

A close-up photograph of several roses. The petals are primarily a vibrant yellow, with some showing a delicate red or pinkish edge. The roses are in various stages of bloom, with some petals tightly curled and others more spread out. The background is dark, making the bright colors of the flowers stand out. The entire image is framed by a thin red border.

The United States Implementation of the People Living with HIV Stigma Index: Report from the First Meeting of the National Steering Committee

Washington, D.C., September 26-27, 2013

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“What we have with the People Living with HIV Stigma Index is the opportunity to change the stigma and discrimination that create so much harm for people living with HIV and our families in the United States. Working across all our diverse communities – together with supportive community organizations, researchers, and healthcare workers – we will learn about each other's experiences, gather an evidence base of the extent, forms, and effects of HIV stigma for different communities, and engage in interventions and advocacy on our own behalf.

The result? People living with HIV joined together in mutual action to address the ignorance, bias, and mistreatment we face, pressing for needed public and health policies and reforms, and strengthening our ability to live lives of health and dignity.”

— Laurel Sprague

Global Network of People Living with HIV, North America, Regional Coordinator

“As someone involved with the HIV response for over 30 years, I have witnessed terrific progress in the areas of HIV education, prevention, treatment, and social protections; however, stigma and discrimination against People Living With HIV (PLHIV) remains the single largest component of the HIV response where we continuously fail to reach real significant progress. UNAIDS considers stigma to be such a driving force behind the epidemic, and such a barrier to HIV testing and treatment, that we have made achieving “Zero HIV related Stigma and Discrimination” one of UNAIDS’ topmost priorities.

The Global Stigma Index Project is a country-specific research program to empower People Living with HIV to lead an effort to research how they experience stigma and discrimination in their own countries and communities, and then develop interventions and strategies to mitigate stigma where it exists. UNAIDS is pleased to join our efforts to combat stigma and discrimination here in the United States.”

— Eric Sawyer

UNAIDS, Civil Society Partnership Advisor



**THE U.S.
PEOPLE LIVING
WITH HIV
STIGMA INDEX**



**THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX**

In Recognition of All Those Affected by Health Disparities Resulting from Stigma

Stigma and broader social inequalities exact a tremendous toll on the lives of so many people within the U.S. Even during the short two-day period over which the National Steering Committee first met, one of our members was unable to attend due to health complications, while another suffered a terrible loss.

This report and the work completed by the Steering Committee are dedicated to the recent hardships experienced by our members. May our ongoing work combat the national injustices that continue to drive health disparities for people living with HIV and other marginalized populations.

Cover photo:

Marcelo Maia of Marcelo Maia Photography, New York City

Additional note:

This report, documenting the proceedings from the first National Steering Committee meeting, is demonstrative of the diligent effort put forth by our meeting rapporteurs, Reed Vreeland (GNP+ North America Young Leaders Caucus) and Jeremiah Johnson (Treatment Action Group).

Background on the United States Implementation

In September 2013, a National Steering Committee of grassroots advocates and researchers in the HIV field convened to make key decisions for the implementation of a United States People Living with HIV (PLHIV) Stigma Index, a project designed by and for people living with HIV to document and quantify discrimination and stigmatization across the nation. At this meeting, they were supported by members of a Technical Advisory Council comprised of researchers, government officials, and members of local communities with experience in HIV stigma reduction, community research, and self-empowerment programs.

Composed of people with research, policy, and grassroots organizing experience, the twenty-seven members of the Steering Committee come from communities of people living with HIV, including sex workers, people who use drugs, women, young people, prisoners, people from the rural and southern United States, gay men and other men who have sex with men (MSM), transgender people, African Americans, Latino/as, and people of Asian and Pacific Island descent and Native American nations. More than 80 percent of the members of the Steering Committee are people living with HIV. All are people who have been personally affected by the epidemic. (For a full list of members, please see Appendix A.)

During the meeting, the International Coordinator of the Global PLHIV Stigma Index educated participants about the guidelines that have been followed in 50 other countries. The committee then created a framework for a project rollout that encompasses the demographic and geographical complexities of the HIV epidemic in the United States.

The goals of the U.S. PLHIV Stigma Index are to:

- Document experiences of stigma and discrimination;
- Mobilize and provide support to networks of key populations and people living with HIV, helping them to work together to improve the well-being of the most marginalized affected groups;
- Reduce internalized stigma and build resilience and the capacity to bring change;
- Develop the research literacy of people living with HIV and key populations, helping them to understand, manage, and use data on the social aspects of HIV stigma and discrimination;
- Provide an evidence base to inform interventions focused on community identified needs; and
- Build a shared advocacy agenda across people living with HIV and key populations, designed for impact in addressing the barriers to well-being created by HIV-related stigma and discrimination.

In addition, Steering Committee members committed themselves to ensuring that the U.S. PLHIV Stigma Index implementation follows the global standard of meaningful inclusion of people living with HIV and key populations in all levels of planning and execution. Committee members voted on U.S. specific questions to add to the existing global questionnaire. The project, with these new questions, will be piloted in Detroit, Michigan. Funds have been raised for the Detroit pilot project to validate the existing survey instrument, as well as the research and advocacy processes for the United States. Eight additional implementation sites were selected by the Steering Committee to represent a broad range of U.S. regions and key populations, dependent on funding. (For more information on site selection, see page 7.)

“Stigma and discrimination are nothing new to transgender women. We have multiple barriers in employment, housing, health care, and schools. Hence, stigmas of HIV often add even more complexity to transgender women who are most impacted by it.”

**—Cecilia Chung
San Francisco, CA**

The campaign for a U.S. PLHIV Stigma Index began in 2011, organized by the North American affiliate of the Global Network of People Living with HIV/AIDS (GNP+NA), under the leadership of Laurel Sprague, the organization's Regional Coordinator. Initial funding is provided by the Ittleson Foundation, with support by the Joint United Nations Programme on HIV/AIDS (UNAIDS), the International Center for Research on Women (ICRW), the Stigma Action Network (SAN), Housing Works, AIDS Partnership Michigan, the Center for Sexuality and Health Disparities at the University of Michigan School of Public Health, and the Global Network of People Living with HIV/AIDS (GNP+).

