

# REVITALIZING THE U.S. NATIONAL HIV/AIDS STRATEGY

## **Meeting Report**

December 11–12, 2012

Washington, D.C.

# **TAG**

Treatment Action Group

New York, NY

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A list of the meeting participants and the meeting agenda are provided in the appendix.

Treatment Action Group (TAG) is an independent AIDS research and policy think tank fighting for better treatment, a vaccine, and a cure for AIDS.

TAG works to ensure that all people with HIV receive lifesaving treatment, care, and information. We are science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions.

TAG catalyzes open collective action by all affected communities, scientists, and policy makers to end AIDS.

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**Meeting Report**  
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## **List of Abbreviations**

ACA – Patient Protection and Affordable Care Act  
ADAP – AIDS Drug Assistance Program  
amfAR – Foundation for AIDS Research  
ART – Antiretroviral Treatment  
ASO – AIDS Service Organization  
CBO – Community-Based Organization  
CDC – Centers for Disease Control and Prevention  
FPL – Federal Poverty Level  
HPTN – HIV Prevention Trials Network  
HRSA – Health Resources and Services Administration  
IDU – Injecting Drug User  
IOM – Institute of Medicine  
LGBT – Lesbian, Gay, Bisexual, Transgender  
MSM – Men who have Sex with Men  
NHAS – National HIV/AIDS Strategy  
NIAID – National Institute of Allergy and Infectious Diseases  
NIH – National Institutes of Health  
NMAC – National Minority AIDS Council  
OAR – Office of AIDS Research  
PEPFAR – President’s Emergency Plan for AIDS Relief  
PrEP – Pre-Exposure Prophylaxis  
SAMHSA – Substance Abuse and Mental Health Services Administration  
TAG – Treatment Action Group  
USPSTF – U.S. Preventive Services Task Force  
WHO – World Health Organization

## EXECUTIVE SUMMARY

On December 11–12, 2012, in Washington, D.C., Treatment Action Group (TAG) hosted a meeting of HIV advocates, service providers, and researchers from across the United States (U.S.) to review the current state of the national HIV response and discuss how to revitalize the National HIV/AIDS Strategy (NHAS). Meeting participants reviewed the latest data, discussed the changing landscape of the HIV response, and developed recommendations for continued and expedited progress. This report summarizes the meeting presentations and discussions, and outlines the key recommendations from participants. In conjunction with this report, TAG is releasing an *Action Plan to Revitalize the NHAS* that incorporates the recommendations from this meeting report. The *Action Plan* is available at [www.treatmentactiongroup.org/hiv/nhas](http://www.treatmentactiongroup.org/hiv/nhas).

New scientific and policy developments have occurred since the introduction of the NHAS in July 2010 that provide the potential to end the AIDS epidemic in the U.S. These developments include advances in understanding how HIV treatment can prevent HIV transmission, and the passage—and the Supreme Court’s upholding—of the Patient Protection and Affordable Care Act (ACA), which will increase access to health care for millions of Americans, including many living with HIV. New approaches to determining how best to allocate investments for the HIV response provide important opportunities for improved and cost-effective health outcomes.

Successful realization of these opportunities requires policy- and program reconfiguration, activism, and education. New research is needed to better understand how to implement these developments most effectively. The NHAS was released prior to many of these new developments and should be reassessed to determine if more ambitious goals and targets are now feasible and, if so, how to realize them.

Meeting participants focused on the following primary areas to improve HIV advocacy and service delivery to reduce infection rates and scale up effective use of treatment.

- **Develop an HIV Implementation Science Agenda.** There is a significant lack of data regarding how to optimize management of HIV treatment and prevention approaches, particularly regarding the incorporation of scientific advances. Implementation science can provide important data regarding how to improve HIV service delivery through each point in the HIV continuum of care.

Recommendation: The community should work with researchers and public health authorities to develop an implementation science research agenda and advocate for its implementation. A first meeting is tentatively planned for May 2013.

- **Improve Outcomes in the HIV Treatment Cascade.** The treatment cascade provides a simple approach to understanding the steps in HIV care from testing through treatment sustainability, as well as the level of current success in utilizing these services. However, in order to be a useful advocacy and monitoring tool, improved access to data is essential.

Recommendation: The U.S. government should facilitate the development by state, local, and other relevant jurisdictions (e.g., correctional systems) of their own cascades, including the development of models, data-set identification, and support to state-level organizations to create treatment and, if possible, prevention cascades to track progress in meeting HIV health goals.

- **Optimize Investments in HIV Prevention and Care.** Despite high levels of federal government funding for HIV services, funding is not well targeted to address those populations and geographies in which it is most needed. More targeted use of HIV investment will lead to improved outcomes and cost savings. More information is needed about the sources, levels, and allocations of funding at federal and state levels, and from within the private sector.

Recommendation: Political, public health, and community groups should develop models using the investment framework<sup>1</sup> to track HIV spending at national, state, and local levels in order to recommend improvements to ensure that funding is used for evidence-based interventions and targeted for populations most in need.

- **Advocate for and Provide Education about Effective Implementation of the ACA and Medicaid Expansion.** The passage of the ACA, Medicaid Expansion, and other health reforms will expand access to services for people living with and at risk for HIV. However, the implementation of these reforms will drastically change the structures in which HIV care is provided. Information dissemination, training, and advocacy are needed to ensure that critical enabling services are provided with continued resources, that the experience and expertise of community-based organizations (CBOs) are well utilized, and that navigation is smooth for patients within the new landscape of health systems.

Recommendations: ONAP and HHS should develop information-dissemination mechanisms and tools to assist CBOs as they transition into new funding structures. Ensure continued support for critical enabling support services through Ryan White funding. Develop patient navigation services to improve health care literacy and utilization.

- **Mobilize Communities and Build Coalitions for Health Access and Human Rights.** The HIV movement needs to align with other health and social movements, such as environment, criminal justice, and immigration movements. HIV is affected by a diverse set of social determinants and issues, and HIV affected these issues as well. Human rights abuses, including increasing criminalization related to HIV status and disclosure, continue to plague efforts to prevent and treat HIV. As the primary target population for new and existing HIV infections, gay communities, and their organizations and donors, have a continued responsibility to address HIV.

Recommendations: Public and private HIV/AIDS and LGBT donors should invest in state and local coalition building and advocacy that link the HIV response with advocacy for the right to health, with specific health advocacy efforts, and with social justice movements. Challenge mainstream national LGBT organizations to return HIV to their agendas and devote resources to that work.

Additional recommendations are found throughout this report. Presentations and slides from the meeting are available at: [www.treatmentactiongroup.org/hiv/nhas](http://www.treatmentactiongroup.org/hiv/nhas).

## INTRODUCTION – GOALS AND OBJECTIVES

Countless Americans have devoted their lives to fighting the HIV epidemic and thanks to their tireless work we've made real inroads. People living with HIV have transformed how we engage community members in setting policy, conducting research, and providing services. Researchers have produced a wealth of information about the disease, including a number of critical tools and interventions to diagnose, prevent, and treat HIV. Successful prevention efforts have averted more than 350,000 new infections in the United States. And health care and other services providers have taught us how to provide quality services in diverse settings and develop medical homes for people with HIV. This moment represents an opportunity for the Nation. Now is the time to build on and refocus our existing efforts to deliver better results for the American people.

—President Barack Obama, *National HIV/AIDS Strategy*<sup>2</sup>

New scientific advances and policy developments which have occurred since the introduction of the NHAS in July 2010 for the first time offer the chance to bring the end of the U.S. AIDS epidemic into sight. Advances in science show that HIV treatment not only lengthens and improves the lives of people living with HIV, but, when used appropriately, also prevents HIV transmission; providing a real opportunity to significantly lower U.S. HIV incidence. Second, the passage of the ACA will increase access to health care for millions of Americans, including many living with HIV. However, the implementation of the ACA will also drastically change the ways in which health care and support services are provided and paid for. The ways in which people receive HIV prevention, treatment and care are in a state of significant transition, a transition that directly affects AIDS service organizations (ASOs). Third, new approaches in determining how best to allocate investments for the HIV response provide important opportunities for improved and cost-effective health outcomes.

These changes—advances in science, in health care coverage, and in investment strategy—offer new and exciting opportunities for ending the U.S. HIV epidemic. However, successful realization of these opportunities will require policy- and program reconfiguration, advocacy, and education. New research is needed to better understand how to implement these developments most effectively. The NHAS was released prior to many of these new developments and should be revised to include the more ambitious goals and targets that are now feasible, and to define how to realize them. The vision statement from the December 2012 *PEPFAR Blueprint: Creating an AIDS-Free Generation* states:<sup>3</sup>

Scientific advances and their successful implementation have brought the world to a tipping point in the fight against AIDS. The United States believes that by making smart investments based on sound science, and a shared global responsibility, we can save millions of lives and achieve an AIDS-free generation.

This ambitious vision should apply not only to the global epidemic, but the epidemic in the U.S. as well. The NHAS provides process-related targets but fails to maximize the full impact expected by fulfilling them. To address the promise of the new science and the ACA, and to capitalize on their opportunity to end the domestic HIV epidemic, TAG hosted a meeting of HIV advocates, service providers, and researchers from across the U.S. to review the current state of the national HIV response and discuss how to revitalize the NHAS. Participants reviewed the latest data, discussed the changing landscape of the HIV response, and developed recommendations for expedited progress. The meeting agenda (see Appendix) outlined the following questions to be addressed:

- How can we enrich the NHAS with the latest science?
  - How do new scientific developments affect the goals, objectives, and strategies of the NHAS?
  - Do these scientific advances allow for the development of a more ambitious NHAS?
  - Do these advances require a revision in the strategies and priorities of the NHAS?
  - How can implementation science be applied to improve service delivery and increase demand?
- How can a strategic investment framework be applied to the U.S. HIV epidemic to improve outcomes and lower costs?
  - How are current U.S. HIV investments spent, and how they are changing?
  - Can the global HIV investment framework be adapted and applied to the U.S.?
  - How can an HIV investment framework contribute to better targeting domestic HIV programs for improved outcomes?
  - Can improving HIV investment strategies support cost reductions in the ACA and Medicaid?
  - How will the ACA and Medicaid expansion affect the service delivery mix, and what are the opportunities to use these mechanisms to optimize HIV programmatic success?
- How can we promote innovative and more effective service-delivery approaches?
  - What is required to adequately scale up testing, treatment, prevention, and social support services?
  - How have community-based providers and state and local AIDS programs revised their service-delivery strategies and approaches?
  - What is the continuing role of services provided through the Ryan White HIV/AIDS Program?



## Putting the Response to HIV in Context

Kenyon Farrow of the Praxis Project in New Orleans provided opening remarks to frame the meeting. His remarks were followed by a full group discussion, both of which are summarized below.

Despite a great deal of discussion about the need for methods to better integrate HIV health services with health care generally, there is considerably less discussion about the need to and value of integration of HIV-specific community mobilization and advocacy within broader areas of social mobilization for health, equity, and justice. One example is the lack of any linkage between HIV and environmental issues that Farrow encountered as a recent conference in Florida. Many social determinants that cause environmental threats to health and quality of life are also those that increase the risk of HIV and hinder the effectiveness of HIV health and prevention services. We need to understand these links better and to build coalitions with social movements to address them; this work can benefit both HIV-specific and broader goals. Criminal justice, prison-reform, and food access provide other clear examples of issues that are affected by HIV and affect HIV outcomes. Yet people working in those other fields have little knowledge of HIV issues or about the very successful community-organizing capacity that exists within the HIV communities.

In addition to building linkages to and coalitions with other social justice– and health movements, we need to strengthen the understanding within our ASOs, particularly at local levels, that the factors that exacerbate HIV go well beyond HIV itself.

Many of us, in our work as advocates and researchers, talk about social determinants, but fall back into a more specific focus on “behavioral” issues in designing local programs and policies. We need to redefine and revitalize education and information dissemination at local levels so that people understand that the epidemic remains a threat in their communities, and learn how they can respond most effectively.

