

Developing a Community-Driven Research Agenda

December 1, 2013





FILLING THE GAPS IN THE U.S. HIV TREATMENT CASCADE:

Developing a Community-Driven Research Agenda

This report was written by David Barr and edited by Mark Harrington and Tim Horn, with assistance from Andrea Benzacar. Treatment Action Group thanks the writer and editors, and especially the Elton John AIDS Foundation for supporting this work.

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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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ISBN 978-0-9895740-4-4

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List of Abbreviations

- ACA Affordable Care Act
- AIDS Acquired immune deficiency syndrome
- amfAR Foundation for AIDS Research
- ART Antiretroviral therapy
- CBO Community-based organization
- CDC Centers for Disease Control and Prevention
- CEWG CFAR ECHPP Working Group
- CFAR Centers for AIDS Research
- CMS Centers for Medicare and Medicaid Services
- ECHPP Enhanced Comprehensive HIV Prevention Planning and Implementation for Metropolitan Statistical Areas (MSAs) Most Affected by HIV/AIDS
- FQHC Federally Qualified Health Center
- HCV Hepatitis Č virus
- HHS Department of Health and Human Services
- HIV Human immunodeficiency virus
- HMO Health maintenance organization
- HRSA Health Resources Services Administration
- IAPAC International Association of Physicians in AIDS Care
- IOM Institute of Medicine
- ITPC International Treatment Preparedness Coalition
- Kaiser Kaiser Family Foundation
- MSM Men who have sex with men
- NHAS National HIV/AIDS Strategy
- NIDA National Institute on Drug Abuse
- NIMH National Institute of Mental Health
- ONAP Office of National AIDS Policy
- PEP Postexposure prophylaxis
- PLHIV People living with HIV
- PrEP Preexposure prophylaxis
- SAMHSA Substance Abuse and Mental Health Services Administration
- SPNS Special Projects of National Significance
- STI Sexually transmitted infection
- TasP Treatment as prevention
- TAG Treatment Action Group
- VA Department of Veterans Affairs

EXECUTIVE SUMMARY

There is established the HIV Care Continuum Initiative, to be overseen by the Director of the Office of National AIDS Policy. The Initiative will mobilize and coordinate Federal efforts in response to recent advances regarding how to prevent and treat HIV infection. The Initiative will support further integration of HIV prevention and care efforts; promote expansion of successful HIV testing and service delivery models; encourage innovative approaches to addressing barriers to accessing testing and treatment; and ensure that Federal resources are appropriately focused on implementing evidence-based interventions that improve outcomes along the HIV care continuum.¹

The HIV Care Initiative and its 2010 precursor, the National HIV/AIDS Strategy, articulate the government's commitment to addressing the HIV epidemic. The Obama administration has made ending AIDS a priority both in the United States and around the world. New opportunities to reduce HIV infection and illness include expanded access to health care through the Affordable Care Act (ACA) and Medicaid expansion, and improved understanding of the prevention impact of HIV treatment. However, despite these advances, there are approximately 50,000 new HIV infections and over 8,000 AIDS deaths each year in the United States.² The possibility of ending the AIDS epidemic in the United States is real. The tools to do so are within our grasp. But there is still much to do and to learn in order to use these tools effectively. Information about effective methods for improving delivery of HIV treatment and prevention services has not been adequately disseminated or put into practice. And many key questions about how to best provide those services remain unanswered.

On June 18–19, 2013, Treatment Action Group (TAG) and amfAR (the Foundation for AIDS Research) sponsored a workshop to develop a community-based agenda to improve implementation of effective service-delivery approaches and identify research priorities for better-quality management of HIV treatment and prevention. The meeting's primary focus was addressing gaps in the United States continuum of HIV care (also known as the treatment cascade). This document represents the outcomes from that meeting, attended by representatives from government, academia, and health care systems, along with community-based advocates and service providers. This executive summary outlines key recommendations and research areas identified at the meeting. The full report provides a more detailed description of the current efforts, expanded research questions, and strategies for further research.

The HIV Treatment Cascade: Mapping Needs and Measuring Progress

The HIV treatment cascade offers a useful tool for understanding the primary steps from HIV diagnosis through long-term retention that are critical in preventing HIV-related illness and viral transmission. The cascade provides a structure for setting service-delivery targets and monitoring success. However, the value of the treatment cascade is limited by several factors, including: 1) the quality of the data available; 2) varying definitions of indicators; and 3) a simplistic view of service provision that fails to capture either the complexity of the challenges and needs, or the actions and resources required to achieve long-term, effective retention in care. Meeting participants discussed the value of the treatment cascade, encouraging improvement in the quality of data used, and the development of cascades at state and local levels in order to set targets and monitor progress. The following recommendations were made:

 The White House Office of National AIDS Policy (ONAP) should work with national, state, city, and other jurisdictions to standardize development of accurate, detailed, and comprehensive HIV treatment cascade/continuum of care data at all levels and by different demographic groups. These data are becoming an essential component for strategic use of investments, target setting, and monitoring progress.