Meeting Summary

Day I — Introduction to the Stigma Index: Drawing the Context

The Overwhelming Need for a United States PLHIV Stigma Index

On the first day of the meeting, members of the National Steering Committee offered testimonies and presentations about how discrimination and stigmatization affects different key groups living with and affected by HIV, including women, transgender people, young people, gay men and other MSM, sex workers, people who use drugs, prisoners and people who have been incarcerated, people in rural areas or low-prevalence states, people who live in the southern United States, African Americans, Latino/as and people of Asian and Pacific Island descent, and people of Native American nations.

Across different key populations, many of the negative consequences of stigma and discrimination remained the same: barriers to healthcare, HIV testing and treatment, social isolation, employment discrimination, depression and other mental health issues, increased legal vulnerability or inappropriate prosecutions, and partner violence. The presentations on day one of the National Steering Committee meeting established a clear need for a project to assess stigma and discrimination across many different highly affected communities in the United States.

The Development of the Stigma Index: A discussion with Liz Tremlett, International Coordinator for the People Living with HIV Stigma Index

Liz Tremlett, International Coordinator for the Stigma Index, contextualized the U.S. Stigma Index implementation within the larger global project. She discussed the history and development of the index and outlined the key international accomplishments to date.

The concept of the People Living with HIV Stigma Index* was first proposed in 2005 as a way to translate anecdotal evidence of stigma into something more useful for policy makers. Through the combined efforts of GNP+, the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF), and UNAIDS, the Stigma Index was developed and first implemented in 2008.

"HIV stigma oftentimes legitimizes intimate partner violence and/or shames the woman into isolation, where she neglects her healthcare, is deprived of her reproductive rights, is more likely to lose child custody battles, and faces tougher criminal sentencing if she is found to be pregnant while HIV positive."

—Waheedah Shabazz-El Philadelphia, PA

* <http://www.stigmaindex.org>

From the inception of the Stigma Index, the meaningful involvement of people living with HIV/AIDS has been considered essential. As such, the process is as important as the results. A key part of the methodology is to have people living with HIV/AIDS involved in all levels of implementation. Individuals living with HIV/AIDS should lead the project, be involved in all decision making, and have budgetary control. Interviewers should also be HIV-positive. This process builds trust, with a sense of joint action, and strengthens the research capacity of community members.

Since its development, the Stigma Index's participants have interviewed more than 40,000 persons living with HIV/AIDS across fifty countries. Notably, the participants have come from diverse backgrounds, with many representing populations that previously had not been adequately studied. More than 1,100 HIV-positive interviewers have been trained globally, and the questionnaire has been translated into more than fifty languages. At present, GNP+ is gathering all of the data into one comprehensive database so that the information can be better utilized and compared across different implementations. In the upcoming year or two, more thorough analyses of how stigma manifests across different groups and national boundaries are planned.

"I believe that stigma on my reservation only adds to the spread of HIV and increases the chances of AIDS-related deaths. We cannot let fear and ignorance continue — my Apache ancestors were warriors and we must continue to fight this [virus] with everything we have."

**—Isadore Boni
Phoenix, AZ**

The PLHIV Stigma Index in Other Countries: Germany

The PLHIV Stigma Index has led to profound, powerful results for HIV-positive people in the countries where it has been implemented. It has increased solidarity and support, strengthened capacity to jointly address community problems, and fostered greater self-efficacy resulting from successful community action for positive change.

PLHIV Stigma Index in Germany

Carolin Vierneisel, of Deutsche AIDS-Hilfe, presented on the 2012 implementation of the Stigma Index in Germany, a project supported and coordinated by the organization and primarily funded by the German government. The German implementation trained a total of 40 HIV-positive interviewers to conduct the survey. They were able to record 1,148 surveys from people living with HIV, a number representing more than 1.5% of the people living with HIV in Germany at the time. The interviewee sample was representative of the epidemiological profile in the country.

Some important findings from the German PLHIV Stigma Index:

- Nearly every fifth person (19%) was denied a health service in the last 12 months.
- 47% of the sexually active participants stated they had been sexually rejected because of their HIV status in the last 12 months.
- 31% said they had felt ashamed because of their HIV status in the last 12 months.
- In the last 12 months, 18 people in the sample had lost their jobs due to HIV-related discrimination—a rate of about 2 people per month.

Data from the German Stigma Index was used in 2012 as part of a World AIDS Day campaign on

reducing employment-related HIV stigma.

Governmental and Organizational Approaches to Combating Stigma

National Institute of Mental Health

Cynthia Grossman, program officer at the National Institute of Mental Health (NIMH) Division of AIDS Research, provided an overview of several NIMH-funded research projects on HIV stigma and discrimination. Grossman offered guidelines and considerations for researchers applying for funds, and explained that the Institute prioritizes projects that achieve a considerable public health impact and advance the science of, and knowledge base concerning, HIV stigma. Projects are also assessed based on strong, substantiated community involvement.

The Stigma Action Network

Anne Stangl, Secretariat Director of the Stigma Action Network (SAN), delivered a presentation to the National Steering Committee in order to share the work presently being done to address stigma and to foster collaboration between SAN and the Global PLHIV Stigma Index. SAN came into existence as the result of a 2008 meeting hosted by the MAC AIDS Fund and ICRW in which global stakeholders were asked about how to address stigma. Attendees recognized that several great efforts were being pursued around the world, but they lamented that the results weren't properly or easily shared with others. One of the main priorities listed at the meeting was the development of a network through which people working to combat stigma could communicate. SAN offers a number of free resources on its website, including an e-library and country-specific pages that greatly facilitate access to existing stigma research. As the U.S. PLHIV Stigma Index progresses, the hope is that the Steering Committee will utilize SAN as a primary channel for passing on information and publicity about various site-specific projects and funding initiatives.

“HIV stigmatization affects the young people I work with—it keeps them from engaging in services, getting tested, staying adherent, and feeling empowered and confident enough to live a healthy life.”

