supported not only by government health campaigns but through people seeing others do it and integrating it into the way they act. In the early 1980's, word of mouth through gay men's social and sexual networks informed people about HIV and changed sexual practices. People have ability to learn new behaviors and access services. We have to use the networks that exist."

- People learn and reinforce health behaviors in a variety of ways. Community networks and peer-to-peer learning remain a powerful way to inform people and reinforce health-related behaviors.

Perspectives on Expanding HIV Treatment Education

The first session of the think tank focused on the history and landscape of HIV treatment and education. The following session showcased some

best practice models, tools and research in HIV treatment and education. Obstacles and threats to enhancing HIV treatment education were also addressed through what was learnt from the presented programs and research.

Community mobilization for HIV treatment

Presenter: M. Monica Sweeney, New York City Department of Health and Mental Hygiene

The Bronx Knows is a large-scale public health initiative to increase voluntary HIV testing so that every Bronx resident between the ages of 13 to 64 learns his or her HIV status and has access to quality care and prevention services. The NYC Health Department collaborated

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with 78 partners at more than 140 sites, to launch The Bronx Knows on National HIV Testing Day, 2008. The Bronx Knows initially set out to test the estimated 250,000 Bronx residents who had never been tested for HIV but quickly surpassed that goal before commencing its 2nd year.

The Bronx Knows has a three-part approach: (1) Make testing available and a routine part of medical care; (2) raise awareness and demand for HIV testing; and, (3) improve prompt linkage to care. The 78 institutional partners include community health centers, health department tuberculosis (TB) and sexually transmitted disease (STD) clinics, hospitals, community-based organizations, educational institutions, faith-based groups, and local businesses such as beauty parlors, many of which organized and sponsored HIV testing events.

The Bronx Knows initiative significantly increased HIV testing and linkage-to-care rates. From 2008 to

2011, more than 600,000 HIV tests were conducted, and self-reported HIV testing rates increased from 69.3% to 79.1% of all Bronx residents ages 18-64 (between 2005 and 2009). A total of 4,800 confirmed HIV-positive tests were identified – of those, at least 1,700 individuals were reported to be newly diagnosed and more than three-quarters have been linked to care. And the work continues -- The Bronx Knows initiative lives on as a community network that encourages routine HIV testing and works to link people to care and support services. The model is now being replicated in Brooklyn with the goal of testing the estimated 580,000 Brooklynites 18-64 who have never been tested for HIV.

Lessons learned from The Bronx Knows Initiative are:

- Routine HIV screening in health care settings along with increased community outreach result in increased number of people learning their HIV status and linking to care.
- Community organizations are capable of participating in HIV testing initiatives and can be integral partners in organizing testing events, offering rapid HIV tests, and reaching some of the most vulnerable, hard-to-reach populations.
- Launching the initiative required time for planning, capacity building and community buy-in. All partners needed training in how to bill and be reimbursed by the State for HIV testing. Ongoing technical assistance was needed, and the NYC Health Department needed dedicated staffing to coordinate and support the effort.

HIV treatment education and support in a healthcare setting

Presenter: Christine Nollen, St. Luke's-Roosevelt Hospital Center

The St. Luke's-Roosevelt Center for Comprehensive Care (CCC) offers a Care Coordination program,

funded by NYC DOHMH, which utilizes an interdisciplinary team, including patient navigators who work in the field, to manage patients who are most medically unstable or at risk of falling out of care. The program (1) links patients to care, (2) educates patients on diagnosis and healthy living, (3) empowers patients to control their own health care, and (4) encourages treatment adherence and self-sufficiency.

Since 2009, the Center enrolled 350 patients into care coordination based on seven criteria:

- Newly diagnosed with HIV.
- Lost to care (i.e., previously active and no visit for past nine months).
- Difficulty keeping appointments, receive sporadic care, or have never been in care.
- Difficulty adhering to HIV treatment.
- HIV treatment naïve, starting treatment, and having particular clinical markers.
- HIV treatment-experienced and re-starting treatments because of drug resistance or a changing treatment regimen.
- On HIV treatment and experiencing recurrent virologic rebound after successful suppression.

Patients enrolled into the program are current patients of the CCC and therefore already have a primary care provider and social worker. Upon enrollment into Care Coordination, each patient receives enhanced support through the addition of a care coordinator and a patient navigator, who is responsible for home visits and escorts to clinical appointments as needed. Each patient navigator manages an active case load of approximately 18 patients. About half the patients are seen weekly by patient navigators, and the rest are seen an average of once per month or once per quarter.

All patients have access to a comprehensive array of services, including primary care, specialty care, mental health and substance use services, women's health services, dental care, on-site pharmacy and special programs for adolescents/young adults, and the formerly incarcerated. The three clinical sites of the CCC offer same-day appointments to facilitate accessibility, and have invested in decorating and designing the clinics nicely to signal to patients that they are valued and welcome.

In addition to the Care Coordination Program and its use of Patient Navigators to help patients stay engaged in care, the Center offers a Peer Support program, comprised of trained CCC patients. Since 2007, the CCC recruited and trained approximately 50 patients to work as peers (with 15 currently active). Each peer was trained to provide approximately 10 hours per week of in-patient support, care facilitation, and community outreach and education. Selected peers were then also trained to support specific populations, such as young adults or formerly incarcerated patients.

The Peer Support program is valuable to the peers as well as to the patients. As patients themselves, peers have a strong connection and interest in supporting people's health. There's a real commitment among the peers to serve and they get real satisfaction from their work. Some are formerly incarcerated, so this work is helpful to their reintegration.

The training, protocols, and clinical supervision for both patient navigators and peers are fairly extensive. Patient Navigators are trained in a curriculum provided by NYC DOHMH that comes from an evidence-based program in Boston. The Peer Support program benefits from a home-grown curriculum that was contributed to by a multidisciplinary group of professional staff.