One central challenge is that the infrastructure supporting HIV community mobilization is fragile, and is now weaker than it once was. For some time, ASOs have depended on government funding to support specific interventions and program operational costs. The implementation of the ACA and uncertainty about the future of the Ryan White HIV/AIDS Program’s payer-of-last-resort policy put this support in a state of flux. It remains unclear if and how continued resources for ASOs will be provided. Funding for local- and state-level advocacy has been significantly lacking for many years. It is this type of support that may be most important at this time. We need to move beyond efforts to generally raise awareness about HIV and promote tolerance, to more specific and dynamic activism and mobilization to ensure that HIV services are available, that appropriate education about HIV is provided in schools, and that the human rights of people living with and at risk for HIV are protected and defended. One key opportunity to build state-level advocacy and coalitions will be in states that refuse to adopt measures under the ACA, such as Medicaid expansion or the creation of health insurance marketplaces. These efforts directly affect HIV and provide opportunities to join with other health movements in ensuring expanded access to affordable care.

On a national level, the major LGBT organizations and donors have mostly excluded HIV from their agendas. Focus has shifted to marriage equality and other issues, which have led some national organizations to shy away from HIV, as they appear to believe it interferes with their strategies to

promote marriage equality. Yet HIV remains the greatest health threat to gay men, especially young gay men of color. It is hard to view the withdrawal from AIDS by national mainstream organizations as anything but neglect of the needs of communities of color. This must change. It will be interesting to see if and how the agendas of these organizations change if the Supreme Court upholds marriage equality in the pending cases.

One key area on which mainstream LGBT organizations can focus is HIV-related stigma, both outside and within gay communities, including growing concerns about criminalization of HIV status and transmission. These issues also present good opportunities for bridging with criminal justice movements.

Many meeting participants highlighted the need for and value of integration of HIV services within health and social-service systems. Such integration is an important component of ACA implementation. However, as we work to integrate HIV into broader health services, we must maintain the essential community-based core that has provided successful HIV-specific approaches to service delivery and advocacy over the past decades. We must also ensure that the history of the AIDS response is shared and remembered, as there are important lessons essential to the next stage of the work. In many ways, the AIDS movement has helped reshape health care in the U.S. and around the world. Many stories are yet untold; including those about many of the successes the AIDS movement has achieved. This legacy is crucial to inform broader discussions regarding health and human rights.

## Are We on Track to Achieve the Goals of the NHAS?

Dr. David Holtgrave of the Johns Hopkins University provided an overview of current efforts to implement the NHAS and what is needed to more effectively meet its current targets. The presentation began with a review of the NHAS targets:

### Reducing New HIV Infections

- By 2015, lower the annual number of new infections by 25 percent (from 56,300 to 42,225).
- Reduce the HIV transmission rate, which is a measure of annual transmissions in relation to the number of people living with HIV, by 30 percent (from 5 persons infected per 100 people with HIV to 3.5 persons infected per 100 people with HIV).
- By 2015, increase from 79 percent to 90 percent the percentage of people living with HIV who know their serostatus (from 948,000 to 1,080,000 people).

### Increasing Access to Care and Improving Health Outcomes for People Living with HIV

- By 2015, increase the proportion of newly diagnosed patients linked to clinical care within three months of their HIV diagnosis from 65% to 85% (from 26,824 to 35,078 people).
- By 2015, increase the proportion of Ryan White HIV/AIDS Program clients who are in continuous care (at least 2 visits for routine HIV medical care in 12 months at least 3 months apart) from 73 percent to 80 percent (or 237,924 people in continuous care to 260,739 people in continuous care).
- By 2015, increase the number of Ryan White clients with permanent housing from 82 percent to 86 percent (from 434,000 to 455,800 people). (This serves as a measurable proxy of our efforts to expand access to HUD and other housing supports to all needy people living with HIV.)

### Reducing HIV-Related Health Disparities

*While working to improve access to prevention and care services for all Americans*

- By 2015, increase the proportion of HIV diagnosed gay and bisexual men with undetectable viral load by 20 percent.
- By 2015, increase the proportion of HIV diagnosed Blacks with undetectable viral load by 20 percent.
- By 2015, increase the proportion of HIV diagnosed Latinos with undetectable viral load by 20 percent.

Source: White House, Office of National AIDS Policy. National HIV/AIDS strategy: federal implementation plan. Washington, D.C.: White House Office of National AIDS Policy; 2010 July. p. 7. Available from: <http://www.whitehouse.gov/files/documents/nhas-implementation.pdf>.

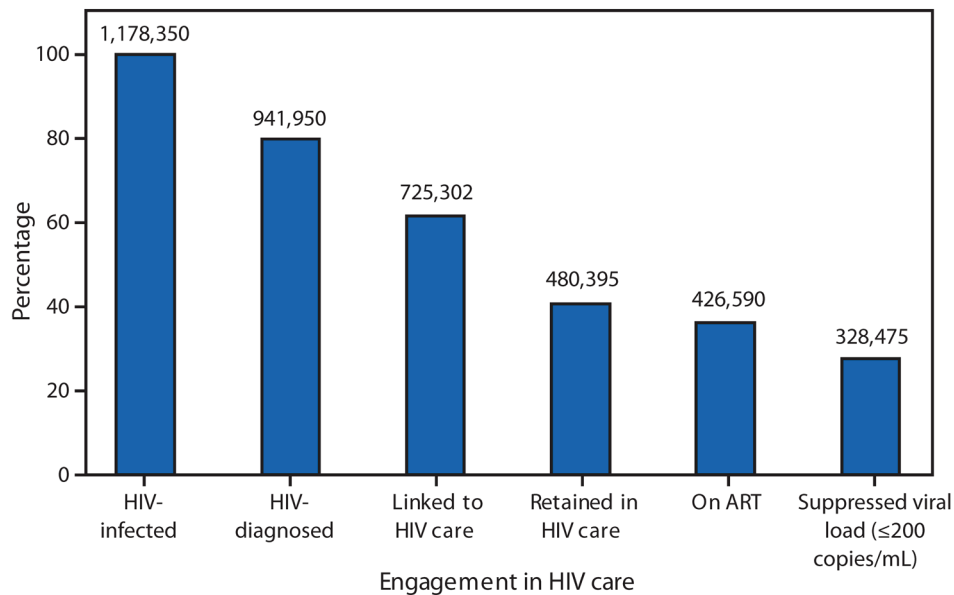
If the NHAS goals are met, approximately 75,800 new infections would be averted through 2015; prevalence would fall from 1,481,000 in 2010 to 1,407,000 in 2015, and about 218,900 more people would be on HIV treatment.

The presentation<sup>4</sup> addressed three primary questions:

- Is it still epidemiologically feasible to attain the incidence- and transmission rate–reduction goals of the NHAS by 2015?
- If so, what costs will be incurred in necessary program expansion, and will the investment be cost-effective?
- Would substantial expansion of prevention services for persons living with HIV (PLWH) augment the other strategies outlined in the NHAS in terms of effectiveness and cost-effectiveness?

The NHAS did not specify resources needed to reach its goals. The federal government still has not provided much information about how much funding is needed. Dr. Holtgrave estimates that an additional \$15.2 billion is needed through 2015 to reach the prevention and treatment targets including support for housing and other essential services. Some of these resources may be provided through ACA implementation and Medicaid expansion, but continued Ryan White funding will be essential to support wraparound services. Greater investment would ultimately be cost-saving, with an estimated \$18 billion saved in medical costs through successful prevention efforts. However, since the release of the NHAS, the CDC total HIV prevention budget has been reduced, once adjusted for inflation. The gaps in meeting treatment needs are clearly demonstrated through the HIV continuum of care/treatment cascade, discussed more fully later in this report.

### Number and percentage of HIV-infected persons engaged in selected stages of the continuum of HIV care—United States



Source: Centers for Disease Control and Prevention (CDC). Vital signs: HIV prevention through care and treatment—United States. MMWR Morb Mortal Wkly Rep. 2011 Dec 2;60(47):1618–23. Available from: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6047a4.htm>.

Dr. Holtgrave examined a diverse set of scenarios for delivery of prevention, care, and support to determine their effect on costs and on meeting NHAS targets, showing that it is possible to meet current targets, but only through increased investments. Holtgrave summarized:

- Simply waiting for expansion of care services in 2014 and 2015 will not be enough to reach NHAS targets for reductions of incidence and transmission rates.
- Additional investment in HIV testing and prevention services for PLWH (in addition to care and housing services) enables us to reach those goals.
- Investing in treatment scale-up without additional resources for prevention interventions may reduce incidence, but not to the levels set in the NHAS. Only through additional investment in other prevention interventions can these goals be achieved.
- Substantial progress toward investing in these services must be made in fiscal year (FY) 2013; otherwise, the window on achieving the NHAS goals will close.
- Cost-effectiveness from HIV investments is usually equal to or better than cost-effectiveness levels in other areas of public health.
- Prevention efforts should focus on identifying who is infected and getting them onto treatment, as well as reducing by half the risks of both HIV-positive and -negative people through other evidenced-based prevention interventions. Both biomedical and behavioral interventions are needed to significantly reduce transmission.

## Seeking an End to AIDS in the United States: The Science Base

Dr. Anthony S. Fauci, the director of the National Institute of Allergy and Infectious Diseases at the NIH, provided an overview of recent scientific progress and challenges, and of the potential impact of scientific advances on meeting NHAS goals.

There are approximately 1.1 million people living with HIV in the U.S. Despite significant decreases in incidence from a highpoint in the mid-1980s, incidence in the U.S. has remained the same since 1990, with approximately 50,000 new infections per year. The large majority of these infections occur in people of color, primarily African American and Latino men, and the primary means of transmission being male-to-male sexual contact. Twenty-six percent of these infections occur in people ages 13 to 24 years. An estimated 60 percent of youth living with HIV do not know their HIV status.

Dr. Fauci focused on the three primary goals of the NHAS: reducing incidence, increasing access to care and treatment, and reducing HIV-related health disparities. Several key interventions are needed to reduce new infections. The first is an increased demand for and use of HIV counseling and testing. An estimated 49 percent of new infections were from the 20 percent of people who are unaware of their HIV status. Increased use of routine HIV testing is now recommended. However, increasing demand for and use of testing among key affected populations is essential to realizing the impact that testing can play in both reducing incidence and increasing the numbers of people in care and on treatment.

Another key prevention intervention that remains inaccessible and underused is harm reduction for injection drug users (IDUs), including opioid substitution therapy and syringe exchange. One study cited showed that treatment with methadone reduced the risk of HIV infection among IDUs by 54 percent. Similarly, an increase in syringe-exchange coverage, an inexpensive and evidenced-based prevention intervention, from the current 2.9% to 10% of need, would prevent an estimated 500 new infections a year. This would cost about \$64 million a year but would save about \$193 million a year in treatment costs. The continued ban on federal funding for syringe exchange is scientifically unjustified and an unreasonable barrier to successful HIV prevention in the United States.

Dr. Fauci reviewed research findings about pre-exposure prophylaxis (PrEP) and microbicides, which, despite increasingly mixed results, may well place in the prevention armamentarium, though defining that role will require further research and costing analyses.

The value of treatment as a prevention tool is now unquestioned. Information dissemination to health care providers, advocates, and communities at risk is needed to ensure that people understand how these new findings can significantly strengthen the fight against AIDS. While definitive data linking treatment to incidence-reduction is still developing, implementation of earlier use of antiretroviral therapy (ART) in San Francisco points a way toward improvement.

## **"Treat All" Policy Proving Effective in San Francisco**

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- **2,245 untreated HIV<sup>+</sup> patients entering care at Ward 86 HIV Clinic, SFGH, 2001-2011**
- **Fraction of patients with undetectable HIV RNA over entire calendar year rose from 34% to 72%**
- **Biggest change in patients with CD >500, after universal ART recommendation in S.F. (Jan. 1, 2010)**
- **Data support feasibility of expanded "test and treat" programs**



Source: Geng EH et al. The effect of a "universal antiretroviral therapy" recommendation on HIV RNA levels among HIV-infected patients entering care with a CD4 count greater than 500/ $\mu$ L in a public health setting. *Clin Infect Dis.* 2012 Dec;55(12):1690–7. doi: 10.1093/cid/cis750.