***—Johnny Guaylupo
New York, NY***

Presentation of NASTAD HIV Stigma Survey Results

Patrick Wilson, professor of Sociomedical Sciences at the Mailman School of Public Health at Columbia University, presented recent results of research on stigma and its consequences from the National Alliance of State and Territorial AIDS Directors (NASTAD) HIV Stigma Survey. The survey was designed to look at many kinds of stigma, including those related to HIV/AIDS, gender performance/femininity among men who have sex with men, homophobia, and racism. By the end of recruitment, researchers had 1,314 respondents from 54 different states or territories. Participants were asked to electronically complete a survey ranking their experiences with the various forms of stigma.

While results varied considerably across locations, the survey shed light on the effects of living in more inclusive policy environments. Participants from states that have policies in place to protect the rights of people living with HIV/AIDS, LGBT individuals, and undocumented immigrants tended to report less experience with stigma. The survey also indicated that several key outcomes for HIV prevention and treatment were linked to perceived stigma. As such, investigators concluded that robust efforts are needed from health departments and public health practitioners in order to reduce stigma.

Day II — Into Action: How Will the Stigma Index Be Implemented?

The Detroit Pilot of the U.S. PLHIV Stigma Index

Wil Bowen, Community Mobilization Coordinator at AIDS Partnership Michigan, provided an overview of the Detroit pilot implementation of the U.S. PLHIV Stigma Index, which is receiving institutional and research support from the University of Michigan. Bowen discussed the principles of community-based research and the current planning process for the involvement of community members living with HIV in all aspects of the planning and implementation process. He highlighted the need to plan for the sustainability of advocacy work based on the research results after the research piece of the project is completed.

In order to build community research capacity, leadership, and trust, Bowen said that it is vital to make the data and survey results comprehensible when disseminating the information back into the communities that it came from.

“When done well, community-based participatory research enables members of communities to ask the questions, create the strategies, and address the issues they feel are most important. The research doesn’t have to be based in assumptions of needs, it can be based in the reality of needs,” Bowen said.

The Detroit pilot of the U.S. PLHIV Stigma Index will be conducted from the end of 2013 through 2014. Results of the pilot will be analyzed and the validated before the Stigma Index is rolled out to other funded sites across the nation.

The Responsibilities of the National Steering Committee

The remainder of the second day was dedicated to developing the guiding vision for the U.S. project, based on the experiences, wisdom, resilience, and hopes of people living with HIV in the United States.

Purpose and Focus for the Project

Following the global model, Laurel Sprague facilitated a discussion in order to establish what Steering Committee members envision as advocacy priorities and objectives for the U.S. PLHIV Stigma Index.

In working groups, members discussed three key points:

1. What are the key challenges that we want to overcome through the use of the U.S. PLHIV Stigma Index?
2. What hurtful or harmful things do we want to change?
3. What positive things do we want to support?

Within a larger group discussion, members then compiled a broad list of issues that they hope to address through advocacy resulting from the Stigma Index. Steering Committee members remarked on a broad range of challenges, ranging from the empowerment of

“In my community, among black men who have sex with men (MSM) living in Jackson, Mississippi, stigmatization can lead to lack of seeking healthcare or taking an HIV test—some young men have privacy concerns or are afraid of being rejected. Many families and churches do not embrace sons who are same-gender-loving individuals.”

**— Cedric Sturdevant
Jackson, MS**

“People living with HIV and AIDS behind the walls, and those formerly incarcerated, still have a voice. No one has the right to take it away from them.”

**— Tre Alexander
Philadelphia, PA**

people living with HIV on an individual level to addressing stigma at institutional, environmental, and organizational levels. A complete list of members' responses is included in Appendix B.

Establishing Questions on Knowledge of Rights within the U.S.

As part of the established methodology for the Stigma Index, the questionnaire is meant to remain largely unchanged across locations in order to maximize comparability of results. However, recognizing that not all HIV epidemics are the same, certain sections may be tailored to address the specific research needs of a particular country or region.

Within working groups, Steering Committee members carefully considered two specific sections of the questionnaire and made key decisions on how to best adapt the questionnaire for implementation in the United States.

To start, the Stigma Index seeks to measure participants' knowledge of protective or anti-discriminatory laws in their country. Steering Committee members were asked to choose a specific U.S. legal document to fill in the blank in the following question:

"Have you heard of the _____? If yes, have you ever read or discussed the content of the _____?"

The *Americans with Disabilities Act* as well as the *National HIV/AIDS Strategy* were provided as two potential options. As a group, the Steering Committee members decided to include the Americans with Disabilities Act in the implementation of the Stigma Index in the United States, since it is a recognizable piece of legislation that provides broad anti-discrimination provisions for people living with and/or suspected of having HIV.

Members were also asked to decide on the importance of four possible types of questions that could be included. Each category had been established based upon previous suggestions from Steering Committee and Technical Advisory Committee members.

1. Questions related to Treatment as Prevention.
2. Questions about the accessibility of basic prevention tools among people living with HIV (e.g., condoms, condom-compatible lubricants, risk reduction programs).
3. Questions about the Affordable Care Act.
4. A question on the effects of specific experiences with discrimination that could be included in one of two forms:
 - a. An open ended question: "How did the issue affect you in the short term and long term? (Include physical, mental, emotional, economic, or other effects.)"
 - b. A close-ended question: "Did you experience any of the following as a result of discrimination?"

Based on group discussions, members decided to include questions from categories 1, 3, and 4b. Categories 2 and 4a will not be included. For a complete copy of original question choices that were presented for the group, consult Appendix C.

"The consequences of stigmatization for people living with HIV in Colorado and other low-prevalence states can be seen in the isolation and loneliness that they may feel. Often they do not have access to a quality medical care provider who has other HIV-positive clients."

***—Barb Cardell
Boulder, CO***

Choosing the Implementation Sites

Eve Mokotoff, managing director of HIV Counts,* provided data tables to the steering committee to guide site selection (see Appendix D). Each table described people living with HIV in a low, medium, or high prevalence area. The number of HIV cases was broken down by race, sex, and risk factors for HIV infection. Moreover, the corresponding percentage of HIV infection was calculated for each of the numbers in these categories. The total number of people living with HIV was noted at the bottom of each table, as well as an idea of how many people comprise 3-4% of people living with HIV.

Site selection focused on ensuring that all communities of people living with HIV in the U.S. would be meaningfully included as participants in the research and action parts of the project. To ensure this inclusion, the sites noted in the table on page 8 were selected.