Both Patient Navigators and Peers need to learn professional boundaries to know when to share their personal experiences, when to provide impartial HIV treatment information, and when to refer questions to the primary care provider or to a specialist. Patient

Navigators are not CCC patients, but many live in or come from communities where patients live. Peers, also CCC patients, generally have limited education, backgrounds of poverty, and chronic health issues including HIV and recovery, so the program incorporates training about stress management, burnout prevention, and relapse prevention. All Patient Navigators and Peers get payment and high levels of supervision. Support and supervision may be the single most important aspect of successful peer programs.

Technologies and tools to support HIV treatment
Presenter: Nawreen Khan (behalf of Dr. Freya Spielberg), George Washington University
New technologies and tools are now available to support people in testing for HIV and in managing their HIV-related health. These include over-the-counter home testing kits and interactive internet-based or mobile device assessment, counseling and testing programs. Research is showing that these new options can provide an expanded number of people with a better experience and a better health outcome at a lower cost. New technologies may also help to reduce historic disparities in healthcare where access is impeded by factors such as distance or stigma.

Direct research and a review of evidence by researchers at George Washington University shows that:

- People who participate in on-line sexual health risk surveys and related STI testing home specimen collection report that these are preferable to clinic based testing and result in reduced sexual risk behaviors.
- Mobile health tools have been shown to help HIV positive patients lower risk behaviors and increase adherence to HIV treatment.
- Mobile health tools help patient navigators provide consistent counseling, track patients, and evaluate services in real time.

- Rapid Oral Fluid HIV testing is more effective in outreach settings and less costly than other strategies such as blood, oral fluid, rapid blood or rapid finger stick.
- Both national and international studies show that Home testing is the preferred HIV Testing method over Clinic Rapid Testing and Home Specimen collection.
- An internet-based public health system that combines assessment, counseling, home specimen collection, home testing and linkage to care is an approach that would likely lead to early detection of HIV infection, and lower viral loads for those who are infected, while improving patient experience and lowering health care costs.

Research to improve effectiveness

Presenter: David Barr, The Fremont Center (on behalf of Tim Horn, Treatment Action Group)

Research and evaluation of HIV treatment education and peer navigation should show whether defined interventions are effective in generating cognitive and behavioral outcomes – e.g. increased information, understanding, confidence, prompt linkage to care, and engagement with service providers and social support – and whether those outcomes translate into desired health impacts – i.e., reduced HIV viral loads, reduced incidence of illness, increased years of life free of disease and disability, and an improved health-related quality of life.

There is strong evidence supporting the efficacy of one-to-one and group-level HIV treatment education. HIV treatment education is defined as provision of literacy- and culturally-appropriate information and other teaching modalities to foster comprehension of HIV disease and HIV treatment so that people:

- Understand the benefits of HIV treatment and are motivated to get started and stay on treatment;

- Understand their HIV treatment options and how to talk with a medical provider or non-clinical provider to secure affordable access to the right medicines;
- Have confidence and support in making treatment decisions and following through on those decisions.

In 2012, an International Association of Physicians in AIDS Care (IAPAC) panel published clinical guidelines supporting interventions to improve entry and retention in care, adherence to HIV treatment, and success in achieving HIV viral suppression (IAPAC, 2012). This review found evidence to recommend:

- One-to-one HIV treatment education and support.
- One-to-one HIV treatment adherence counseling.
- Group HIV treatment education and counseling.
- Multidisciplinary (health team-based) HIV treatment education and counseling.

Peer navigation is an emerging profession, gaining acceptance during the past 30 years as a way to keep people in care and improve health outcomes. HIV treatment peer navigators are individuals who have similar HIV treatment needs and community backgrounds as the patients. They are trained, supervised, and supported to work both in the clinic and in communities to ensure that patients:

- Have HIV treatment information;
- Are accessing healthcare and support services (including facilitating appointments, assisting with transportation, and accompanying people to visits when needed);
- Can understand and negotiate their best options for HIV treatment (including managing care across multiple providers and services, and resolving challenges such as bad service provision);

- Have a positive peer role model and peer support, especially in adhering to HIV treatment through common issues such as depression or alcohol or drug dependence.

Across a total of 117 retrospective and observational studies looking at HIV-related peer support, there is evidence that peer-based interventions have a positive effect on HIV-related knowledge and attitudes and self-reported behaviors such as substance use or sexual activity (Simoni, 2011). However, studies are thus far less likely to show that peer-based interventions can impact biological outcomes such as HIV infection rates or HIV viral suppression. Few studies have been conducted to show whether peer-based interventions are effective in helping people to link to healthcare, stay in care, or re-engage in care.

Cultural and social determinants

Presenter: Alex Garner, National Minority AIDS Council

HIV treatment education and support for health literacy and wellness should be implemented in ways that account for the cultural and social factors that affect people's ability to understand, access, and stay in HIV treatment and care. These include expectations about what healthcare can and should deliver, experiences and expectations of discrimination or poor service within healthcare settings, the extent to which people trust each other and support each other in health, and people's literacy, poverty, mental health, substance use, and history of violence, and incarceration.

These factors are important. For example, when Massachusetts and Washington DC are compared, people living with HIV in Massachusetts do far better in achieving high rates of HIV treatment success than people living with HIV in Washington DC, even though both communities have very high rates of individuals in care. The two communities are vastly different when breakdown of race and poverty level are examined. These and other factors relate to

the conditions under which people are born, grow, and age, and differences in the ways that people perceive and access healthcare. HIV treatment education needs to be reimagined and expanded to go beyond the clinic and the virus and engage with people in a way that's responsive to their beliefs, perceptions, and daily lives.

Supporting people's ability to access and stay in HIV treatment means helping them deal with dislocation due to criminalization, incarceration, insecure housing, and unemployment. In February 2013, NMAC and Housing Works issued a joint report making four recommendations that would help improve linkage to care and HIV treatment outcomes:

- Make appropriate, affordable housing available to all low-income people with HIV;
- Remove post-incarceration barriers to subsistence income and health insurance;
- Improve prerelease discharge planning for inmates with HIV to meet housing and other essential needs;
- Evaluate the effectiveness of housing-based intervention for formerly incarcerated people with HIV.

Scaling up HIV treatment requires progress in social justice. Many people do not get tested for HIV, delay treatment initiation and fall out of care because they're afraid of discrimination, poor health services, and the costs of healthcare. Treatment education and support can help to rectify this and improve engagement in care.