While the value of ART as a treatment intervention is well established, the success of ART is dependent on the ability of people to access health care consistently and to adhere to treatment—barring discovery of an effective, safe, and scalable cure—over a lifetime. Data describing the HIV treatment cascade make clear that much work is needed to increase access to and retention in care. Continued and combined use of both biomedical and behavioral interventions are needed to prevent infection and increase effective use of treatment. Additional research (e.g., HIV Prevention Trials Network or HPTN 065 "test, link to care, and treat" study) is now under way. The results of such studies will provide important information on how to increase demand for HIV testing, link people to treatment, and retain them successfully in care to achieve treatment success. Dr. Fauci stated that additional implementation science research was needed to better understand how to best incorporate scientific advances into care and address the gaps in the treatment cascade.

Dr. Fauci described the implementation of the ACA as a crucial factor in reducing HIV-related health disparities, citing the following factors:

- With ACA, more people will enter the "care cascade" with increased availability (no co-pays/deductibles) to routine prevention services and HIV testing/counseling;
- No denial of coverage for pre-existing conditions and no annual limits on coverage;
- Investments in public health surveillance, community-based programs, and culturally competent outreach and care; and
- People living with HIV will be eligible for coordinated care provided by health homes for Medicaid beneficiaries with chronic conditions.

We must refocus prevention efforts on the people in places at greatest risk and adopt a more strategic and coordinated approach that combines effective HIV interventions and that stimulates innovation to develop new, effective, and scalable tools.

Dr. Fauci stressed that efforts to end AIDS in the U.S. can succeed. There is now very strong and specific information about where the problems lie and what strategies are most effective to address them. While more information is needed about how best to implement new approaches, the opportunities to make significant headway are here now. The question is whether the country will meet the challenge.



## Creating a Continuum of Care: The HIV Treatment Cascade in the United States

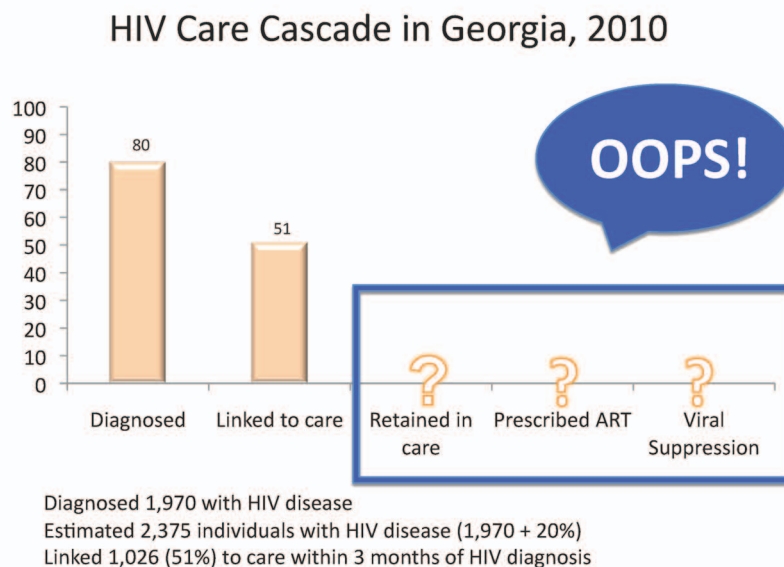
Melanie Thompson, MD, of the AIDS Research Consortium of Atlanta, described the HIV treatment cascade in the United States and what is needed to improve data collection and patient monitoring. Her presentation was divided into five challenges: (1) finding data to build a cascade; (2) standardizing the metrics; (3) recognizing that cascades differ by context; (4) addressing implementation barriers; and (5) understanding how the ACA will affect the care cascade.

### Challenge 1: Finding Data to Build a Cascade

The presentation of the HIV treatment cascade is a useful tool for activists, educators, and policymakers. It provides a simple visual characterization of the steps in HIV treatment delivery, the numbers of people who should be in care at each step, and the numbers of people who actually are in care at each step. The cascade presents an immediately understandable picture of the current gaps in care across the spectrum.

Dr. Thompson supported the value of the cascade as both a monitoring and an advocacy tool. However, she stressed that current cascades offered by the CDC as well as others are based primarily on models, limited local or regional studies, meta-analyses, and studies based on samples with selection bias, such as the Medical Monitoring Project, but not on longitudinal, individual patient data. In some cases, broad estimates about the number of people linked to care are based on very small data sets.

Following the CDC cascade model, colleagues in Georgia began the task of developing a care cascade using available databases. Dr. Thompson presented the initial output from this process. The figure below illustrates the lack of complete data that hinders the ability to adequately monitor the use and effectiveness of care delivery and the need for additional efforts to integrate existing databases.



Source: Thompson, M. Creating a Continuum of Care: The HIV Treatment Cascade in the U.S. Paper presented at: Revitalizing the U.S. National HIV/AIDS Strategy Meeting; 2012 December 11–12; Washington, D.C.

At national, state, and some local (e.g., San Francisco) levels, good data exist, but obtaining access to them is difficult, and even when access is available, interaction among multiple databases is challenging. Information about the numbers of people actually taking ART is incomplete—something that may get even more difficult under the ACA, with the proliferation of private insurance plans for those previously covered by the public sector. The cascades have also not yet incorporated current U.S. treatment recommendations into their metrics. Based on current U.S. guidelines, the number of people who should be on ART could be as high as the total number of people infected. The treatment cascade is a construct. We need to move from construct to data. To do so, systems are needed to collect real and useful data that monitor entry into and successful retention in care.

## Challenge 2: Standardizing the Metrics

To compare cascades across jurisdictions or populations, standard metrics must be used. Currently, indicators have multiple definitions from different sources (HRSA, HHS, IOM), making it difficult to interpret and compare outcomes. The two figures below provide a good example of conflicting definitions for measuring retention in care.

**Monitoring HIV Care in the United States** INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES  
Advising the nation • Improving health

**Table 1: Core Indicators for Clinical HIV Care**

<b>Proportion of people newly diagnosed with HIV who are linked to clinical care for HIV within three months of diagnosis</b>
<b>Rationale:</b> Early linkage to care improves individual health outcomes and reduces transmission of the virus to others.
<b>Proportion of people with diagnosed HIV infection who are in continuous care (two or more visits for routine HIV medical care in the preceding 12 months at least three months apart)</b>
<b>Rationale:</b> Continuous HIV care results in better outcomes, including decreased mortality and reduced transmission of the virus to others.
<b>Proportion of people with diagnosed HIV infection who received two or more CD4 tests in the preceding 12 months</b>
<b>Rationale:</b> Regular CD4 testing permits providers to monitor individuals' immune function, determine when to start antiretroviral therapy (ART), and assess the need for prophylaxis for opportunistic infections.
<b>Proportion of people with diagnosed HIV infection who received two or more viral load tests in the preceding 12 months</b>
<b>Rationale:</b> Regular viral load (plasma HIV RNA) testing is important for monitoring clinical progression of the disease and therapeutic response in individuals on ART.

**7 Core HHS Indicator Measures**

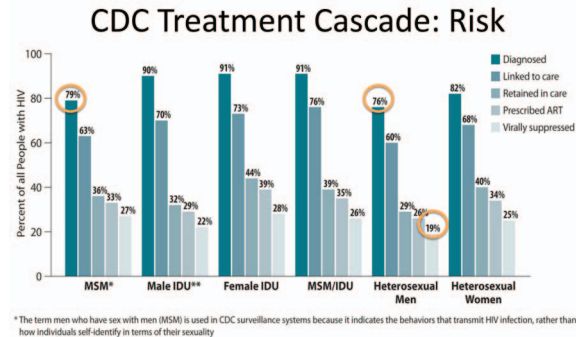
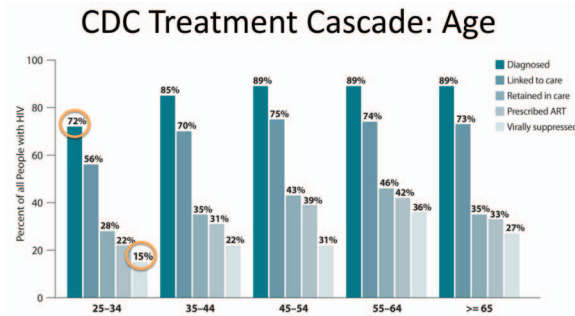
Measure	Numerator	Denominator
HIV Positivity	# HIV positive tests in 12-month period	# HIV tests conducted in 12-mo
Late HIV Diagnosis	# persons with a dx of Stage 3 HIV (AIDS) within 3 mo of dx of HIV infection in 12-mos	# persons with an HIV diagnosis in the 12-mos
Linkage to HIV Medical Care	# who attended a routine HIV medical care visit within 3 months of HIV dx	# who attended a routine HIV medical care visit within 3 mo of HIV dx
Retention in HIV Medical Care	# with an HIV dx and at least 1 HIV medical care visit in each 6 mo period of the 24 mo measurement period, with a minimum of 60 days between the 1 <sup>st</sup> medical visit in the prior 6 mo period and the last medical visit in the subsequent 6 mo period	# with an HIV diagnosis with at least 1 HIV medical care visit in the first 6 mo of the 24-mo measurement period
Antiretroviral Therapy (ART)	# with an HIV dx who are prescribed ART in 12 months	# with an HIV diagnosis with ≥ 1 HIV medical care visit in 12 mo
Viral Load Suppression	# with HIV diagnosis with a viral load <200 copies/mL at last test in the 12-month period	# with HIV diagnosis who had at least one HIV medical care visit in the 12-months
Housing Status	# with HIV diagnosis who were homeless or unstably housed in the 12-month period	# with HIV diagnosis receiving HIV services in the last 12 months

Source: Institute of Medicine. Monitoring HIV Care in the United States: Indicators and Data Systems. Washington, D.C.: The National Academies Press; 2012.

Source: Forsyth A. Secretary Sebelius approves indicators for monitoring HHS-funded HIV services. 2012 August 8. Available from: <http://blog.aids.gov/2012/08/secretary-sebelius-approves-indicators-for-monitoring-hhs-funded-hiv-services.html>.

### Challenge 3: Cascades Differ by Context

Disparities in HIV-related health outcomes and the use of health services become apparent when treatment cascades are broken down by race, age, or risk factor. One cascade does not fit all. Graphs describing the treatment cascade at state and local levels are needed to better understand where the gaps in care lie.



Source: Centers for Disease Control and Prevention. Key graphics from CDC analysis showing proportion of people engaged in each of the five main stages of HIV care [Internet]. 2012 July 27 (cited 2013 April 1). Available from: <http://www.cdc.gov/nchstp/newsroom/2012/Continuum-of-Care-Graphics.html>.

The federal government, through the CDC or another HHS agency, should provide resources and guidance to assist state and local jurisdictions in creating their own care cascades.

Disaggregated cascade data will be more useful:

- Use cascade to monitor specific targeted populations over time: race/ethnicity, age, risk, gender.
- Use local outcomes to build cascades of geographic areas: states, local jurisdictions, clinics, zip codes, census tracts.
- Use cascade to educate and advocate for better continuity of care and treatment success.

### Challenge 4: Implementation Barriers

There are significant barriers to each step in the treatment cascade and, for many, effective interventions to address them are unknown. This points to the need for an implementation science research agenda to identify and address these barriers and identify successful means of overcoming them. Dr. Thompson provided examples of challenges in each step of the cascade as described in the table below.