These sites each have specific priority communities as their foci; however, the broadest outreach possible to different communities will also take place in order to incorporate the widest possible diversity of experiences of people living with HIV into the research and the resulting advocacy.

The local work will be conducted under the guidance of local steering committees led by people living with HIV, including representatives from local community-based organizations, public health, academics, and government.

Funding the Index and Next Steps

The National Steering Committee will convene by conference call to discuss the next steps for funding the U.S. PLHIV Stigma Index, and members are looking to engage local funders and coordinate innovative community-based initiatives to raise funding and support for the project.

If you would like to learn more about the U.S. PLHIV Stigma Index, or would like to contribute organizational or funding support, please contact:

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“Stigma issues for Native Americans in general encompass lack of access to medical care, inadequate housing and culturally competent case management, ongoing discrimination in the workplace. Stigma surrounding HIV is huge in Native American communities, both on and off our reservations —and it is definitely worse on our reservations.”

***—Shana Cozad
Klowa Nation, OK***

* <http://www.hivcounts.org/>

Focus populations	Sites								
	Metro Detroit, MI (pilot)	NYC, Newark NJ, & Phila, PA)	D.C., Balt., MD	North Carolina	Florida	Puerto Rico	Deep South (AL, LA, MS)	U.S. West (CO, NM, AZ)	California Coast
Women	✓	✓	✓	✓	✓	✓	✓	✓	✓
Gay men and other MSM	✓	✓	✓	✓	✓	✓	✓	✓	✓
Heterosexual men	✓	✓	✓				✓		
Transgender people	✓	✓	✓			✓	✓		✓
Young people	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sex workers	✓	✓	✓			✓			✓
People who use or have used drugs	✓	✓	✓			✓	✓		✓
People who have been incarcerated	✓	✓	✓				✓	✓	
Immigrants		✓	✓		✓				✓
Native Americans	✓		✓	✓				✓	
Other racial minorities/ ethnicities	✓	✓	✓	✓	✓	✓	✓	✓	✓
Living in urban area	✓	✓	✓		✓				✓
Living in rural area				✓		✓	✓	✓	
Newly HIV diagnosed		✓		✓	✓				✓

Appendix A: National Steering Committee, United States

Name and location	Affiliation(s)
Tre Alexander, Pennsylvania	Prison Care Outreach, Institute for Community Justice, Philadelphia FIGHT
George Ayala, California	Global Forum on MSM and HIV
Isadore Boni, Arizona	San Carlos Apache Tribe; National Native American AIDS Prevention Center, Community Advisory Council Member
Todd Brennen, California	St. James Infirmary (medical and social services for female, transgendered, and male sex workers)
Korey Anthony Chisholm, New York	GNP+ Youth Programme Advisory Group
Martha Cameron, Washington D.C.	Institute for Public Health Innovation (focus on immigrants)
Barb Cardell, Colorado	Positive Women's Network – Colorado
Cecilia Chung, California	Asian & Pacific Islander Wellness Center; Transgender Law Center
Shana Cozad, Oklahoma	Kiowa Nation; National Native American AIDS Prevention Center (Consultant)
Deloris Dockrey, New Jersey	International Community of Women Living with HIV
Alex Garner, Washington D.C.	National Minority AIDS Council
Johnny Guaylupo, New York	Housing Works
Lee Hertel, Minneapolis	International Network of People who Use Drugs (INPUD)
Monica Johnson, Louisiana	HEROES (focus on southern and rural people living with HIV)
Naina Khanna, California	Positive Women's Network – USA
Loan Mai, New York	MD Land, International (focus on Asian Americans)
Renee McCoy, Washington	Metropolitan Community Churches, Global AIDS Programs; Lifelong AIDS Alliance (Seattle)
David Ernesto Munar, Illinois	AIDS Foundation of Chicago
Christopher Roebuck, California	University of California, Berkeley (focus on trans* people)
Jahlove Serrano, New York	AIDS Institute, Consumer Advisory Committee; GNP+NA Young Leaders Caucus
Waheedah Shabazz-El, Pennsylvania	HIV Prevention Justice Alliance (focus on women and prisoners)
Andrew Spieldenner, New York	US People Living with HIV/AIDS Caucus; Hofstra University
Sean Strub, Pennsylvania	The Sero Project
Cedric Sturdevant, Mississippi	My Brother's Keeper (focus on southern and rural gay men of color)
Miriam Vega, New York	Latino Commission on AIDS; Society for the Psychological Study of Social Issues, United Nations NGO representative
Reed Vreeland, New York	GNP+NA Young Leaders Caucus
Phill Wilson, California	The Black AIDS Institute

Convened by The Global Network of People Living with HIV, North America (GNP+NA), Laurel Sprague, Regional Coordinator.

Technical support from Eric Sawyer, UNAIDS; and from the International Partnership for the PLHIV Stigma Index: The Global Network of People Living with HIV (GNP+), The International Community of Women Living with HIV (ICW), and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Appendix B: Issues to address through advocacy resulting from the Stigma Index

- Increase funding for efforts to reduce HIV-related stigma as well as for HIV prevention, care, and treatment.
- Support the meaningful engagement of people living with HIV in all HIV/AIDS work.
 - Develop ways to measure meaningful inclusion of people living with HIV.
 - Build research skills and capacity for people living with HIV.
- Increase individuals' strength, resilience, and recourse to stigma.
- Build safer environments.
 - Encourage greater recruitment of peer navigators to bring people into care.
- Shape public HIV messaging in media, across communities, among researchers, within public health, and through social media.
 - Work to de-sensationalize HIV and those living with HIV.
- Undo all forms of criminalization that contribute to the HIV epidemic. Change discriminatory laws directed toward:
 - Undocumented immigrants;
 - People living with HIV;
 - Sex workers; and
 - Transgender people.
- Work to change hostile healthcare environments, including public health environments.
- Reduce community stigma, including:
 - Stigma within HIV positive communities.
 - Increasing the inclusion of heterosexual individuals in HIV/AIDS work.
- Develop interventions specifically for people living with HIV in order to promote their positive health, dignity, and HIV prevention goals.
- Increase awareness of stigma in the U.S.
- Support community based organizations in finding ways to increase the resilience of people living with HIV.
- Eliminate violence related to stigma.
- Reinvigorate activism to find a cure for HIV.
- Support the involvement of family members of people living with HIV in HIV/AIDS work, including partners and children.
- Decrease stigma at institutional, environmental, individual, and organizational levels.
 - Including religious, healthcare, and educational structures.
 - Decrease structures that create invisibility.
- Link stigma to HIV-related health outcomes.
 - Inform interventions for key populations.
 - Identify commonalities across populations.
 - Identify and address intersecting stigmas.
- Increase evidence of stigma-related harm to support our efforts to challenge stigma.
- Improve wellbeing through tools to change public attitudes and educate individuals who are HIV negative.
- Increase shared responsibility for sexual health.
- Increase sexual and reproductive health rights.
- Bridge the gaps between positive and negative communities.
- Eliminate discrepancies between different states.
- Protect peoples' personal life and privacy.