Mobilization for social justice must take place on individual and community levels. People living with HIV need to disclose their status and help share experiences and reduce stigma of HIV treatment and HIV-related stigma in general. Nothing is more powerful than hearing another person's HIV story, whether they are HIV-negative or HIV-positive. People need to build effective networks of friends

and family and support each other through HIV and also depression, addiction, and life challenges. Improving access to HIV treatment and health can also strengthen communities and the value and quality of our lives.

Discussion

Following these presentations, meeting participants discussed the following themes:

Reinforce a culture of advocacy

As demonstrated by examples such as the Bronx Knows initiative, people are capable of seeking out HIV testing, treatment, and healthcare. Peer-led community social mobilization is at least as important as top-down information and support by health providers in increasing people's expectations, demand, and advocacy for HIV-related wellness and treatment.

"For me, as a black man, I am a health navigator for three family members including my grandmother. Every three weeks, I go to Florida to visit my grandmother and help her negotiate the healthcare that she needs. It's clear that the healthcare structure is not working for her or for a lot of people. Our task in HIV treatment education is more than just information about the insurance and the pills and the providers. We need to build a culture of expectations and advocacy."

"The real issue is not about funding new jobs for treatment educators and patient navigators. The real issue is giving people the information and skills to do what they need to do for themselves. I'll give an example: A secretary in my office, a woman with an associate degree, recently needed a doctor for her mother-in-law's heart problem. She's not well educated, she doesn't have good health insurance, but she figured out what medical procedure was needed, the right specialists to do the work, and how to get her mother into the right hospital to get that healthcare. Everyone can be an educated treatment advocate."

"We can develop education to improve treatment outcomes without infantilizing people. I was born in a one-room house, but it's bullshit to say that that is what defines me. Everyone can advocate for themselves. We need to get our communities to understand that."

"I got involved in the fight against AIDS in the 1980s in ACT UP in Atlanta. That's where I got information and also an understanding of AIDS activism. In early ACT UP, we mobilized from anger. Now I only see shame. We can't mobilize from shame. And we shouldn't have to."



Design programs to address structural determinants of health

People's motivations and actions related to HIV are heavily influenced by the contexts of their daily lives and the environments in which they live. Campaigns to increase people's use of HIV testing and treatment need to be designed with the input of people who are most at risk of dropping out of care, especially people who are young, low-income, living in the South, living in rural areas, and African-American.

Additional research is needed on the social determinants of health. Too much is presumed and not quantified about the correlations and causal relationships that link socio-economic factors, such as poverty, literacy, housing, incarceration, religion, sexuality, race/ethnicity, social engagement (e.g., levels of peer support, trust and confidence), and levels of health engagement (e.g., knowledge about HIV status, understanding about treatment, and access to health information and services) to health outcomes (e.g., reduced illness, improved treatment outcomes, and improved quality of life). Programs need to test whether interventions to increase social engagement and health engagement do yield positive health outcomes, and document the

cost-effectiveness of these interventions. Having this evidence would strengthen the design and scalability of community-based HIV treatment programs.

“Even when we control for income, access to health services, and individual health behaviors, Black Americans have worse health outcomes. The legacy of American slavery must be considered. Social determinants should be considered. Instead of putting on Band-Aids, we really need to open the wound and treat it.”

“Yesterday, I went to my partner’s public interest law office in Atlanta. For the last months, they have been getting death threats because they work for LGBT civil rights. People in the South live in a society that still has a high degree of racism and discrimination, manifested in laws, politics and religion. Refusal to expand Medicaid and opposition to healthcare reform is a part of it. What effect does that have on young Black gay men and young women at risk for HIV?”

“Social determinants matter. As an example, many schools are trying to campaign parents to provide healthy snacks for their kids. But why aren’t parents providing healthy snacks? It’s not just information, its cost. A parent can provide all three kids with an inexpensive snack for the same cost of providing just one with an orange. The health campaign won’t work without tackling the underlying reasons, and without involving the people who are affected in figuring out the solution.”

“We need to increase access to health insurance, of course, and we need to improve the health services, but we also need to help people address their health while they’re occupied with the challenges of merely sustaining their lives, sustaining where they live, and being sure of where they get their next meal. Even in places where prenatal care is accessible and free for everyone in need, there are still women showing up only on the day of delivery because of other priorities and constraints in their lives.”

“If we determine the influence of the society we live in, then we might see how to deal with it.”

It is important to note that the discussions focused on the need to move ahead, even in the face of these social determinant challenges. Acknowledging that these issues are there and not easily or immediately solvable should not stop the sector from progressing on needed enhancements to HIV treatment, education and wellness.

Promote a goal of wellness

The improvement of HIV treatments and the transformation of HIV into a manageable health condition is still not fully reflected in current HIV education. Much of HIV treatment education starts from a framework of preventing serious symptomatic illness. Many people do still first learn of their HIV status when they develop symptoms of immune deficiency. It is important to educate people about the virus, the immune system, the need for healthcare visits and regular tests, and the goal of viral suppression. But there is also an opportunity to reframe HIV treatment education in a wellness perspective to focus on the asymptomatic person and sustained management of overall health.

“We are in a new era now in which HIV is easier to manage than a condition like diabetes. In the goal of wellness, we may need to reeducate ourselves. Beyond taking the pills and visiting the clinic and knowing your viral load, maybe education starts from the angle that people are going to be OK and need to maintain that.”

Clarify who provides education and healthcare navigation

HIV treatment education and patient navigation is currently done by a mix of people in clinical and non-clinical settings. These include paid educators, social workers, case managers, and counselors and also unpaid community activists.

Many professions have opportunities to engage patients about their health and HIV treatment, mirroring the points of contact that an HIV-positive person has. Therefore community-based peers, emergency departments, HIV test counselors, nurses, pharmacists, and community social service providers all need to have a good understanding about HIV treatment and wellness and should be prepared to provide information as they engage with patients.