<b>Social determinants affecting each point in the cascade</b>	<ul style="list-style-type: none"> <li>• Stigma and discrimination</li> <li>• Racism, sexism, homophobia</li> <li>• Poverty</li> <li>• Risk of criminalization</li> <li>• High incarceration rates and difficulty with transition</li> <li>• Housing instability</li> <li>• Employment instability</li> <li>• Coexisting conditions: substance use, mental health disorders</li> </ul>
<b>HIV testing challenges</b>	<ul style="list-style-type: none"> <li>• Testing must be free and accessible</li> <li>• Stigma deters testing <ul style="list-style-type: none"> <li>– Fear of loss of job, loss of insurance, or increased premiums</li> <li>– Pre-existing conditions until ACA implementation</li> <li>– Rejection by family and friends, effect on children, social ostracizing</li> <li>– Domestic violence</li> </ul> </li> <li>• Mixed messages: high-impact (targeted) testing vs. “know your status”; funding streams dictate testing availability</li> <li>• Home HIV testing: not inexpensive; how to track numbers and linkage</li> <li>• Fourth generation Ag/Ab testing will bring about increased need for surveillance and services for acute infection</li> </ul>
<b>Linkage and retention challenges</b>	<ul style="list-style-type: none"> <li>• Barriers include Ryan White eligibility requirements for low-income populations <ul style="list-style-type: none"> <li>– Identity, income, residency, HIV status</li> </ul> </li> <li>• Transportation, child care</li> <li>• Clinics only open when patients are at work; taking off work costs money, risks job</li> <li>• Comorbidities require seeing different doctors</li> <li>• Frequent doctor visits = disclosure</li> <li>• Co-pays</li> <li>• Other life priorities, lack of education about why care is important</li> <li>• Depression, substance use disorders</li> </ul>
<b>ARV and viral-suppression challenges</b>	<ul style="list-style-type: none"> <li>• Fear of toxicity</li> <li>• Cost: high co-pays, high deductibles, Medicare “donut hole”</li> <li>• Meds = disclosure</li> <li>• Drugs for comorbidities</li> <li>• Potential drug interactions</li> <li>• Lack of education about benefits</li> </ul>

Additional challenges do not fall within the confines of the treatment cascade. For example, HIV-related opportunistic infections remain a serious problem, especially given the large number of people who enter care at later stages of HIV disease. Yet, surveillance systems are lacking to track these infections and to better understand how to address them. Comorbidities such as addiction, diabetes, and viral hepatitis present a big challenge. Patients with heart conditions or HCV are not treated at Ryan White clinics, presenting difficulties for patients who have to seek out multiple doctors and facilities as well as deal with complex treatment regimens and toxicity management.

### ***Challenge 5: How the ACA Affects the Treatment Cascade***

While the ACA will expand access of care for many, several challenges will still remain for patients as they try to access care. The ACA may help make premiums more affordable, but many patients will still be left with high deductibles and co-pays that they cannot afford and that could lead to inconsistent drug access, interrupted treatment, and avoidable progression to illness. Substance use treatment and mental health services may only be minimally covered. Transportation, case management, and other support services may be not covered at all. As we make the transition away from health services provided through Ryan White–funded clinics, many concerns remain unaddressed. Many existing Ryan White clinics are likely not prepared or structured to file for and receive insurance payments. Co-pays and deductibles now paid by state Ryan White funds may not be covered for ACA plans. Undocumented people, who now are able to receive health services through Ryan White clinics, will not be able to receive care through Medicaid expansion. Traditional health insurance often does not provide wrap-around services. Will Ryan White funding still be available to provide these critical enabling services that patients depend on?

Dr. Thompson recommended several areas for further research:

- Operational research to optimize/standardize measurement
- Comparative evaluation of monitoring strategies in conjunction with intervention studies
- Comparison of retention measures with one another
- Comparative evaluation of case management in community settings
- Comparative evaluation and cost-effectiveness for best practices for implementation of case-management interventions
- Comparative evaluation of other intervention approaches: peer support, patient navigation, health literacy, life skills
- Prospective evaluation of pay-for-performance interventions

## **What Can Implementation Science Tell Us About How to Fill the Gaps in the HIV Prevention- and Treatment Cascade?**

Dr. Bruce Schackman of Weill Cornell Medical College discussed how implementation science could help us in better understanding how to improve HIV service delivery.

Implementation science is the study of methods to promote the integration of research findings and evidence-based interventions into health care policy and practice and hence to improve the quality and effectiveness of health services and care. While these objectives may seem similar to program monitoring and evaluation—to understand what is working well and what is not working well—monitoring and evaluation focuses on measuring services provided, while implementation science uses scientific rigor to understand the etiology of gaps between expected results and observed outcomes, and develops metrics and models to fill those gaps most effectively and efficiently.

The origins of implementation science include operations research, industrial engineering, and management science. Today, implementation science encompasses a broader range of methods and skills including decision science and operations research, health systems research, health outcomes research, health and behavioral economics, epidemiology, statistics, organization and management science, finance, policy analysis, anthropology, sociology, and ethics. Examples of HIV-related implementation science research include studies of how to optimize prevention of mother-to-child transmission of HIV, male circumcision, syringe distribution, and treatment of drug users with antiretroviral therapy and opioid substitution therapy. For implementation science to become an established field in HIV/AIDS research, there needs to be better coordination between funders of research and funders of program delivery and greater consensus on scientific research approaches and standards of evidence.

As a newly emerging field, implementation science as well as its definition and the type of research it encompasses may vary according to setting and sponsor. However, the intent of implementation science and related research is to investigate and address major bottlenecks (e.g., social, behavioral, economic, management) that impede effective implementation, test new approaches to improve health programming, as well as determine a causal relationship between the intervention and its impact.

### ***Examples of implementation science***

- Comparisons of multiple evidence-based interventions
- Identification of strategies to encourage provision and use of effective health services
- Identification of strategies to promote the integration of evidence into policy and program decisions
- Appropriate adaptation of interventions according to population and setting
- Identification of approaches to scale up effective interventions
- Development of innovative approaches to improve health care delivery
- Conducting of impact evaluations for population-based interventions

### **Examples of research funded by the NIH**

- Implementation of evidence-based early detection of cancer through African American churches
- Testing of an organizational implementation strategy in children's mental health
- Implementation science to increase use of evidence-based pediatric brain injury guidelines

### **Examples of global health research funded by the WHO and PEPFAR**

- Implementation of a rapid test and same-day treatment to prevent congenital syphilis
- Effectiveness of prevention of mother-to-child HIV transmission programs in Africa (PEARL).<sup>6</sup> Randomized clinical trials (RCTs) are not always the ideal way to rigorously identify the best method of implementing an intervention already known to be effective. While RCTs measure *efficacy* in (often) academic settings, implementation science can measure *effectiveness* in real-world ones. Thus "quasi-experimental studies" can also be useful across a full range of methods, including:
  - Experimental and quasi-experimental studies
    - Cluster-randomized trials
    - Comparisons of intervention "packages"
  - State-transition and agent-based simulation models
    - Feasibility and efficiency
    - Cost-effectiveness
  - Qualitative methods
    - Focus groups and surveys
  - Quality improvement
    - Fidelity assessments
    - Continuous process-improvement designs

The challenges in successful implementation science research include insufficient coordination between funders of research and funders of delivery—who owns implementation science? The research requires interdisciplinary collaboration, which can result in a lack of consensus on scientific approaches. There are often different expectations between researchers and implementers about *validity* and *generalizability*. While researchers want a high degree of certainty, implementers may be more interested in reducing uncertainty. Similarly, researchers often want broad generalizability, while generalizability may not be a priority for implementers.

Initially, the PEPFAR budget included no funding for evaluation or implementation science research. However, funding was made available, and PEPFAR is now supporting several studies. Similar work could be funded through the Ryan White programs, CDC prevention networks, or other mechanisms.

Dr. Schackman then discussed cost-effectiveness research. He noted that cost-effectiveness is not same as cost-savings. Being effective does not necessarily save money, but instead is focused on value for money. After all, it is good if people live longer and doing so is cost-effective (yet they will incur greater health costs). Cost-effectiveness analysis is about comparative assessment of worth. Many

health interventions are not cost-saving, but they are cost-effective. Cost-effectiveness is evaluated from the societal perspective. Cost-effectiveness analysis does not directly address the cost impact on specific budgets.

A few examples of recent research were described. One involved the cost-effectiveness of PrEP among MSM in Kenya. Although using PrEP in a larger population of MSM with lower incidence would be very expensive and might not be cost-effective in relation to the number of infections averted, if a population with higher incidence can be identified, then PrEP can be targeted to this group and could be cost-effective.

Another example involved the use of generic regimens in U.S. The study found that a switch to a generic first-line ARV regimen would result in substantial savings. However, the switch to the generic regimen, which might involve moving from a single pill once daily to several pills, might result in poorer adherence. Although the risks to individuals were deemed minor, the study raises an important question about whether it is worth the individual risk to save a great deal of money that could then be used to put more people on treatment and to expand HIV prevention and testing efforts. Addressing these issues is further complicated by the fact that economic savings will vary among payers (e.g., state ADAPs vs. state Medicaid programs or the Department of Veterans Affairs), and there is no guarantee that the money saved would be reinvested in HIV programming.

### ***Who should fund the domestic HIV implementation science research agenda?***

The NIH will have a role in helping to identify methods. But the NIH does not deliver services; its expertise in this area is limited. HRSA and the CDC may be more amenable to supporting this work. Ryan White and other mechanisms could support this research, as in theory could ACA implementing bodies.

Investigation into health-services delivery is certainly important. But so is research into the effectiveness of community-based support services. Communities need to participate in the development and implementation of this research as it moves forward.

The development, with integral community participation, of an implementation science research agenda to address the continuum of HIV prevention, treatment, and care and to optimize services and interventions to end the domestic AIDS epidemic, is a key recommendation to emerge from this meeting.



## How Could a Strategic Investment Framework Be Applied to the U.S. HIV Epidemic to Improve Outcomes and Lower Costs?

David Barr, substituting for Dr. Bernhard Schwartländer of UNAIDS, described the HIV investment framework,<sup>7</sup> which focused on lower- and middle-income countries. However, this framework is also applicable in the U.S., and much of the language from this investment framework has already been adopted into U.S. government policy as seen in the recent *PEPFAR Blueprint* as well as in the NHAS.

The investment framework proposes to move from a commodity-based approach to HIV spending, and instead reallocate resources to specific activities that are proven most effective, adapting these activities to the specific contexts at country levels—i.e., place more funding into syringe exchange and opioid substitution therapy in countries where injecting drug users (IDUs) have a high HIV burden. By increasing investments now and targeting them appropriately, it would be possible to meet the 2015 targets agreed to by UN member states in 2011 and provide cost savings by 2020. These targets include 15 million people on ART, a 50 percent reduction in sexual transmission, and the elimination of vertical (mother-to-child) transmission.

The investment framework provides a structure for reallocation of resources to six basic program activities, selected because of their proven effectiveness. They are:

- Treatment, care, and support
- Vertical-transmission prevention
- Condom procurement and distribution
- Key-populations programs (MSM, IDUs, sex workers)
- Male circumcision (where appropriate)
- Behavior-change programs

The investment framework describes additional critical enabler activities that require funding to ensure a sustainable environment in which the basic activities can be effective, including:

**Social Enablers**, to make possible environments conducive to sound AIDS responses, including:

- Outreach for HIV screening
- Linkage from testing to care
- Treatment literacy
- Stigma reduction
- Advocacy to protect human rights
- Monitoring of the equity and quality of program access and results

**Program Enablers**, to create demand for and help improve the performance of key interventions, including:

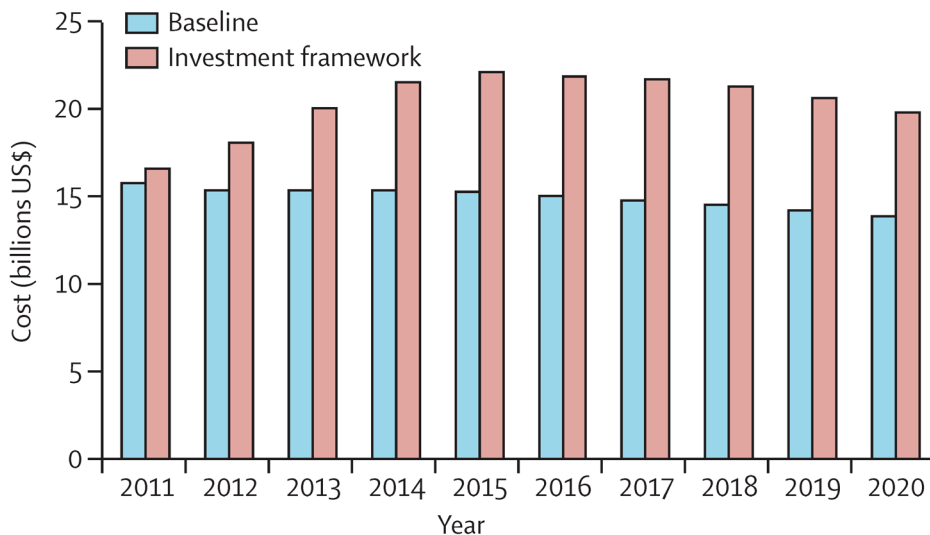
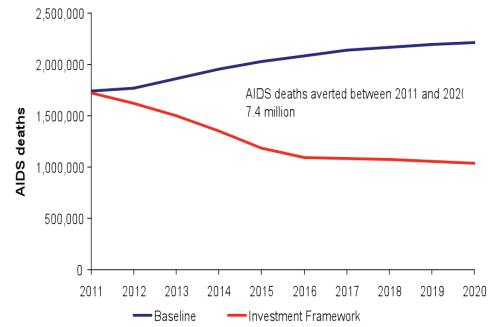
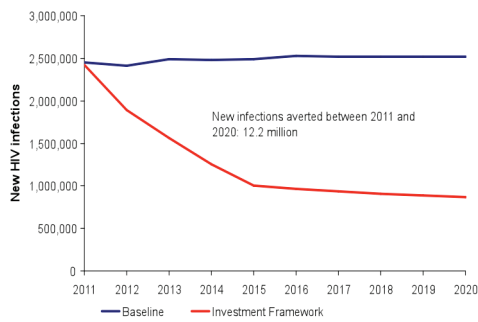
- Incentives for engagement in health services
- Methods for improving retention on ART
- Capacity-building for CBO development
- Strategic planning
- Communications infrastructure
- Information dissemination
- Efforts to improve service integration and linkages from testing to care