Appendix C: Original question choices presented to the National Steering Committee

- A) The Stigma Index seeks to measure participants' knowledge of protective or anti-discriminatory laws in their country. What legal document do we want to use for the U.S. for this question?

Options:

- 1) Have you heard of the Americans with Disabilities Act?

If yes, have you ever read or discussed the content of the Americans with Disabilities Act?

- 2) Have you heard of the National HIV/AIDS Strategy?

If yes, have you ever read or discussed the content of the National HIV/AIDS Strategy?

- 3) Other choices?

- B) We can add additional, country-specific, questions to the PLHIV Stigma Index survey. Which of the following, if any, do you think are the most important additions to the survey? Please rank them from most to least important as additions.

Options:

- 1) Questions related to Treatment as Prevention, for example:

- Have you ever felt coerced into taking medications?
- Have you ever felt coerced by a health provider to take medications to reduce your risk of transmitting HIV, even if you didn't feel you needed medications for your own health?
- Do you feel supported by your healthcare providers to make decisions for yourself about your health care?
- How satisfied are with your treatment regimen?
- How satisfied are you with the medical services you receive?
- How satisfied are you with the support services you receive?
- Others?

- 2) Questions about the accessibility of basic prevention tools among people living with HIV, e.g., condoms, condom-compatible lubricants, risk reduction programs.

- How accessible are male condoms if you want to use them? __ Easily accessible, __ Somewhat accessible, __ Not very accessible, __ Not accessible, __ I don't know, __ Not applicable
- How accessible are female condoms if you want to use them? __ Easily accessible, __ Somewhat accessible, __ Not very accessible, __ Not accessible, __ I don't know, __ Not applicable
- How accessible are condom-compatible lubricants if you want to use them? __ Easily accessible, __ Somewhat accessible, __ Not very accessible, __ Not accessible, __ I don't know, __ Not applicable

- Have you ever participated in a risk reduction program or harm reduction program for yourself? __Yes, __No, __Not sure
 - How accessible are risk reduction or harm reduction programs if you want to attend them? __Easily accessible, __Somewhat accessible, __Not very accessible, __Not accessible, __I don't know
 - Other questions?
- 3) Questions about the Affordable Care Act
- Have you heard of the Affordable Care Act? __Yes, __No, __Not sure
 - If yes: Given what you have heard about the Affordable Care Act, do you believe that it has led to better or worse care for you? [Pre-January: "Do you believe that it will lead to..."] __Much worse, __Somewhat worse, __About the same, __Somewhat better, __Much better, __Not sure.
 - Have you enrolled in a new healthcare program under the Affordable Care Act? [Pre-January: "Do you plan to enroll..."] __Yes, __No, __Not sure
 - Have your treatment options changed under the new law? [Pre-January: "Will your treatment options change?"] __Yes, __No, __Not sure
 - Has anyone advised you about your options for health care coverage under the Affordable Care Act? __Yes, __No, __Not sure
 - Other questions?
- 4) A lawyer working on HIV discrimination cases asked if we could include a question about the effects of discrimination, such as being denied care. She said this would be useful in court to show harm or damages, when, for example, someone has been denied dental care but ultimately finds another dentist.

For example, after the section on discrimination or on human rights violations we could ask an open-ended question:

- a. How did the issue affect you in the short-term and long-term? (Include physical, mental, emotional, economic, or other effects)

Alternatively, we could come up with a close-ended question:

- b. Did you experience any of the following as a result of the discrimination?
- Depression
 - Anxiety
 - Income loss
 - Withdrawing from family or friends
 - Avoiding health care
 - Avoiding social support
 - Missed days at work
 - Other response choices

Appendix D: Demographic and epidemiologic data for the 8 selected sites

Site 1: East Coast Urban Corridor

People Living with HIV (PLHIV), NYC¹ / Philadelphia² / Essex County³, NJ, 2011 or 2012

	Number NYC	Number Phila.	Number Essex Co.	Total no. Region	Percent
Race / Ethnicity					
Black	50,819	12,061	7,569	70,449	49%
White	23,518	3,713	680	27,911	20%
Hispanic	37,041	2,770	1,406	41,217	29%
Asian / Native Hawaiian / Pacific Islander	1,996	136	NA	2,132	1%
Am Indian / Alaska Native	255	NA	NA	255	0%
Multi / Other / Unk	464	477	92	1,033	1%
Sex					
Male	81,637	13,590	5,847	101,074	71%
Female	32,456	5,567	3,900	41,923	29%
Risk factor for HIV					
Male-Male Sex (MSM)	40,680	6,230	1,569	48,479	34%
Injection Drug Use (IDU)	19,813	4,995	2,155	26,963	19%
MSM / IDU	NA	582	192	774	1%
Blood Products / Other	31	19	NA	50	0%
Heterosexual Contact	22,274	6,637	4,286	33,197	23%
Perinatal	2,490	291	NA	2,781	2%
Undetermined	28,836	403	1,545	30,784	22%
				3% PLHIV	4% PLHIV
TOTAL (Region)	142,997	100%		4,290	5,720

¹ Data from: <http://www.nyc.gov/html/doh/downloads/pdf/dires/2013-1st-half-surveillance-table.pdf>