A second theme of discussion was how to rationalize the layers of staff who now share responsibility for patient support in clinics. There is a concern that creating new funding for HIV treatment educators and peer navigators may not fix the ineffectiveness of already bureaucratic healthcare structures.

A further concern is the potential burden and expectations placed on the role of peers. Peer-based information and counseling is understood to be valuable, but evidence from peer programs suggests that they can only be sustained with training, supervision, support, and remuneration.

“I encourage a shift in thinking. Let’s not have this be a fight for our organizations and our jobs. Let’s fight for structures and resource allocations that best serve the health and wellness of HIV-positive people. Right now we pay for a lot of people in clinics to educate, coordinate and navigate. Maybe we should reframe the competencies against what we need as outcomes, and rethink the positions for what’s most effective.”

“There are case managers; isn’t this their job?”

“Can we really sustain a profession of patient navigators for HIV treatment? What about patient navigation for treatment for asthma, diabetes, hepatitis, or cancer?”

Build treatment literacy of healthcare providers

Healthcare reform and Medicaid expansion are expected to bring many thousands of HIV-positive

people into care and onto HIV treatment for the first time. For example, a recent Harvard University study calculated that just in Mississippi, as many as 10,000 HIV-positive people may become newly eligible for Medicaid and 4,000 may become eligible for insurance subsidies, thereby increasing the number of HIV-positive people seeking healthcare (Harvard TAEP, 2013). Many of these individuals will be going to healthcare providers who have had only limited experience with HIV-positive patients. There is a need to train and support primary healthcare providers to be literate about HIV treatment counseling and monitoring, and to link them with specialist expertise when needed.

“We need to train primary care providers to do most of the HIV treatment counseling, and then specialists in case of complex issues. Look to the examples of aging or diabetes: we don’t all go to gerontologists and endocrinologists for routine care.”

“My sister runs a wellness clinic in Louisiana, and I know they don’t have even basic information about HIV treatment. The investment in information dissemination has not yet been made. Treatment information has got to be out there, in basic paper format and in ways that are accessible to people.”

Resources for HIV Treatment Education

The final series of presentations at the think tank sought to establish the reality of the new world of health and health insurance in the post-Affordable Care Act (ACA) implementation world. Through the perspective of community based organizations and PLWHAs the presentations addressed issues of government programs, provider assistance, and the role of funders as sources of support for enhancing HIV treatment literacy.

Funding through the Affordable Care Act and Medicaid

Presenter: Harold Phillips, Health Resources and Services Administration, U.S. Department of Health and Human Services

HIV testing, treatment and care in the United States is primarily funded by several national health programs, including the Ryan White HIV/AIDS Program, Medicaid, Medicare, the Veteran's Administration, the Substance Use and Mental Health Services Administration (SAMHSA), Title X family planning, and the Centers for Disease Control and Prevention (CDC). All of these agencies provide funding for patient education and community education.

The passage of the Affordable Care Act (ACA) in 2010 created new opportunities to support HIV treatment education, health literacy, and patient wellness.

- The ACA provided incentives for states to expand eligibility for Medicaid, which already provides health coverage for half of all HIV-positive people in regular care (more than 220,000 HIV-positive people).
- Federal agencies have also resourced several funding mechanisms and incentives to healthcare providers to better prevent and manage chronic health issues, including through patient-centered medical homes, expanded behavioral health services, co-located health services, community health teams, community health workers, training programs for healthcare providers, and demonstration projects.
- The Affordable Care Act also provides funding for four types of consumer assistance: consumer assistance programs, navigators, in-person assistors, and certified application counselors. All of these are focused on expanding enrollment in health insurance plans.

- Consumer assistance programs and navigators as defined under the ACA are very different from some of the traditional ways many HIV providers have used navigators in the provision of HIV care and treatment.

- HIV providers must identify insurers offering plans on their state's ACA marketplace and negotiate to be included as Essential Community Providers in Qualified Health Plan provider networks.

- The Center for Consumer Information and Insurance Oversight (CCIIO) has a list that includes links to state agency websites. For Federal and partnership states, State departments of insurance may provide the best link to Qualified Health Plan issuers.

There is evidence that housing status is perhaps the most important factor in determining an HIV-positive person's access to health care, their health outcomes, and how long they will live.

Funding through the Ryan White Care Act

Presenter: Andrea Weddle, HIV Medicine Association

The Ryan White HIV/AIDS Program supported the development of a highly effective care model for people with HIV who are uninsured or under-insured. The retention in care and viral suppression rates for Ryan White clients – two key indicators for monitoring HIV care – are 76% and 70% respectively. The percentage of clients that are virally suppressed jumps to 75% for people who are retained in care.

Although 70% of Ryan White clients have some form of insurance coverage, most public and private insurance fails to adequately support the comprehensive care required for effective management of a chronic condition, such as HIV infection. The more than \$2 billion currently

appropriated to the Ryan White Program annually remains a critical investment to ensure access to care and treatment for many people living with HIV.

Currently fewer than 15% of people living with HIV in care at Ryan White-funded programs have private health insurance; 32% have Medicaid coverage and 14% Medicare. HIV clinics rely on Ryan White funding to provide the comprehensive care that most people with HIV require to successfully live with and manage the disease. Ryan White funding can represent a majority of a clinic's revenue even when a majority of the clinic population has some form of insurance coverage. As an example, 71% of patients at a Ryan White-funded in the Mid-West have some form of insurance coverage, but Ryan White funding represents 64% of the program's revenue. Without the funding, clinics based at an academic health center would not be able to maintain the level of care and treatment that many of its patients need.

With the implementation of the Affordable Care Act (ACA) and the continuation of the Ryan White program, we have an historic opportunity to dramatically improve access to health care and health care outcomes for people with HIV.