A third category of investment focuses on social-, economic-, and health-development activities that are both affected by HIV and which HIV itself affects. The investment framework identifies an appropriate percentage of these costs to be included within an HIV budget. For example, gender-based violence affects HIV outcomes and vice versa. The investment framework attempts to determine what percentage of funding for gender-based violence should be included AIDS-specific budgets. Some such areas are:

- Health systems and multiple health issues
- Gender-equality efforts
- Education and justice sectors
- Social protection and welfare
- Food security
- Community systems
- Housing

Community mobilization is primary in the investment framework. Community-driven outreach and engagement connect people facing similar issues and engage them in HIV-related interventions. Community-based support activities enhance quality of life and adherence, and increase the numbers of people on treatment, engaged in harm reduction or drug treatment services, or using sexual- and reproductive-health services. CBOs have a key role in advocacy, transparency, and accountability efforts at national and local levels to ensure that high-quality health services are available and accessible to everyone. Finally, the investment framework is rooted in ensuring rights-based approaches to service delivery, which require community participation and oversight.

The investment framework estimates that a relatively modest yearly increase of resources peaking at 2015 would produce dramatic results as described in the figures below. Conversely, reduced or flat funding would lead to not only increased infection rates and AIDS deaths, but increased costs as well. The most cost-effective step governments can take now is to invest more in the most effective interventions against HIV.



Source: Schwartländer B, Stover J, Hallett T, et al.; Investment Framework Study Group. Towards an improved investment approach for an effective response to HIV/AIDS. *Lancet*. 2011 Jun 11;377(9782):2031–41. doi: 10.1016/S0140-6736(11)60702-2. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/21641026>. (Accessed 2013 March 26)

Participants then discussed whether and how the investment framework might be applied in the U.S. The current NHAS runs only through 2015. The investment framework projects dramatic results globally by 2015, but cost savings are not realized until 2020. One key component in revitalizing the NHAS will be to plan over a longer period of time to put the epidemic on the road to the endgame and to better see a return on the investment. One challenge in applying the investment framework to the U.S. is the diverse systems with programmatic responsibility and which cover different costs, including a large private sector component. Another key issue in the U.S. is that ARV drugs costs are much higher than in lower- and middle-income countries.

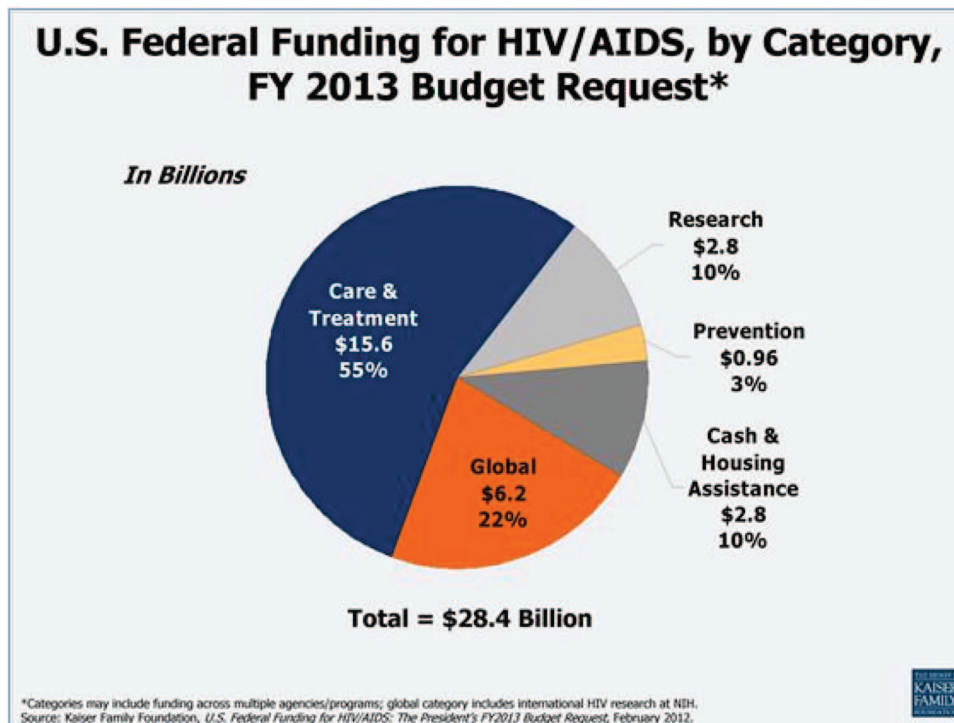
Whatever the evolving mix of federal, state, local, private-sector, and nonprofit service provision, all must commit to supporting the critical enabling services. Despite the broad embrace of the investment framework by UNAIDS, the Global Fund, and many governments including Tanzania, South Africa, and China, there has been no attempt to ensure adequate funding of these services.

In the U.S., however, there is already a structure for this that could be used. Critical enablers are or could be part of Ryan White. As activists, educators, researchers, and public health officials, we need to make the case for why this set of critical enablers—and funding for them—is critical in order for the ACA to succeed and to reverse the HIV pandemic.

## Domestic Investments in HIV Prevention and Care: Where Is the Money Going? Where Should It Be Going?

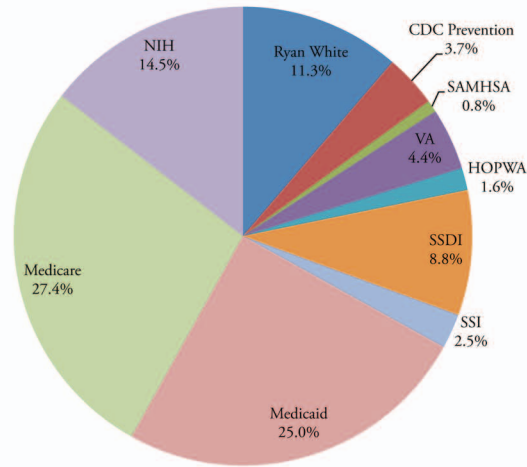
Chris Collins, director of public policy at amfAR, provided an overview on current domestic spending for HIV prevention, treatment, and care, and how that spending will change over the coming years. Accurate tracking of the U.S. domestic expenditures for HIV is difficult given the diverse group of funding sources—these include multiple sources within the federal government, state government contributions, the large and diverse private-sector insurance coverage, and philanthropy.

The majority (55%) of U.S. federal funding for HIV is spent on treatment and care, with a much smaller share (3%) allocated for prevention. Most spending on treatment covers the costs of antiretroviral drugs, which cost far more in the U.S. than anywhere else in the world. More than half of U.S. government HIV funding is provided through Medicaid and Medicare programs. The CDC funds most of the prevention efforts. Critical enabling services, a small part of the U.S. budget, are provided primarily through Ryan White and SAMHSA, with other agencies providing smaller amounts of resources.



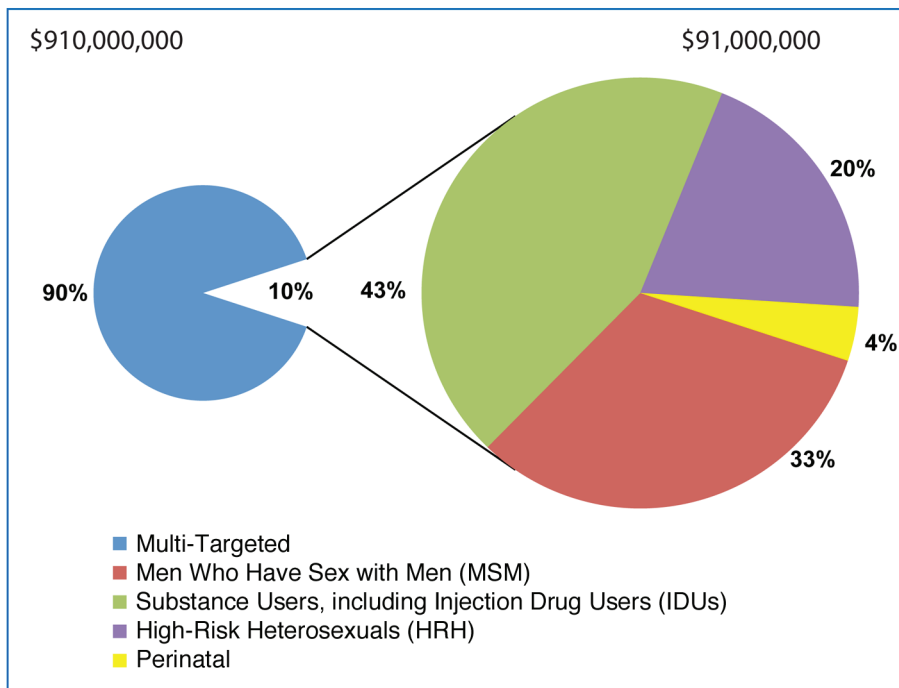
Source: Kaiser Family Foundation. U.S. federal funding for HIV/AIDS: The president's FY2013 budget request. 2012 February. Available from: <http://www.kff.org/hiv/aids/upload/7029-08.pdf>.

## Federal Funding – Domestic HIV/AIDS, FY 2012



Source: Department of Health and Human Services. HHS operational plan: achieving the vision of the national HIV/AIDS strategy. Washington, D.C.: Department of Health and Human Services; 2011 February. Available from: <http://aids.gov/federal-resources/national-hiv-aids-strategy/nhas-operational-plan-hhs.pdf>.

## FY 2010 CDC, SAMHSA, IHS, and OS HIV/AIDS Funding



Source: Department of Health and Human Services. HHS operational plan: achieving the vision of the national HIV/AIDS strategy. Washington, D.C.: Department of Health and Human Services; 2011 February. Available from: <http://aids.gov/federal-resources/national-hiv-aids-strategy/nhas-operational-plan-hhs.pdf>.

Despite substantial federal investment, funding is not getting to where it is most needed. The figure above illustrates combined allocations targeting key populations. Funding is also geographically disproportionate, with areas of higher incidence and prevalence—primarily the South—often receiving inadequate funding. Reallocation of funding to better target those at greatest risk and provide a focus on evidenced-based, high-priority interventions, especially treatment scale up can achieve better health outcomes and reduce new HIV infection rates. The CDC has stated that it is now revising prevention allocations to states and cities to better focus resources where they are most needed, and is placing a greater focus on viral load as a key baseline measure. The scope of these reallocations remains to be seen.

The U.S. government has already adopted many of the values of the investment framework in its global programs and has developed models showing what could happen if activities were scaled up using it. The recently published *PEPFAR Blueprint* shows modeling indicating likely impact on HIV incidence. Overall, PEPFAR does a better job at generating data and identifying effective models of service delivery than the U.S. government does for domestic programs. There is a need to replicate these efforts domestically.

Several studies now have found that domestic HIV prevention resources can be most effective when services focus on MSM and IDUs for screening, and behavioral interventions (a.k.a. “prevention for positives”) for people living with HIV.<sup>8</sup> A model from Philadelphia found that testing MSM in nonclinical settings was particularly cost-effective, followed by adherence support and screening in clinical settings. The least cost-effective intervention was behavioral modification among the general HIV-uninfected population. Multiple models and studies suggest that the most effective course of action would be to increase funding for prevention targeting MSM and African Americans, with a focus on scaling up testing, treatment, adherence support, and education for people living with HIV.