² Data from: <http://www.phila.gov/health/pdfs/2011SurveillanceReportFinal.pdf>

³ Data from: <http://www.state.nj.us/health/aids/repa/county/documents/essex.pdf> (Second Table 1,3 and 5 - Persons Living with HIV/AIDS)

Area of Residence at Diagnosis, NYC¹

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
Borough					
Bronx	23,805	21%	Bronx County 2,084	714	952
Brooklyn	27,949	25%	Kings County 1,312	838	1,118
Manhattan	33,939	30%	NY County 2,391	1,018	1,358
Queens	16,376	14%	Queens County 863	491	655
Staten Island	1,933	2%	Richmond County 489	58	77
Outside NYC	9,427	8%		283	377
Unknown	664	<1%		20	27
TOTAL	114,093	100%	See above	2,414	4,564

Area of Residence at Diagnosis, Philadelphia³

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
TOTAL	19,157	100%	1,317	575	766

Area of Residence at Diagnosis, Essex County⁴

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
TOTAL	9,747	100%	1,524	292	390

¹ Data from: <http://www.nyc.gov/html/doh/downloads/pdf/dires/2013-1st-half-surveillance-table.pdf>

² Rate is per 100,000 population in 2010 and is from <http://www.aidsvu.org>

³ Data from: <http://www.phila.gov/health/pdfs/2011SurveillanceReportFinal.pdf>

⁴ Data from: <http://www.state.nj.us/health/aids/repa/county/documents/essex.pdf> (Second Table 1,3, and 5 - Persons Living with HIV/AIDS)

Site 2: Washington D.C. and Baltimore

People Living with HIV (PLHIV), Washington D.C.¹ and Baltimore², 2011

	Number D.C.	Number Baltimore	Total no. Region	Region Percent
Race / Ethnicity				
Black	11,307	14,250	25,557	77%
White	2,374	2,751	5,125	16%
Hispanic	904	442	1,346	4%
Asian / Native Hawaiian / Pacific Islander	**3	43	43	0%
Multi / Other / Unk	363	483	846	3%
Sex				
Male	10,882	11,367	22,249	67%
Female	4,174	6,631	10,805	33%
Risk factor for HIV				
Male-Male Sex (MSM)	6,114	3,508	9,622	29%
Injection Drug Use (IDU)	2,132	5,918	8,050	24%
MSM / IDU	491	575	1,066	3%
Blood Products / Other / Ped / Perinatal	198	376	574	2%
Heterosexual Contact	4,201	3,922	8,123	25%
Undetermined	1,920	3,699	5,619	17%
		3% PLHIV	4% PLHIV	
TOTAL (Region)	33,054	992	1,322	

¹ Data from:
<http://doh.dc.gov/sites/default/files/dc/sites/doh/publication/attachments/2012AESRFINAL.pdf>
(Tables 1 and A1)

² Data from: <http://phpa.dhmh.maryland.gov/OIDEOR/CHSE/Shared%20Documents/Baltimore-Towson%20MSA%20HIV%20AIDS%20Epidemiological%20Profile%2012-2011.pdf> (Tables 13,20, and 25)

³ For DC only: other race includes mixed race individuals, Asians, Alaska Natives, American Indians, Native Hawaiians, Pacific Islanders, and unknown.

Area of Residence at Diagnosis, Washington D.C.¹

	Number	Percent	RATE²	3% PLHIV	4% PLHIV
TOTAL	15,056	100%	2,436	452	602

Area of Residence at Diagnosis, Baltimore³

	Number	Percent	RATE²	3% PLHIV	4% PLHIV
TOTAL	9,747	100%	1,524	292	390

¹ Data from:
<http://doh.dc.gov/sites/default/files/dc/sites/doh/publication/attachments/2012AESRFINAL.pdf>
(Tables 1 and A1)

² Rate is per 100,000 population in 2010 and is from <http://www.aidsvu.org>

³ Data from: <http://phpa.dhmh.maryland.gov/OIDEOR/CHSE/Shared%20Documents/Baltimore-Towson%20MSA%20HIV%20AIDS%20Epidemiological%20Profile%2012-2011.pdf> (Tables 13,20, and 25)

Site 3: North Carolina

People Living with HIV (PLHIV), North Carolina,¹ 2011

	Number	Percent			
Race / Ethnicity					
Black	17,337	66%			
White	6,681	26%			
Hispanic	1,544	6%			
Asian / Native Hawaiian / Pacific Islander	131	1%			
Am Indian / Alaska Native	206	1%			
Other / Unk	269	1%			
Sex					
Male	18,397	70%			
Female	7,771	30%			
Risk					
Male-Male Sex (MSM)	11,596	47%			
Injection Drug Use (IDU)	2,836	11%			
MSM / IDU	758	3%			
Blood Products	116	<1%			
Heterosexual Contact	10,492	40%			
Pediatric	371	1%			
Undetermined ²					
Area of Residence at Diagnosis					
			RATE³	3% PLHIV	4% PLHIV
Wake County (Raleigh)	2,721			82	109
Durham County (Durham)	1,467			44	59
Cumberland County (Fayetteville)	1,236			37	49
TOTAL (North Carolina)	26,168	100%	310	785	1,047

¹ Data from: http://epi.publichealth.nc.gov/cd/stds/figures/Epi_Profile_2012.pdf (Appendix tables: I, J, and M)

² Risk is statistically adjusted to reassign cases reported without risk to a category so undetermined is presented as 0.