While the ACA will provide access to health care coverage that will support basic medical care, the Ryan White HIV/AIDS Program will be needed to cover the range of health and social services not covered by the ACA's "Essential Health Benefits" or by Medicaid or Medicare. These services may include critical core medical services, such as home health, medical nutrition therapy, medical case management, HIV treatment adherence support, medical case management, nutritional support, and oral healthcare as well as other services that have proven so important to keeping people with HIV in care, such as case management, psychosocial support and medical transportation. In addition, while premium and subsidy support will be available to lower income individuals, cost sharing will be a barrier for some people with HIV given the number of services and prescription drugs that people with HIV need to stay healthy. Ryan White assistance

will be needed to help pay premiums and cost sharing to avoid disruptions in care. Looking ahead, the Ryan White HIV/AIDS Program will remain essential in providing affordable care and supporting continuity of care for people living with HIV.

Funding through philanthropic foundations

Presenter: Sam Avrett, The Fremont Center

Compared to the nearly \$15 billion spent by the federal, state, and local governments on HIV, private philanthropic grant-making for HIV is relatively small, totaling approximately \$98 million. A total of 21 grant-makers invested more than \$1 million each for HIV programs in the U.S. in 2011.

Private funding has an important role, even in the context of larger government funding. Private foundations often fund what government will not fund, such as advocacy work. Foundations can support innovations in service delivery, which can then be adopted and brought to scale with government funding. Foundations also fund important policy work, and trainings, meetings, and organization core costs that are the basis for community organizing and advocacy.

With regard to HIV treatment education, health literacy, and wellness, philanthropic grant-makers should clarify and communicate:

- How they interact with grantees to better understand their needs and priorities;
- How changes in the field (in science, organizations, and government funding) are changing their HIV funding priorities and approaches;
- How they define success and measures of success in their grants; and
- How they reinforce grantees' capacity, such as through large unrestricted grants renewed over multiple years.

Community HIV treatment service providers and advocates also need to improve the ways they communicate with grant-makers. From the perspective of grant-makers, there is a need for applicants to write better proposals that describe their programs more accurately and in ways that are compelling to the funder. Many requests and proposals are not relevant to the funder's stated priorities and many are clearly copied from government funding applications. Proposals should be grounded in specific aims and objectives, evidence about actual or potential impact, and examples of new leadership, advocacy, and program or policy improvements. Another important consideration is how to mobilize new funders, beyond the existing pool of committed HIV funders, to increase the number of large grant-makers dedicated to HIV.

Discussion

During the final part of the meeting, participants engaged in two rounds of structured small-group discussions about key issues and potential actions. Each group discussion was followed by a report-back and plenary discussion. In the first round, participants were asked to talk about the role of HIV treatment literacy and health literacy within the context of either community mobilization or service delivery, and then identify challenges and approaches to improving HIV treatment literacy and health literacy within those contexts. In the second round of small groups, participants were asked to identify specific actions that might be taken by working groups as follow-up to the meeting, using four themes of content, social determinants, policy, and leadership.

Community mobilization

Participants agreed on a broad definition of HIV treatment literacy in relation to community mobilization that includes: HIV treatment education, skills, and empowerment, communicating with others through social networks and coalitions, and participation in health advocacy. HIV treatment

education, health literacy, and wellness would necessarily include different strategies for different people, and serve as a basis of community mobilization. For some, HIV treatment literacy is about self-care. For others, it is about having an impact on the health of others, on health policies and programs, or on the course of the HIV epidemic. HIV treatment literacy has multiple intended goals including health and wellness, viral suppression, and access to quality healthcare and other support services. Participants said that the framing and tone of HIV treatment messages are crucial.

“We need to define the target groups for HIV treatment literacy and HIV-related health literacy, and for each target group identify and document materials that reinforce positive concepts and images for HIV treatment and viral suppression. Don't make people feel ashamed. For example, communications about black gay men and HIV have too often reinforced stigma and have set people up for failure. We need to avoid doing this.”

“We need an HIV treatment message that states that our lives matter. Some people living with HIV have resilience, but others have internalized a message that they deserve to fail. We have to start with a goal of empowering people.”

“What are the messages that will get people's attention? How about the fact that successful HIV treatment keeps you healthy and prevents transmission? ‘Treatment can take the threat of HIV out of your life.’ Is this a motivation to talk about HIV, get tested and get healthcare? It's worth exploring.”

Effective HIV treatment education requires tailoring the messages, the messengers, and the communication methods to each target audience. For example, HIV treatment, health, and wellness can be promoted through civil rights and social justice movements, through African-American and LGBT rights organizations, or through other coalitions and networks such as churches or media celebrities. People talked about social marketing strategies,

media campaigns, use of social media, webinars, trainings, and printed materials.

“We have to think about how to work with the NAACP, the faith communities, and others to get the message out.”

“We should look at different strategies and opportunities that are not just within our HIV experience. For example, the recent political mobilization that got people to the polls. In economically poor communities in Alabama, Mississippi, and rural Georgia and North Carolina, people got the message. It was a success not only in getting people to vote but getting communities working for change. How can we tap into that? How do we make public health political?”

“Social media also has a lot of potential. In hepatitis C, there’s at least one network that’s been effective in using social media to help people understand the disease, share treatment information, and get people into care. We need to use and expand this kind of work.”

“Look at ways that people already learn about HIV treatments and other medicines and drugs. There’s a capacity in the community where men gets lots of information about partying that includes PrEP. In Florida, there’s apparently a party pack with meth, Truvada, and Viagra, called MTV. Someone made that available! There obviously are some networks that exist that have ability to transfer information. We have to tap into that with another level of conversation. Networks exist, and we need to learn how to use them.”

Social determinants play a crucial role in people’s ability to understand, access, and stay in HIV treatment and care. These include issues such as community-level literacy, poverty, mental health, substance use, violence, and incarceration. Social perceptions and beliefs, including the expectation of discrimination or poor service within healthcare settings, also affect expectations about what healthcare can and should deliver. These issues were

not seen as a barrier to HIV treatment mobilization but as part of the reasons for the work.

“The civil rights movement proceeded in the context of huge poverty and other barriers. The HIV movement has shown we can be successful against enormous odds. We can move ahead with HIV treatment mobilization as a part of tackling these larger social determinants and in spite of them. Start from a unifying message, such as ‘you have a right to health, and anything that impedes your health can be overcome.’”