Data indicate that incidence is falling in Massachusetts and in San Francisco. The common denominators include: universal access to and expanded uptake of health care; health care provided in ways that are respectful of the needs of affected populations; support for critical enabling services such as housing, nutrition, transportation, mental health, and supportive environments; and collaboration among public health, academic, provider, and community actors. Both settings have also moved toward a more targeted prevention focus. Details about Massachusetts are included below in the presentation from Rebecca Haag.

## **How the ACA and Medicaid Expansion Affect the Provision of HIV Service Delivery**

Dr. Julia Hidalgo, of George Washington University, discussed the impact of ACA implementation and Medicaid expansion on the provision of HIV service delivery.<sup>9</sup> Some of these changes have already or are now taking place, including:

### ***Coverage changes***

- Expanded Medicaid coverage for childless adults with income up to 138 percent of the federal poverty level (FPL), with eight states expanding coverage
- Established Preexisting Condition Insurance Plans (PCIPs)
- Extended dependent coverage for adult children up to 26 years of age

### ***Health benefit changes***

- Prohibited individual and group health plans from placing lifetime limits on coverage, rescinding coverage, and denying children coverage due to pre-existing medical conditions
- New health plans must provide:
  - Prevention services with an A or B rating by the U.S. Preventive Services Task Force (USPSTF) for free, including HIV screening for individuals at high risk
  - Free coverage for certain women’s preventive services such as annual HIV counseling and screening for all sexually active women
  - Financial incentives to Medicaid programs offering coverage with no cost-sharing for preventive services rated A or B by the USPSTF

### ***Health care systems redesign***

- New Medicaid state option for beneficiaries with chronic conditions to designate a provider as a medical home, with HIV added recently as a designated condition
- Grants awarded to design person-centered models coordinating services to Medicaid/Medicare dual-eligibles

### ***Payment systems***

- Medicaid payments to primary care doctors will increase to 100 percent of the Medicare payment rates
- Increased funding for federally qualified health centers (FQHCs) and planning grants for agencies seeking to become federally qualified

Changes that will take effect in 2014 include:

### **Coverage changes**

- Expanded Medicaid coverage for most individuals with incomes up to 138 percent of the federal poverty level (FPL), with 100 percent of federal funding from 2014 to 2016 and stepwise decreases in 2017 and onward
- Creates state-based Marketplaces and Small Business Health Options Program Exchanges through which coverage can be purchased
- Provides refundable and advanceable tax credits and cost-sharing subsidies to eligible individuals
- Prohibits pre-existing condition exclusions in issuing and renewing health insurance
- Prohibits annual limits on the dollar value of coverage
- Requires U.S. citizens and legal residents to have qualifying health coverage and a phased-in tax penalty for individuals without coverage

### **Health benefit changes**

- Creates a Basic Health Plan (BHP) for uninsured individuals with incomes of 138 percent to 200 percent of the FPL who are eligible to receive premium subsidies
- Health plans in the individual and small group markets, Medicaid benchmark and equivalent packages, and the BHP must include an essential health benefits package

The ACA requires coverage for a set of minimum essential health benefits, many of which affect HIV, many of which are currently covered through Ryan White HIV/AIDS–funded programs. It remains to be seen if and how the Ryan White HIV/AIDS Program will continue to provide resources for these services. The ACA also mandates the development of “medical homes” that will also affect HIV care delivery. In a medical home, a provider or group of providers is responsible for coordinating a given patient’s care, with some kind of financial incentive to do so.

Components include:

- **Personal physician**, for continuous, comprehensive care;
- **Physician-directed medical practice**, where the physician leads a team of individuals at the practice level, who together take responsibility for ongoing care;
- **Whole person orientation**, where the physician is responsible for all of the patient’s health care needs or arranges care with other qualified professionals;
- **Coordination and/or integration of care** across all elements of the health care system and community (e.g., family, public, and private community-based services);
- **Quality and safety** achieved through accountability, evidence-based medicine, decision support tools, and other mechanisms;
- **Enhanced access** to care; and
- **Payment** that appropriately recognizes the added value provided to patients.



About 50 percent of state Medicaid programs have initiated some form of medical-home programs. Funding for case management and other costs to develop more comprehensive programs is also available through the ACA. An enhanced federal match is offered for services that provide the glue to coordinate care, including:

- Comprehensive care management, care coordination, and health promotion;
- Comprehensive transitional care from inpatient to other settings, including appropriate follow-up;
- Patient and family support;
- Referral to community and social support services; and
- Health information technology to link services.

HIV is not the foremost concern of state policy makers, health-exchange panels, Medicaid program staff, and insurers. There will be significant variability in state-level coverage, benefits, and payment systems. The HIV community must organize and mobilize to ensure that HIV-positive beneficiaries' needs are met. Many people with HIV and their family members will need significant help in choosing the insurance plan that best meets their needs.

The essential health benefits package for people with HIV is likely to vary considerably geographically and by public- and commercial systems, insured population, insurer, and service-delivery systems (e.g., fee-for-service or managed care). Managed care service delivery and payment models are likely to be adopted. Many HIV programs are likely to be unfamiliar with these models, may not participate in insurance plans, and may not have staff sufficiently credentialed to serve as providers. HIV clinical and support providers must learn to market their services to ensure they have a role in HIV care delivery.

HIV clinical providers are likely to be insufficiently reimbursed for their services unless the Ryan White HIV/AIDS Program funds are used for balanced billing. Sexually transmitted infection (STI), tuberculosis (TB), family planning, and other public health systems will experience significant pressure to integrate in the broader health care financing system. Roles for CBOs may be available, but will need to be defined and marketed to health care plans and insurers.

Other key considerations include:

- Ensuring access to HIV screening, medication education, treatment adherence, PrEP, and health education and risk reduction (HERR) will be challenging unless financial incentives are in play;
- The prevention-with-positives paradigm may be unsustainable in a new financing and delivery system;
- Access to HIV-experienced providers may be decreased;
- Medication benefits may not be sufficiently covered;
- Physical- and behavioral-service payment systems may be implemented separately;
- Access to HIV care in rural areas will continue to be limited;
- Violations of ACA protections are likely and must be documented;
- The ACA does not address the need for equity and transportability of health insurance benefits when HIV-positive individuals move to another state; and
- Application of HIV quality measures and improvement processes to public and commercial health insurance systems will be challenging.

## STATE-LEVEL ACTION – PROGRAMS AND ADVOCACY PANEL DISCUSSION

*Sonia Rastogi, U.S. Positive Women’s Network, Oakland, California*

Ms. Rastogi discussed the impact of trauma on HIV care for women. HIV is concentrated among African American women, particularly those in the South. The HIV health outcomes for these women are also considerably worse than average, with shorter life expectancy and a higher rate of AIDS-defining illnesses. These women tend to find out about their HIV status late in the course of their disease.

Contributing to these disparities are the high rates of violence, childhood sexual and physical abuse, and post-traumatic stress disorder that many women face. These rates are higher among women living with HIV. Research has shown a clear link between trauma from violence and abuse and increased risk of HIV infection and poorer outcomes in care among those who have experienced trauma.

Rastogi offered several recommendations for an amended NHAS to address the dual issues of trauma and HIV:

- Identify, support, and resource trauma-informed demonstration projects that address violence against women and the impact of trauma in women’s lives;
- Identify emerging, and bolster existing, advocacy and policy efforts that combat the structural root causes that put all women at risk for HIV in the first place;
- Identify and craft strategic entry points into the ACA and Medicaid expansion for the Ryan White HIV/AIDS Program—model to be adapted into primary care and care for chronic diseases; and
- Invest in research, including:
  - female-initiated and female-controlled prevention options;
  - understanding the physiological impacts of trauma;
  - understanding the hidden health care costs of stigma (how much are we spending on health care that does not recognize or address stigma); and
  - operational science and implementation science (opportunity to build from the ground level).

***Chris Norwood, Health People, Bronx, New York***

Community-based advocacy service delivery has been essential to a successful HIV response since the beginning of the epidemic. Community-based service-delivery and advocacy remain essential to ensuring increased demand for and effective, sustainable use of health services.

Health People has invested in the development of peer-support programs since its inception. These approaches are one of the important outcomes from the AIDS movement. Not only are they effective in HIV care, but they are now used to address a diverse array of health needs including in people with diabetes, asthma, and obesity.

Resources for these services are increasingly hard to come by. While the ACA will enable more people to access health care, it will not provide the resources needed for these critical enabling services. This can and should be the function of continued Ryan White HIV/AIDS Program support.

In order for peer-based services to be effective, people need training, access to up-to-date information, and supervision. Determining the most effective use of peer-based services is an important avenue for further research. The entire area has been under-evaluated and underresearched.

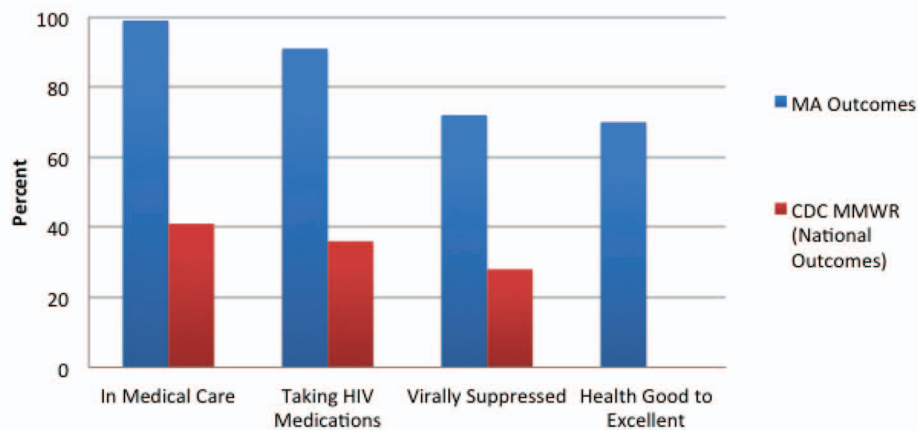
**Rebecca Haag, AIDS Action Committee, Boston, Massachusetts**

Reform of the Massachusetts health care systems provides an important model for achieving successful HIV outcomes if the political will exists to do so. The following reforms were enacted in Massachusetts:

- Expanded Medicaid coverage to pre-disabled people living with HIV with an income up to 200 percent of the FPL (2001)
- Enacted private health insurance reform (“Romneycare”) with a heavily subsidized insurance plan for those with income up to 300 percent of the FPL (2006)
- More ADAP funding spent on insurance than on prescription drugs, while maintaining unrestricted formulary and 500 percent of the FPL eligibility (2006)
- Waiver from the Ryan White HIV/AIDS Program’s 75 core medical/25 support service rule supporting ability to provide necessary services (2007)

These reforms produced much better health outcomes than the contemporaneous national data:

**MA Outcomes vs. National Outcomes**

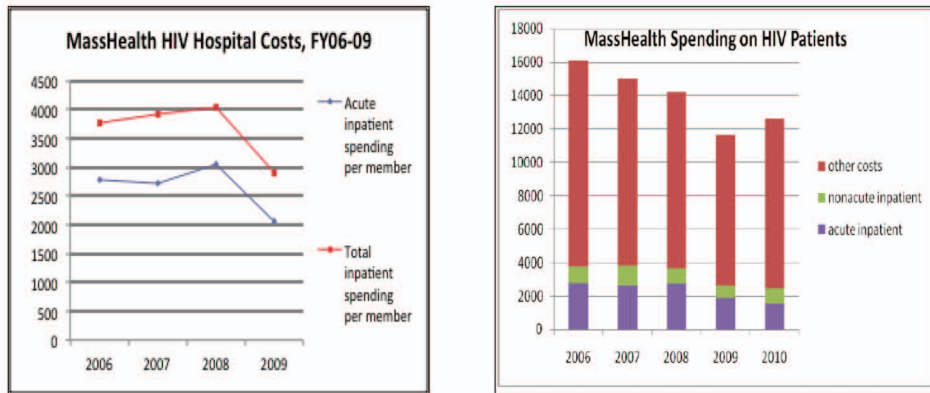


- Between 2006 and 2009, Massachusetts new HIV diagnosis rates fell by 25 percent compared to a two percent national increase.
- Current Massachusetts new HIV diagnosis rates fell by more than 50 percent.
- Between 2002 and 2008, Massachusetts AIDS mortality rates decreased by 44 percent compared with 33 percent nationally; Massachusetts cost per Medicaid beneficiary living with HIV has decreased, particularly the amount spent on inpatient hospital care.
- The Massachusetts Department of Public Health estimates that reforms reduced HIV health care expenditures by approximately \$1.5 billion.