³ Rate is per 100,000 population in 2010 and is from <http://www.aidsvu.org>

Site 4: Florida

People Living with HIV (PLHIV), Florida,¹ through July 31, 2013

	Number	Percent			
Race / Ethnicity					
Black	49,811	48%			
White	30,166	29%			
Hispanic	21,067	20%			
Asian / Native Hawaiian / Pacific Islander	442	0%			
Am Indian / Alaska Native	81	0%			
Multi	1,385	1%			
Sex					
Male	72,612	71%			
Female	30,340	29%			
Risk factor for HIV					
Male-Male Sex (MSM)	43,817	43%			
Injection Drug Use (IDU)	8,433	8%			
MSM / IDU	3,394	3%			
Blood Products	183	0%			
Heterosexual Contact	34,611	34%			
Perinatal	1,522	1%			
Undetermined / Other	10,992	11%			
			RATE²	3% PLHIV	4% PLHIV
TOTAL	102,952	100%	593	3,089	4,118

¹ Data from: <http://www.floridahealth.gov/diseases-and-conditions/aids/surveillance/documents/msr/2013-msr/MSR0813.pdf> (Table 5)

² Rate is per 100,000 population in 2010 and is from <http://www.aidsvu.org>

Site 5: Puerto Rico

People Living with HIV (PLHIV), Puerto Rico,¹ 2012

	Number	Percent			
Race / Ethnicity					
Hispanic	19,927	100%			
Sex					
Male	13,711	69%			
Female	6,216	31%			
Risk factor for HIV					
Male-Male Sex (MSM)	3,857	19%			
Injection Drug Use (IDU)	7,103	36%			
MSM / IDU	919	5%			
Blood Products ²					
Heterosexual Contact	6,998	35%			
Perinatal	276	1%			
Other	43	<1%			
Undetermined	71	<1%			
			RATE³	3% PLHIV	4% PLHIV
TOTAL	19,927	100%	584	598	797

¹ Data from: Puerto Rico Dept of Health: Puerto Rico HIV Surveillance Semestral Report

² Blood products are likely included in Other

³ Rate is per 100,000 population in 2010 and is from <http://www.aidsvu.org>

Site 6: Deep South

**People Living with HIV (PLHIV)
Alabama¹ (AL), Louisiana (LA)², and Mississippi (MS),³ 2012**

	Number LA	Number AL	Number MS	Total no. Region	Percent
Race / Ethnicity					
Black	12,898	7,805	7,424	28,127	69%
White	5,037	3,503	2,319	10,859	26%
Hispanic	716	240	243	1,199	3%
Asian / Native Hawaiian / Pacific Islander	65	0	18	83	0%
Am Indian / Alaska Native	30	0	19	49	0%
Multi / Other / Unk	118	388	231	737	2%
Sex					
Male	13,205	8,563	7,106	28,874	70%
Female	5,659	3,373	3,148	12,180	30%
Risk factor for HIV					
Male-Male Sex (MSM)	6,280	4,945	3,857	15,082	37%
Injection Drug Use (IDU)	1,801	859	602	3,262	8%
MSM / IDU	824	467	401	1,692	4%
Blood Products / Other	82	31	30	143	0%
Heterosexual Contact	3,332	2,542	1,732	7,606	19%
Perinatal	200	83	78	361	1%
Undetermined	6,345	3,009	3,564	12,918	31%
			3% PLHIV	4% PLHIV	
TOTAL (Region)	41,054	100%	1,232	1,642	

¹ Data from: http://www.adph.org/aids/assets/HIV_Surveillance_2012_R.pdf (Table 1)

² Data from: <http://new.dhh.louisiana.gov/assets/oph/HIVSTD/hiv-aids/2012/FOURTHQuarter2012.pdf> (Page 2)

³ Data from: http://www.msdh.state.ms.us/msdhsite/index.cfm/14.4769.150.pdf/Living_with_HIV_2012.pdf

Area of Residence at Diagnosis, Louisiana¹

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
TOTAL	18,864	100%	452	566	755

Area of Residence at Diagnosis, Alabama³

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
Jefferson - PHA IV (Birmingham)	3,339	28%	NA	100	134
TOTAL (Alabama)	11,936	100%	290	358	477

Area of Residence at Diagnosis, Mississippi⁴

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
Public Health District V* (10 counties including Hinds County and the City of Jackson)	3,940	38%	NA	118	158
*The next largest health district has 13% of the state's cases					
TOTAL (Mississippi)	10,254	100%	338	308	410

¹ Data from: <http://new.dhh.louisiana.gov/assets/oph/HIVSTD/hiv-aids/2012/FOURTHQuarter2012.pdf> (Page 2)

² Rate is per 100,000 population in 2010 and is from <http://www.aidsvu.org>

³ Data from: http://www.adph.org/aids/assets/HIV_Surveillance_2012_R.pdf (Table 1)

⁴ Data from: http://www.msdh.state.ms.us/msdhsite/index.cfm/14.4769.150.pdf/Living_with_HIV_2012.pdf

Site 7: U.S. West

**People Living with HIV (PLHIV)
Arizona (AZ)¹, Colorado (CO)², New Mexico (NM),³ 2011 or 2012**

	Number AZ	Number CO	Number NM	Total no. Region	Percent
Race / Ethnicity					
Black	1,706	1,720	249	3,675	12%
White	8,309	7,436	1,505	17,250	58%
Hispanic	3,754	2,214	1,368	7,336	25%
Asian / Native Hawaiian / Pacific Islander	192	119	22	333	1%
Am Indian / Alaska Native	498	91	266	855	3%
Multi / Other / Unk	246	118	246	610	2%
Sex					
Male	12,630	10,354	3,031	26,015	87%
Female	2,075	1,344	437	3,856	13%
Risk factor for HIV					
Male-Male Sex (MSM)	8,780	7,545	2,079	18,404	62%
Injection Drug Use (IDU)	1,596	846	311	2,753	9%
MSM / IDU	1,252	973	339	2,564	9%
Blood Products / Other	197	44	17	258	1%
Heterosexual Contact	1,526	1,149	341	3,016	10%
Perinatal	0	70	15	85	0%
Undetermined	1,354	1,071	366	2,791	9%
			3% PLHIV	4% PLHIV	
TOTAL (Region)	29,871	100%	896	1,195	

¹ Data from: <http://www.azdhs.gov/phs/edc/odis/documents/hiv-epidemiology/2012/2012-state-of-arizona.pdf>

² Data from HIV/AIDS in Colorado Surveillance Report – 4th Quarter 2012 (through December 2012) <http://www.colorado.gov/cs/Satellite/CDPHE-DCEED/CBON/1251621434445>

³ Data from: <http://nmhealth.org/ERD/HealthData/documents/NMDOH-ERD-HIVAIDS-AnnualReport-2012-EN.pdf> (Table 2.1)

Area of Residence at Diagnosis, Arizona¹

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
TOTAL	14,705	100%	240	441	588