Participants noted that during the 1980’s and 1990’s, HIV service organizations and HIV treatment activists pioneered many core concepts in chronic disease self-management approaches by teaching people how to identify and treat opportunistic infections, demand and access quality healthcare, make informed HIV treatment decisions, and improve treatment adherence. But during the past decade, there’s been important expansion of patient self-management programs for other chronic diseases like asthma, diabetes and hypertension, and these have generated useful models, effectiveness data, and training programs. As with the HIV models of self-management, these patient self-management programs generally include trainings and peer-led support groups that help people to understand how to manage their lives in the face of chronic illness, set goals, and develop skills in making health decisions and negotiating health services. Participants felt that more should be done to communicate these models from other disease areas to HIV service providers and people living with HIV in order to update HIV self-management approaches and advocate for funding to get these programs expanded for people living with HIV.

“In healthcare policy debates, we hear a lot about costs of health care but we should hear more about empowering people to have better health. The models exist for people with chronic conditions to self-manage. We could do a lot more to get health service providers and communities mobilized around supporting people to manage their health,

know the standards of care they deserve, and know how to advocate to get the best care.”

New mobilization for HIV treatment education, health literacy, and wellness will require widespread and increased community demand as well as the leadership and infrastructure to create and support that demand. The need is particularly acute in resource-poor communities, among African-Americans, and among men.

“We need to examine how we are transferring information and strategies from resource-rich cities to new leaders in smaller and less-resourced communities. It’s critical to support leaders in disenfranchised communities where there isn’t a large public health system or a strong set of HIV service providers.”

“Across the country, the HIV epidemic is black. Therefore how do we create a movement and empowerment around HIV treatment education, health literacy, and wellness in a black context? We have to think about the various platforms for leadership, communication, and dissemination of health messages among black people. The U.S. HIV epidemic is also predominantly among men. How do we organize men around their health?”

Health and social services

Participants determined that health literacy is a foundation for all health services. Everyone in HIV-related health services – including social service providers and patients – needs to be literate about HIV treatment and wellness. All health programs serving HIV-positive people should provide accurate HIV treatment information along with counseling and support for patients in their understanding and self-management of HIV treatment decisions. Competency requirements should be defined for health professionals, and quality standards should be defined for HIV treatment information and counseling.

Several examples were provided detailing how healthcare providers may have different expectations about the quality and goals of their services depending on where they practice. Other participants described how HIV-positive people from differing communities may have very different expectations about healthcare, which in turn impact how they access, negotiate, and advocate for that care.

“Service providers have to understand and accommodate what’s going on in people’s lives and improve what people expect. There’s interesting work already underway. For example, the University of Miami has a survey form for patient to document what’s going on in their life that day, which gives the provider useful background information. AID Atlanta has enrolled hundreds of people in an “Elite Society of the Undetectables” to reinforce people’s pride in being virally suppressed, reinforced by special events and other group activities. These things get at the reasons why people do or don’t stay in care. How do we collect and share these kinds of examples?”

Methods to build HIV treatment literacy and an HIV-related wellness perspective among health and social service providers were discussed by participants. Methods included working with professional associations to ensure integration of these topics into professional training curricula, continuing education and recertification requirements, and thematic education programs (such as trainings by and for LGBT clinicians or black clinicians).



HIV service providers are so overwhelmed that it is difficult to step back and think strategically. It is challenging for programs to remain current with updated information or revamped approaches. People do not often think across professions or

beyond their particular area of service. This lack of coordination and/or communication between providers and patients can undermine effectiveness. Other barriers, including geographical location, limited use of technology, lack of information-sharing, poor technology in health record management, and use of old systems that hinder more efficient care delivery and undermine patient support.

HIV service organizations therefore need the time and space to take a hard look at some of the big changes that are needed in the field. A big question is how to manage HIV as a chronic condition instead of as an incident infection or a fatal disease. Many HIV organizations were organized as sick care and need to be rethought to provide wellness care.

- If the goal is wellness and patient self-management, health organizations might need a different or smaller combination of professional and peer providers, and different incentives to reward patient retention and patient satisfaction.
- For the new landscape of HIV treatment and wellness, organizations might need to re-think the types of trainings, conferences, and other mechanisms by which they share experience and practices.
- For patient-centered outcomes, health and social service providers need to improve partnerships and collaborations and need to forge new ways to share surveillance data and certain privacy-protected patient data to help people link to services, stay in care, and help all providers do a better job.

“In Georgia, we are improving in terms of coordinated HIV programming across institutions. Recently the Georgia health department has looked at ways that all hospitals can share basic patient information to identify who has fallen out of care and link them back into care. Legislation is now being advanced to allow providers to share information. Where else are there policy efforts like this, what are

the best approaches to address privacy concerns, and what are our collective recommendations?”

“There are great local models in Louisiana, New York, and elsewhere that show how to share health information across institutions to ensure that people with HIV link to treatment and care and get follow-up support. We should communicate about these models and push for these at a national level. Let’s work together to make this happen.”

Another major issue is the shift of HIV-related funding streams because of healthcare reform, as well as federal and state funding constraints. HIV care may increasingly be subsumed within general health care delivery and dedicated HIV centers may be phased out. But, these dedicated HIV programs have an important accumulation of program capacity, expertise, and experience in working with people living with HIV. Broader sets of health and social service providers do not yet have this HIV expertise and have not yet adopted best practices pioneered by HIV-dedicated providers. As HIV is integrated into primary care, it is important not to lose that expertise and experience created over the past 30 years.

For example, even though national guidelines recommend that routine HIV testing be offered to all sexually active individuals between the ages of 13 and 64, most Federally Qualified Health Centers (FQHCs) have not yet adopted this practice. As another example, more than 20 years of the Ryan White CARE Act and other dedicated HIV funding have helped HIV service providers to build integrated service models that include medical care, mental health and substance use services, sexual health education, benefits case management, nutrition support, employment support, and supportive housing. The new healthcare landscape prioritizes comprehensive patient-centered services through mechanisms such as medical homes, but funding streams may be shifting in a way that defunds experienced HIV service providers and funds other providers that do not have the program

components, experience, or capacity to meet the needs of people living with HIV.