Source: JSI Research and Training, Inc. Massachusetts and southern New Hampshire HIV/AIDS consumer study final report. 2011 December.

Source: Centers for Disease Control and Prevention (CDC). Vital signs: HIV prevention through care and treatment—United States. MMWR Morb Mortal Wkly Rep. 2011 Dec 2;60(47):1618–23.

## Massachusetts Reform Demonstrates Successful Implementation, Reduces Costs



Source: Massachusetts Office of Medicaid. Data request from Robert Greenwald.

The steps taken in Massachusetts show that it is possible to surpass NHAS goals, yet doing so requires decisive action. The key step in Massachusetts—getting HIV covered under the Medicaid program—happened because of activism and the use of political power. As a result of this work, 95 percent of people living with HIV in the state are in some stage of HIV care. Problems still exist: syringe exchange is not fully covered. The success in lowering incidence has led the CDC to reduce funding to the state, thus jeopardizing sustainability. Strong HIV-specific advocacy has led to imbalances in service provision—people living with HIV may be eligible for more or better services than people with other health conditions.

Today, in the U.S., HIV is about “invisible” people; poor people; sexual, ethnic, and racial minorities; women; immigrants; and those who are undocumented, discriminated against, and otherwise marginalized. HIV continues because of this. In the U.S., it is about people who do not count. We will never stop HIV unless we address the needs of these people. We need to find sources of money. The ACA offers a way to get people into the system to help them and their families stay healthy. We must engage them in the system. It is essential for the HIV community to understand health financing, but it may be unrealistic to expect community groups as they currently exist to be able to handle complicated financial issues—these are mostly small groups that cannot invest in the adequate systems.

## BREAK-OUT GROUP REPORTS AND RECOMMENDATIONS

Each break-out group was given a set of questions and issues to address.

### Implementation science research agenda

- What is the value of implementation science for advocates and community-based providers?
- Identify key questions to address leaks in the HIV treatment cascade and implement combination preventions approaches.
- How can the impact of social support services and community mobilization on HIV health outcomes and prevention be measured?
- Identify strategies to ensure the development and implementation of the research agenda.

There was strong agreement among the participants of a need for and value to the development of and investment in an implementation science research agenda. The outcomes from this research will not only improve health outcomes and use of health services, but will serve as an important advocacy tool. A key recommendation emerging from the meeting is a follow-up meeting specifically focused on the development of this agenda. TAG will organize the first discussion in spring 2013.

Implementation science is seen as a key tool in better understanding how to address the gaps in the treatment cascade, implementing combination prevention approaches, and addressing the social determinants that affect the HIV response. The development of this research now will align with the staged implementation of the ACA and Medicaid expansion. The work will also be a key tool in advocating for continued resources and critical enabler support through the Ryan White HIV/AIDS Program. The participation of affected communities in the development and implementation of this research is essential.

We need to understand better how both needs and effective strategies differ within different contexts. Some factors to consider include:

- Disease burden within a community, city and state;
- Demographics of those affected, including race, gender, age, sexual orientation, socioeconomic status, geographic location, and incarceration- and immigration status;
- Structure of the state's health care delivery and financing; and
- Capacity of both the health systems and the community to provide services.

Some priority issues that should be addressed through implementation science research include:

- Understanding the motivators that both increase demand for HIV services and help to retain people in care over the long term;
- Research allocations for work focused on MSM are well below what is needed, especially given the high rates of HIV in this population;
- The obstacles that keep people from utilizing HIV counseling and testing services;

- Comorbidities and social determinants of health-impact engagement in HIV care and HIV health outcomes;
- The impact of improved coordination among federal agencies on health systems and the use of those systems by patients;
- The impact of community-based support on impact demand for and continued use of health services;
- Which models, including peer-based approaches, are most effective at supporting engagement in and use of health services;
- The contribution of stigma and discrimination to gaps in the treatment cascade and in the effective use of prevention interventions;
- The continued value of behavioral interventions and how these interventions should be integrated with biomedical interventions to prevent HIV transmission and support retention in care; and
- The impact of the structure and selection of health care insurance plans on health outcomes.

The development and implementation of an implementation science research agenda presents many challenges:

- The availability and reliability of data is a significant challenge. It will be important to identify what data are available, what gaps exist and how to fill them;
- Diverse data sets are difficult to harmonize and translate. Moving toward an agreed-to set of indicators and definitions across federal and other governmental agencies; the private sector is a key to better research outcomes;
- The need for more and better data must be tempered by the need to protect patient confidentiality. Conversely, laws protecting patient privacy may interfere with the ability to obtain and utilize needed information to improve services;
- It is unclear where the implementation science research is primarily housed. It is not a traditional function of the NIH. Yet other federal agencies do not have the research capacity necessary to oversee this effort. PEPFAR eventually was able to budget for implementation science and evaluation. Similar funds should be available for NHAS implementation and coordinated through the Office of National AIDS Policy; and
- Similarly, it is unclear how this research will be funded and which agency or agencies are best suited to coordinate the budgeting of this work.

### **Incorporation of new science into prevention and treatment policy and program development**

- What is the potential impact of “treatment as prevention” on community mobilization and outreach efforts?
- How do HIV counseling, testing, and linkage to care need to change to incorporate new data on the prevention impact of earlier HIV treatment?
- What methods of communication are needed to inform affected communities about scientific advances in HIV treatment and prevention?
- How do federal funding and programmatic structures encourage or hinder integration of treatment and combination prevention interventions?

There was strong agreement among the meeting participants that recent scientific advances in our understanding of how to prevent HIV transmission and how to better track the use of treatment provide important opportunities for a drastic reduction in new infections and improved health outcomes. The treatment cascade was seen as a particularly valuable tool as it succinctly captures both the progress and gaps in meeting treatment goals.

One key recommendation from the meeting is devising additional treatment and, if possible, prevention cascades at both state and population levels. These would not only allow all constituents a current snapshot of where we are in meeting NHAS goals and targets, but these cascade models would provide a foundation for developing state-level plans to end HIV, and would provide an essential advocacy tool to push for additional resources.

However, the development of treatment and prevention cascades at state levels and for different populations presents several challenges:

- There are significant gaps in the data necessary to complete treatment cascades at state and population levels. Obtaining the data is one challenge. But in some instances, there are few data to obtain.
- Available data sets are not able to communicate with each other. Indicators measuring similar targets are defined differently by different agencies.
- The need to ensure protection of patient privacy and confidentiality is important and can conflict with the need to obtain complete data about the use of health services.
- The treatment cascade presents a linear view of utilization of care. However, people come in and out of care and change providers. The accuracy of any cascade is difficult to sustain.
- While it is relatively easy to devise a linear cascade for treatment, the development of a prevention cascade is harder to envision.

The prevention impact of HIV treatment is profound. More data are needed to determine the impact that scale-up of treatment is having on incidence. However, treatment alone is not enough to reduce incidence to the levels needed. Combination prevention approaches, including behavioral interventions, condom distribution and use, syringe exchange, opioid substitution therapy, and PrEP are needed to reduce new infection rates to levels that will lead to an end of the HIV epidemic in the U.S. More information is needed about the types of behavioral interventions that are most effective not only in preventing transmission, but in ensuring retention in care and maintaining viral suppression.



The use of treatment as a prevention tool does not end the need for behavioral interventions, but it may change the behavioral approaches that are needed.

A new wave of information dissemination is needed to ensure that all constituencies understand the potential impact of recent scientific advances. Health care providers, donors, administrators, policy makers, support service providers, and especially members of affected communities need information to understand the value of treatment, the increased possibilities of prevention, and the ability to remove the threat of HIV from their communities. Information needs to be provided in formats that people understand. Opportunities to discuss this information are needed. This work presents a new and exciting opportunity to improve health literacy and revitalize discussion within affected communities about HIV and about the role of and relationships within our communities to realize this promise.

However exciting the advances in science, ending AIDS in America requires more than pills and condoms. The social determinants that affect people's ability to use health care, negotiate safer sex and drug use, and adhere to treatment are many. Poverty; lack of opportunity; incarceration; lack of housing, mental health services, and food security; gender-based violence; sexism; racism; homophobia; HIV-related stigma; criminalization of HIV status; and repressive drug and immigration policies are just a few of the many obstacles that impede successful HIV outcomes.

Upcoming reauthorization of the Ryan White HIV/AIDS Treatment Extension Act of 2009 will be a key moment to ensure continued support for critical enabling services. Information about scientific developments and opportunities for progress will be key advocacy tools in this regard.

### Strategic investment of funds at federal, state, and local levels

- What information is needed to develop an HIV investment framework for the U.S.?
- What areas of HIV programming are underfunded and overfunded based on current evidence?
- How can community advocates better assess and monitor current HIV spending at national, state, and local levels?
- What are key strategic approaches to ensure application of evidenced-based funding allocations at state and local levels that will lead to reduced HIV disease and transmission?

The meeting participants saw the use of the investment framework to both track and revise HIV spending at federal, state, and local levels as a useful advocacy tool. Experience in Massachusetts over the past decade shows clearly that universal access can lead to much higher rates of testing, linkage to care, coverage, and treatment success. A common approach is need to get information on state- and federal-level funding streams, including sources and amounts of revenue and how funds are being spent. The speed at which data become available must also be improved.

Recommendations included:

- Development of a web-based tool to track the HIV treatment cascade at state levels to ensure accountability, coordination, and most importantly a clear blueprint to improve health outcomes;
- Support for a state-level strategy that allows state- and local-level health infrastructure to measure outcomes and funding for prevention, care, treatment, and research;
- Advocacy for increased transparency regarding the allocation of funds, service delivery utilization, and outcomes;
- Identification of ways to measure progress on coordination of efforts by federal agencies and between federal and state programs (the fourth pillar of the NHAS);
- Development of evaluation data regarding the impact of critical enabling services (such as housing) on health outcomes to advocate for continued support of these services; and
- Continued funding of critical enabling services through the Ryan White HIV/AIDS Treatment Extension Act.

Dr. Holtgrave reported that an additional \$15 billion is needed to meet the NHAS objectives. However, this amount includes discretionary and entitlement program costs together. Many incremental costs have been built into the ACA implementation plan. Many states have already built into Medicaid the amounts needed for expanding HIV services. Thus, much of the additional money that is needed overall has already been built into plans in the form of entitlement programs. Therefore, advocacy should focus on ensuring that the new services covered under ACA implementation do indeed become a reality, and that the remaining supportive services, housing, and prevention activities are covered by needed discretionary funding. A more sophisticated understanding is required to determine what is needed under entitlement programs and in discretionary programs.

### Continued support for and integration of social support and health services

- What are the roles of social support and community mobilization in increasing demand for and effective use of HIV health services?
- How do federal funding and programmatic structures encourage or hinder integration of treatment and combination prevention interventions?
- As the ACA and Medicaid expansion are implemented, what is the continued role of Ryan White funding?