Area of Residence at Diagnosis, Colorado³

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
TOTAL	11,698	100%	265	351	468

Area of Residence at Diagnosis, New Mexico⁴

	Number	Percent	RATE ²	3% PLHIV	4% PLHIV
TOTAL	3,468	100%	145	104	139

¹ Data from: <http://www.azdhs.gov/phs/edc/odis/documents/hiv-epidemiology/2012/2012-state-of-arizona.pdf>

² Rate is per 100,000 population in 2010 and is from <http://www.aidsvu.org>

³ Data from HIV/AIDS in Colorado Surveillance Report – 4th Quarter 2012 (through December 2012) <http://www.colorado.gov/cs/Satellite/CDPHE-DCEED/CBON/1251621434445>

⁴ Data from: <http://nmhealth.org/ERD/HealthData/documents/NMDOH-ERD-HIVAIDS-AnnualReport-2012-EN.pdf> (Table 2.1)

**People Living With HIV (PLHIV)
Top Counties in California¹ through June 30, 2013**

County	Total	3% PLHIV	4% PLHIV
Los Angeles	45,317	1,360	1,813
San Francisco	15,334	460	613
San Diego	12,577	377	503
Orange	6,880	206	275
Alameda (Oakland)	5,488	165	220
Riverside	5,177	155	207

**People Living with HIV (PLHIV)
Los Angeles County,² 2012**

	Number	Percent
Race / Ethnicity		
Black	9,328	21%
White	15,237	34%
Hispanic	18,622	41%
Other (Asian / Pacific Islander / American Indian / Alaska Native)	1,724	4%
Multi / Missing	563	1%
Sex		
Male	40,315	89%
Female	5,159	11%
Risk factor for HIV³		
Male-Male Sex (MSM)	34,917	77%
Injection Drug Use (IDU)	2,443	5%
MSM / IDU	2,904	6%
Blood / Occup / Perinatal	142	<1%
Heterosexual Contact	4,794	11%
Perinatal	261	1%
Undetermined	14	<1%

			RATE ⁴	3% PLHIV	4% PLHIV
TOTAL	45,474	100%	513	1,364	1,819

¹ Data from: <http://www.cdph.ca.gov/data/statistics/Documents/SSSemiAnnualRptJune2013.pdf>

² Data from: <http://publichealth.lacounty.gov/wwwfiles/ph/hae/hiv/2012AnnualHIVSurveillanceReport.pdf> (Table 15)

³ Risk is statistically adjusted to minimize undetermined risk.

⁴ Rate is per 100,000 population in 2010 and is from <http://www.aidsvu.org>

**People Living with HIV (PLHIV)
San Francisco¹, through June 30, 2013**

	Number	Percent			
Race / Ethnicity					
Black	2,042	13%			
White	9,747	62%			
Hispanic	2,737	17%			
Asian/ Native Hawaiian / Pacific Islander	862	5%			
Am Indian / Alaska Native	92	<1%			
Multi / Other / Unk	311	2%			
Sex					
Male	14,531	92%			
Female	913	6%			
Transgender ²	347	2%			
Risk factor for HIV					
Male-Male Sex (MSM)	11,401	72%			
Injection Drug Use (IDU)	992	6%			
MSM / IDU	2,201	14%			
Blood Products	20	<1%			
Heterosexual Contact	502	3%			
Pediatric (<12 years)	37	<1%			
Undetermined	287	2%			
Transgender	347	2%			
			RATE³	3% PLHIV	4% PLHIV
TOTAL	15,791	100%	2,022	474	632

¹ Data from: <http://www.sfdph.org/dph/files/reports/RptsHIVAIDS/HIV-AIDS-qrpt201306.pdf>
(Tables 15, 16, and 17)

² Transgender info collected since September 1996

³ Rate is per 100,000 population for San Francisco County in 2010 and is from <http://www.aidsvu.org>

Appendix E: Priority focus populations for each site selected

Pilot site:

Detroit, MI (metro area)

Inclusion of people living with HIV from the following groups: women across race, ethnicity, age, sexual orientation and gender identity (specifically inclusive of transgender women); men who have sex with men and heterosexual men across race, ethnicity, and age (with a focus on young African American, Latino, Native American and Arab American men who have sex with men); people who have been incarcerated; people who use or have used drugs, people who are or have been sex workers; and individuals living in an urban area

Sites:

East Coast Urban Corridor (New York City, Newark, and Philadelphia)

Particular focus on inclusion of women, immigrants, men across sexual orientation and gender identity of varying age; people of African, Latino, and Asian descent; people who have been incarcerated; people who use or have used drugs; people who do or have done sex work; urban people; and the newly diagnosed

Washington D.C. and Baltimore

Particular focus on inclusion of women, immigrants, men across sexual orientation and gender identity of varying age; people of African, Latino, and Asian descent; Native Americans; people who use drugs; people who have been incarcerated; people who do or have done sex work; and urban people living with HIV

North Carolina

Particular focus on inclusion of urban and rural women of African American, Latino, and Native American descent, across sexual and gender orientations and ages; gay men and other men who have sex with men; and those newly diagnosed

Florida

Particular focus on inclusion of newly diagnosed people living with HIV, both U.S.-born and immigrants; women; gay men who have sex with men; young people; racial minorities; and those living in an urban area

Puerto Rico

Particular focus on inclusion of men who have sex with men and transgender communities; women; people who use or have used drugs; current or former sex workers; other racial minorities; and individuals living in rural areas

Deep South (Alabama, Louisiana, and Mississippi)

Particular focus on inclusion of African Americans and Latinos; gay men and other men who have sex with men; heterosexual men; women; rural people, and young people across sexual and gender identities; people who have been incarcerated; and people who use or have used drugs

U.S. West (Colorado, New Mexico, and Arizona)

Particular focus on inclusion of women; gay men and other men who have sex with men; young people; those with a history of incarceration; Native Americans; rural people, and people in low HIV-prevalence areas living with HIV

California Coast (Los Angeles to Oakland and San Francisco)

Particular focus on inclusion of immigrants, refugees, and asylees; gay men and other men who have sex with men; transgender people; women; Latinos and Asian Americans; people who use or have used drugs; people who do sex work; urban people living with HIV; and the newly diagnosed