Participants felt that there is a risk that some dedicated HIV programs will close down because organization leaders are not ready to adapt to changing funding environments, a reluctance to change programs, and because of barriers in getting organizations to be able to work together. Expanded HIV treatment education, health literacy, and wellness therefore needs to be presented in the context of organizations' needs to ensure that their programs are fundable and funded.

"There's substantial work underway, and plenty of opportunity, to help health departments, health care providers, and community-based organizations to identify people who either have never been linked to HIV care or who have fallen out of care and bring these individuals into successful treatment, care, and support. For example, last November, Project Inform organized a think-tank at which public health officials and community advocates made recommendations on these issues. More can be done in this area."

Recommended Actions

Content

- Produce an issue paper that defines HIV treatment literacy and HIV-related health literacy, and communicates the definitions, concepts, and goals to all relevant stakeholders. Through websites, meeting presentations, and printed materials, communicate:
 - Goals for HIV-positive people, including health and wellness, viral suppression, and access to quality healthcare and other support services.
 - Examples of programs targeting key populations that have reinforced positive (rather than shaming) concepts of HIV treatment and viral suppression.

- Evidence about cost-effective models for HIV service providers to provide HIV treatment information, education, and counseling to patients and support patients in their understanding and self-management of HIV treatment decisions.
- Standards for health professionals, including competencies, service quality standards, and successes in achieving retention in care and intended clinical outcomes.
- Work with coalitions engaged in HIV awareness, such as African-American and LGBT rights organizations and churches and other faith-based networks, to ensure that they include accurate information about HIV treatment in their social marketing strategies, media campaigns, use of social media, webinars, trainings, and printed materials.
- Develop a patient-centered health literacy website for health care providers, health departments, and people living with HIV/AIDS, structuring the website with tabs and tools related to HIV treatment education, health literacy, and wellness. The University of North Carolina and Boston University have useful models. This website can be a way to define core competencies, offer online and human resource training, and establish a means of certification so that community organizations can expand their programs for health literacy.
- Consider partnerships or a working group with other community organizations and training networks, for example Project Inform or the AETCs, to cooperate in developing content and disseminating and delivering information and training in a way that is aligned and coordinated.
- Look for upcoming events, such as the US Conference on AIDS (USCA), at which to share information.

Social Determinants

- Produce a short review of the social determinants affecting HIV-related health literacy. The recent 2013 Institute of Medicine report “U.S. Health in International Perspective: Shorter Lives, Poorer Health”, which included a broad examination of social determinants of health outcomes, provides a useful model for this work.
- Work with a broad range of coalitions to:
 - Document and highlight HIV-positive people’s knowledge and expectations about HIV treatment and healthcare.
 - Showcase innovative practices that document and improve community-level HIV treatment literacy and expectations.

Policy

- Develop a policy paper on health literacy and wellness, looking beyond HIV to include other chronic conditions, reviewing best-practice models, core competencies, and effectiveness data, and reviewing how these are addressed in the National HIV/AIDS Strategy and healthcare reform.
- Work with HRSA, the CDC, SAMHSA, and the NIH to identify and advocate for new funding and training opportunities for community-based HIV service providers to reorganize and develop programs focused on wellness, health literacy, and people’s empowerment and self-management for long-term HIV treatment.

Leadership

- Support new leadership among HIV-positive people to communicate about the importance of HIV treatment education, health literacy, and wellness.

- Focus new leadership development in communities of color, particularly people working in resource-poor communities and those who are available to contribute time and leadership on these issues.
- Convene emerging and established leadership in an HIV-positive caucus to develop a consensus statement on the need for and opportunities of HIV treatment, health literacy, and wellness, aiming to rebrand and embody HIV treatment using a wellness perspective.
- Spotlight those leaders on a website, showing people from all walks of life talking about living with HIV, what health literacy means to them, and how they interact with healthcare providers and their own health maintenance.
- Engage those leaders as public speakers, advisors on content, advisors in identifying strong organizations and innovative practices in their communities, and as allies in mobilizing communities of color on HIV treatment education, health literacy, and wellness.
- Work with the leaders at HIV service delivery programs to support advocacy to ensure that program capacity and expertise are not lost as health care delivery mechanisms are restructured. Work with service providers to help programs navigate funding stream changes if and as the “HIV silo” is dismantled. Best practices and experience should be documented and shared, in order to support maintenance of funding streams to sustain effective HIV-related health programs.
- Work with Federal government agencies, industry foundations, and private funders to design and implement new funding for HIV treatment education, health literacy, and wellness.

Conclusion and Next Steps

The National HIV Treatment Education, Health Literacy and Wellness Think Tank yielded important information on how best to move forward given the different opportunities and challenges of HIV treatment in the 21st century. An outcome of the Think Tank was the important need to divide the information discussed into four working groups: content, policy, HIV leadership and social determinants of health.

The working groups will provide critical input towards developing an “HIV Health Literacy and Wellness Blueprint”. The Blueprint will include evidence-based HIV treatment education program guidelines to ensure that people living with HIV/AIDS can make an informed decision to start treatment, access quality healthcare and adhere to their medications.