A more ambitious and strategic NHAS 2.0 is needed with guided long-term, investment-based outcomes (e.g., no new AIDS diagnoses and no new transmissions). A more ambitious NHAS must include expanded opportunities for community mobilization including resources, tools, and strategies. Among the useful items in such a list might be:

- Communications tools to describe the potential and positive outcomes that can be achieved through the ACA and Medicaid expansion, including community-friendly and locally specific ACA navigation guides, a policy guidebook for effective community mobilization and monitoring, and creation of a “story bank” of successes and failures based on human-rights reporting standards;
- Initiation of state-level task forces on service integration and ACA expansion—and on relevant issues associated with the CDC, HRSA, and SAMHSA—that report to an agency within the HHS;
- A similar tool focused on prevention, as a supplement to the treatment cascade;
- Development of state-level plans to end AIDS using the treatment cascade and investment framework as models;
- Formation of alliances with other groups advocating on behalf of chronic health issues such as diabetes, asthma, and hepatitis C;
- Use of NIAID HIV research centers to provide opportunities for expanded care in states that are not open to the possibilities of the ACA and Medicaid expansion;
- Creation of an OAR-like structure to coordinate service delivery to reduce inefficiency across federal agencies;
- Use of the experience and expertise developed by ASOs over the past 30 years in the development of health homes and exchanges. The HIV experience should be considered a model for other health areas;
- Peer-based support. Patient navigation is key to helping people into and through health service systems, accessing information, and following through on health decisions. Peer-based support is one important element and approach to such navigation, but it is not the only approach. The definition of peer-based support should be a broad one, going beyond HIV status;
- Training and technical support. These are essential in building a cadre of community support services that works in partnership with health systems and is able to rapidly incorporate research results into program development; and
- Inclusion of education departments in discussions about and delivery of health literacy services, especially given the high incidence of HIV among young people.

## RECOMMENDATIONS FROM SECOND BREAK-OUT SESSION

Four groups were convened:

- Community organizations and networks
- Federal/national government
- State/local government
- Research

The first three groups focused on the development of three specific recommendations to revitalize and implement the NHAS through the incorporation of new science, improved investment strategies, and new legislation (ACA, Medicaid expansion). The research group was asked to identify 3–5 primary questions that must be answered through clinical trials and implementation science approaches in order to meet the goals of a revitalized NHAS.

### Community organizations and networks

- Encourage the use and adaptation of the cascade model by community-based organizations as a comprehensive tool for mobilizing community members and advocates to set targets and monitor progress at state and local levels.
- Identify the informal and formal networks that exist that are open to coalition-building and partnership. The HIV community should “stop just being HIV” and align more broadly with social justice and human rights movements.
- Improve the understanding of and engagement in research by CBOs.
- Empower new generations of AIDS activists. There is a need to redefine and reinvigorate the role that people living with and directly affected by HIV play in program- and policy development and implementation; empowering new activists is critical.

### State and local government

- Create diverse local ACA implementation models for states that do and do not comply with or accept the ACA and other health reforms. These include health home models and services in the marketplaces with reimbursement for community services and groups.
- Increase and use resources for policy advocacy and mobilization to put bodies on the ground at the local and state levels. Give them the tools they need; and ensure continuity during this transitional time. To do so, communicate aggressively with donors that resources are needed for advocacy.
- Increase access to comprehensive sexuality education inside and outside schools.

### **Federal government**

- Advocate for access to data to track the utilization of services and funding. Develop consistent indicators to track progress across all federal and state agencies.
- Ensure that HIV care is provided to all who need it regardless of immigration status.
- Monitor and evaluate how HIV resources are allocated and recommend reallocations as needed to ensure that funding is targeted to populations most in need and for evidenced-based activities.
- Ensure continued resources through Ryan White, both to ensure a smooth ACA transition and to provide funding for critical enabling services in support of the ACA.

### **Research**

- Organize a community-driven research agenda, incorporating implementation science, clinical trials, and behavioral science and program evaluation to better understand how to implement new scientific advances, improve the uptake and utilization of health, support, and prevention services, and encourage cost-savings and cost-effectiveness.

## NEXT STEPS

Mark Harrington, executive director of TAG, outlined next steps following the meeting. He emphasized the need to advocate for a revised NHAS, as the current document expires in 2015. The time to begin working on that revision is now.

It was suggested that a sign-on letter be drafted and accompany dissemination of this report to build support for the recommendations developed at the meeting.

The development of the research agenda is a high priority for TAG. It was suggested that a first meeting be held in spring 2013. Affected communities will help to set the project agenda. Participants should include research funding agencies, local/state health authorities, and other key stakeholders.

The National Minority AIDS Council (NMAC) will organize a meeting in April to identify effective, community-based service delivery models, develop opportunities and mechanisms to improve understanding of research and health literacy approaches within CBOs, and develop patient navigation approaches. In preparation for that meeting, TAG will undertake a mapping exercise to track current HIV implementation science efforts at the NIH and elsewhere.

AmfAR will organize work defining how to assist state-level organizations in the development of treatment-cascade models to identify needs and monitor progress in their respective states. They will also look for ways to access the necessary data to develop these models.

In January 2013, TAG will hold a preliminary meeting to develop state- and city-level plans to end AIDS in New York State. If advocates and providers are able to get the state government to develop and endorse such a plan and commit the necessary resources to it, this would be a potential model to advocate for in other localities. There could be a common set of toolkits that community groups could develop and share.

Two events were noted at which the issues and recommendations raised at this meeting could be further discussed. One was the Creating Change conference in January 2013. The second was SYNChronicity, HealthHIV's annual national meeting "that prepares individuals and organizations working in HIV and primary care to succeed in the dynamic healthcare environment by syncing systems, programs, models and policies."

Funding is needed to support these efforts moving forward at national, state, and local levels. A meeting with potential donors to discuss the recommendations from this meeting was also suggested. NMAC, amfAR, AIDS United, and TAG agreed to facilitate this meeting.

## CONCLUSION

As David Holtgrave's presentation showed, it is still possible to meet the 2015 goals of reduced HIV incidence and transmission rates as set out in the NHAS. Doing so requires immediate scale-up of HIV testing, treatment, and combination prevention approaches. This would not only serve to meet the NHAS goals, but would also be cost-effective. Although further information is needed to improve implementation, the tools to reach these goals—and go well beyond them—are now available to us. Expanded health care access, intensified integration of community-based and health care services, use of evidenced-based prevention interventions, and scale-up of treatment to maximize viral load suppression will lead to better health outcomes, reduced costs, and lower rates of HIV transmission. The key unanswered question is whether the political will exists to realize this promise.

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APPENDIX

**Revitalizing the U.S. Domestic HIV/AIDS Response:  
New Science and New Approaches to Improve Outcomes and Reduce Costs**

Fairfax Embassy Row  
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December 11–12, 2012

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**Revitalizing the U.S. Domestic HIV/AIDS Response:  
New Science and New Approaches to Improve Outcomes and Reduce Costs**  
December 11–12, 2012  
Washington, D.C.

**Agenda**

DAY 1 – TUESDAY, DECEMBER 11, 2012

9:00–9:15 a.m.	Opening – Introductions
9:15–9:30	Goals/Objectives of the Meeting and Agenda Review Mark Harrington, Treatment Action Group
9:30–9:45	Revitalizing Community-Based Responses to AIDS Kenyon Farrow, The Praxis Project
9:45–10:00	Discussion

**Session 1: Enriching the NHAS with the latest science**

- How do new scientific developments impact the goals, objectives, and strategies of the NHAS?
- Do these scientific advances allow for the development of a more ambitious NHAS?
- Do these advances require a revision in the strategies and priorities of the NHAS?
- How can implementation science be applied to improve service delivery and increase demand?

(Each speaker will present for 15 minutes followed by Q&A)

10:00–10:25	Are We on Track to Achieve the Goals of the NHAS? David Holtgrave, PhD, Johns Hopkins University
10:25–10:50	Creating a Continuum of Care: The HIV Treatment Cascade in the U.S. Melanie Thompson, MD, AIDS Research Consortium of Atlanta
10:50–11:15	What Can Implementation Science Tell Us about How to Fill the Gaps in the Service Continuum (Combination Prevention/Treatment Cascade)? Bruce Schackman, PhD, Weill Cornell Medical College
11:15–11:30	Break
11:30–12:30	Facilitated Discussion

## Session 2: How could a strategic investment framework be applied to the U.S. HIV epidemic to improve outcomes and lower costs?

- Can the global HIV investment framework be adapted and applied to the U.S.?
- How can an HIV investment framework contribute to better targeting domestic HIV programs for improved outcomes?
- Can improving HIV investment strategies support cost reduction in the ACA and Medicaid?

12:30–1:00	How Could an HIV Investment Framework be Applied in the United States? Bernhard Schwartländer, PhD, UNAIDS
1:00–2:00	Lunch
2:00–2:20	Keynote Address: Seeking an End to AIDS in the United States: The Science Base Anthony S. Fauci, MD, NIAID, NIH
2:20–3:00	Q&A – Facilitated Discussion
3:00–3:30	How Will the ACA and Medicaid Expansion Affect the Service Delivery Mix, and What Are the Opportunities to Use These Mechanisms to Optimize HIV Programmatic Success? Julia Hidalgo, PhD, Positive Outcomes
3:30–4:00	Overview of Current U.S. HIV investments and How They Are Changing Chris Collins, amfAR
4:00–4:15	Break

## Session 3: Identifying innovation service delivery approaches

- How have community-based providers and State AIDS programs revised their service delivery strategies and approaches?

4:15–5:15	Panel Presentation: Four program examples of state/local approaches to delivery of treatment, prevention, and support services <ul style="list-style-type: none"><li>• Rebecca Haag – AIDS Action Committee (Boston, MA)</li><li>• Chris Norwood – Health People (Bronx, NY)</li><li>• Sonia Rastogi – WORLD (Oakland, CA)</li><li>• Nicholas Alan Carlisle – AIDS Alabama (Birmingham, AL)</li></ul>
5:15–5:45	Facilitated Discussion
7:00–9:30	Group Dinner (off-site)

## DAY 2 – WEDNESDAY, DECEMBER 12, 2012

9:00–9:30 a.m.	Review from Day One/Break-Out Group Instruction
9:30–10:45	Break-Out Session One
10:45–11:00	Break
11:00–12:00	Break-Out Session Two
12:00–1:00	Lunch
1:00–3:00	Report-Backs and Facilitated Discussion
3:00–3:15	Next Steps/Closing

### **BREAK-OUT GROUPS**

There are two break-out group sessions in the morning on the second day of the meeting. The ultimate goal of the meeting is the development of specific, action-oriented next steps to advance and improve the HIV response in the U.S. through incorporation of new science, better investment strategies, and implementation of the ACA and other legislation that will shape health policy and health care delivery. The recommendations that emerge from this meeting should form the basis for an updated version of the NHAS.

#### ***Session One***

The first session will focus on priority issue identification in the four themes of the meeting. Four groups for the first session are proposed:

1. Incorporation of new science into prevention and treatment policy and program development
2. Strategic investment of funds (including Medicaid expansion/ACA) at federal, state, and local levels
3. Implementation science agenda
4. Continued support for and integration of social support and health services

#### **Incorporation of new science into prevention and treatment policy and program development**

- What is the potential impact of “treatment as prevention” on community mobilization and outreach efforts?
- How do HIV counseling, testing, and linkage to care need to change to incorporate new data on the prevention impact of earlier HIV treatment?
- What methods of communication are needed to inform affected communities about scientific advances in HIV treatment and prevention?
- How do federal funding and programmatic structures encourage or hinder integration of treatment and combination prevention interventions?

## **Strategic investment of funds at federal, state, and local levels**

- What information is needed to develop an HIV investment framework for the U.S.?
- What areas of HIV programming are underfunded and overfunded based on current evidence?
- How can community advocates better assess and monitor current HIV spending at national, state, and local levels?
- What are key strategic approaches to ensure application of evidenced-based funding allocations at state and local levels that will lead to reduced HIV disease and transmission?

## **Implementation science agenda**

- What is the value of implementation science for advocates and community-based providers?
- Identify key questions to address leaks in the HIV treatment cascade and implement combination prevention approaches.
- How can the impact of social support services and community mobilization on HIV health outcomes and prevention be measured?
- Identify strategies to ensure the development and implementation of the research agenda.

## **Continued support for and Integration of social support and health services**

- What is the role of social support and community mobilization in increasing demand for and effective use of HIV health services?
- How do federal funding and programmatic structures encourage or hinder integration of treatment and combination prevention interventions?
- As ACA and Medicaid expansion are implemented, what is the continued role of Ryan White funding?

## ***Session Two***

In the second session, four groups would convene:

- Federal/national government
- State/local government
- Community organizations and networks
- Research

The first three groups will focus on the development of three specific recommendations to revitalize and implement the NHAS through the incorporation of new science, improved investment strategies, and new legislation (the ACA, Medicaid expansion). The research group will be asked to identify 3–5 primary questions that must be answered through clinical trials and implementation science approaches in order to meet the goals of a revitalized NHAS.