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Meeting Participants

1. Alex Garner, National Minority AIDS Council/ NMAC
2. Andrea Weddle, HIV Medicine Association/ HIVMA
3. Ann Prochilo, Prochilo Health
4. Bill Farrand, Test Positively Aware Network/ TPAN
5. Carlos Maldonado, Latino Commission On AIDS/ LACOA
6. Carole Treston, Association of Nurses in AIDS Care/ ANAC
7. Christine Nollen, Center for Comprehensive Care. St. Luke's-Roosevelt Hospital Center
8. Christopher Cannon, National Alliance of States and Territorial AIDS Directors/ NASTAD
9. Cornelius Baker, fhi360
10. Daniel Montoya, National Minority AIDS Council/ NMAC
11. Danielle Houston, Center for AIDS
12. David Barr, The Fremont Center
13. David Evans, Project Inform
14. Dazon Dixon Diallo, Sister Love
15. Deirdre Grant, AVAC: Global Advocacy for HIV Prevention
16. EMD Serono, Inc.
17. Glen Pietrandoni, Walgreens Pharmacy
18. Harold Phillips, Health Resources & Services Administration/ HRSA
19. Joan Holloway, International Association of Providers of AIDS Care/ IAPAC
20. Jose Zuniga, International Association of Providers for AIDS Care/ IAPAC
21. Joseph Elias, National Minority AIDS Council/ NMAC
22. Julia Hidalgo, George Washington University
23. Kali Lindsey, National Minority AIDS Council/ NMAC
24. Kate Geortzen, The Foundation for AIDS Research/ AmfAR
25. Kim Johnson, National Minority AIDS Council/ NMAC
26. Kyle Murphy, National Minority AIDS Council/ NMAC
27. Leisha-Mckinley Beach, Black AIDS Institute
28. Mark Snyder, Gilead
29. Marsha Martin, Urban Coalition for HIV/AIDS Prevention Services/ UCHAPS
30. Matt Sharp, AIDS Treatment Action Coalition/ ATAC
31. Moises Agosto-Rosario, National Minority AIDS Council/ NMAC
32. Monica Sweeney, New York City Department of Health
33. Nancy Mahon, MAC AIDS Fund
34. Nawreen H. Khan, George Washington University
35. Paul Kawata / NMAC
36. Paulette Heath, Janssen
37. Rhondette Jones, Center for Disease Control /CDC
38. Rob Newells, NMAC's TEAM Navigator
39. Ronald Johnson, AIDS United
40. Sam Avrett, The Fremont Center
41. Sapna Mysoor, MPH, API Wellness Center
42. Scott Campbell, Elton John Foundation
43. Tim Horn, Treatment Action Group/TAG
44. Tom Leano, Merck
45. Venton Jones, National Black Gay Men's Advocacy Coalition/ NBGMAC

Meeting Agenda

Facilitators: David Barr and Moisés Agosto

Day One

8:00 – 9:00 Registration & Continental Breakfast

9:00 – 9:30 Welcome, introductions and think tank expected outcomes.

Explanation of meeting structure and working groups.

Paul Kawata & Moises Agosto

9:30 – 10:00 Opening Speaker:

- The Role of Treatment Education and Patient Navigation in Meeting NHAS Goals - Daniel Montoya, NMAC

10:00 – 10:30 Discussion

10:30 – 11:00 The landscape. HIV Treatment Literacy: The Past and Future

- o Treatment education community history - Matt Sharp, AIDS Treatment Action Coalition
- o Current needs and opportunities - Sam Avrett, The Fremont Center
- o What do people need to know about HIV treatment and prevention in 2013 and beyond? How has the treatment literacy curriculum changed? - David Evans, Project Inform

11:00-11:15 Break

11:15 – 12:30 Group Discussion: Defining Treatment/Health Literacy Needs throughout the Treatment/Prevention Cascade

- o How can we expand the understanding of treatment education so that it includes the most current information, such as, the continuum of care, health literacy, and biomedical interventions?
- o What are the motivating messages/questions that will engage individuals and communities in seeking out treatment and prevention?
- o What is the role of people living with HIV in service delivery and education?
- o How we can utilize new technologies and social media to create better education materials and improve health literacy.

12:30 – 1:30 Lunch

1:30 – 2:45 Current approaches to treatment literacy and patient navigation:

- o The Bronx Knows - Monica Sweeney, NYC DOH
- o Peer education and Patient Navigation in HIV - Christine Nollen. St. Luke's-Roosevelt Hospital Center
- o New Technologies to Support Patient Navigators in HIV Prevention, Treatment Adherence and Connection to Care. – Nawreen Khan, George Washington University

2:45 – 3:00 Break

3:00 – 3:15 What do we need to know? An Implementation Science and Program Evaluation Agenda for Treatment Literacy and Patient Navigation - Tim Horn, TAG

3:15 – 4:30 Group Discussion

- o How do we identify effective approaches to treatment/prevention/health literacy?
- o What works where and for whom?
- o What kind of tools for treatment education programing and evaluation could be developed for community base driven interventions
- o Are peer-based models still an important component of service delivery? If so, how can these be supported?

4:30 – 5:00 Cultural and social determinants and health disparities: Meeting the challenge of social determinants during implementation - Alex Garner, NMAC

Day Two

9:00 – 9:15 Recap from Day One and Agenda Review

9:15 – 9:45 The Roadmap: Providing health education and patient navigation in the age of ACA.

- o Opportunities to resource treatment education and patient navigation services through the ACA and Medicaid expansion - Harold Phillips, HRSA
- o The Continued Role of Ryan White funding to support critical enabling services. Example of the impact of expanded health coverage - Andrea Weddle, HIVMA
- o The role of private sector funding – Sam Avrett, The Fremont Center

10:00 – 10:15 Break

10:15 – 11:15 Breakout Groups:

- Policy development: What is needed to expand treatment literacy and critical enabling services?
 - ☐ How can CBOs be reimaged to meet treatment needs after implementation of ACA?
 - ☐ What advocacy is needed at federal, state and local levels to ensure funding and infrastructure for patient navigation, treatment literacy and support services?
 - ☐ How can the private sector create opportunities to expand treatment education?
 - ☐ What kind of advocacy and policy is needed to get funds and reimbursement for treatment education and navigation?
- Social Determinants: What role does each part of the community play?
 - ☐ How can HIV service providers and advocates be structured to better address the environment in which services are offered?
 - ☐ How can community mobilizations be used to expand the reach and maximize the success of treatment education?

- ☐ How can the PLWH community lead on the issue of treatment education?
- ☐ How can the concept of treatment be redefined in the context of social determinants?

11:15 – 12:15 Report Back and Discussion

12:15 – 1:15 Lunch

1:15 – 2:15 The Framework: Developing Working Groups

- Content and curriculum
- Policy
- Social determinants
- HIV+ leadership

2:15 – 3:00 Report Backs and Discussion

3:00 – 3:30 Establishing a blueprint for treatment education. (Group Discussion)

- Re-cap of priorities from discussion
- Next steps to create action plans

CLOSE



A report by the National Minority AIDS Council.