- To enhance the value of the HIV treatment cascade/continuum of care, ONAP should:
 - Mandate adoption of the standardized cascade measures published by the Institute of Medicine (IOM).
 - Make funding and technical support available for state and city level cascade development.
 - Determine how to improve the overall quality of data for cascade development, with a priority focus on improving estimates of new HIV infections and of people who have HIV.
 - Lead work with all relevant agencies to coordinate alignment of their respective databases and make data easily available to health departments, service providers, and people with HIV in order for them to develop and use specific and accurate treatment cascades.
 - Provide guidance for state and local agencies to develop treatment cascades specifically for those most at risk.

Identifying Barriers to HIV Testing and Sustained Engagement in Care

Sustained engagement in health care is challenging in many circumstances. HIV presents special challenges because of the stigma associated with the disease and the continued discrimination against those most at risk, including gay men, transgender people, people who use drugs, and sex workers. The long asymptomatic stage of HIV disease also presents challenges, as people will often forego medical care until they feel sick. HIV also affects younger people with lower incomes who are less likely to have consistent and adequate health insurance. And many states with high rates of HIV have thus far refused to expand Medicaid through the ACA, forgoing an opportunity to help people get the care they need.

Low levels of HIV testing and knowledge of HIV status are a primary barriers to scaling up treatment, and are therefore a crucial area for increased research. Any efforts to increase demand for testing should go hand in had with systematic attempts to remove testing barriers. Further, testing programs must always be tied to effective and immediate linkage to care and support, whether HIV diagnosis is positive or negative.

Key Questions:

- 1. What incentives and information are needed to encourage people with HIV to enter and remain in care?
- 2. What are the particular engagement and retention challenges for HIV-positive youth and others at greatest risk, including incarcerated and transgender people—populations in which little research has been conducted?
- 3. As people with higher CD4 counts and fewer symptoms are offered HIV treatment, what are the determinants of treatment acceptance and adherence, and how can these be optimized?
- 4. What strategies are currently working to motivate testing across all populations?
- 5. How can HIV testing be effectively integrated with other health services, including screenings for breast cancer, diabetes, HCV, drug treatment, and hypertension?
- 6. What entities are responsible for linkage to care throughout the cascade, and which models work best?
- 7. Which behavioral, demographic, economic, and social-health variables best identify differences in treatment cascade outcomes?

Stigma, Discrimination, and Criminalization

Thirty years into the epidemic, stigma and discrimination against, and criminalization of, both people living with HIV (PLHIV) and those most at risk continue to create significant challenges to obtaining and using effective health care. The effects of racism, homophobia, transphobia, misogyny, violence, trauma, and criminalization must be carefully considered in the creation of any treatment cascade that can effectively monitor treatment outcomes.

Key Questions:

- 1. What strategies can effectively reduce stigma in communities facing high HIV risks in order to facilitate engagement and retention in care?
- 2. How can HIV programs be more effectively linked with social service- and employment programs?
- 3. How does stigmatization of HIV-positive gay men within sexual and social networks affect engagement in care, disclosure of HIV status, and prevention efforts? What strategies effectively change stigmatizing language and behavior?

Strengthening the Provider–Person with HIV Relationship to Optimize Outcomes along the Care Continuum

The relationships between a person and his or her health care– and social service providers are another key element that affects engagement in care. Some health care systems have developed dedicated HIV facilities at which staff members are well trained in the medical, social, and behavioral aspects of HIV care. However, many health care providers lack the experience and understanding of affected populations necessary to provide appropriate and non-stigmatizing care.

The implementation of the ACA may exacerbate these problems as more patients receive care through health management organizations (HMOs). These plans may have 30,000 members, of whom 350 will be living with HIV, so the incentive for providers to carefully address the particular health care– and social service needs of their HIV-positive clients may be limited. While the ACA will expand access to care for many more people living with HIV, ensuring cultural competencies and proper clinical management within health care settings will become more difficult as more people are distributed across these systems.

Key Questions:

- 1. What are effective methods to improve communication between individuals and providers about sexual and drug-using histories and practices?
- 2. What is the impact of community-based service provision on increasing demand for and sustained use of health and social services?
- 3. How can the impact of ACA implementation on quality of HIV care be measured?

Health and Treatment Literacy

The data on treatment as prevention (TasP) and early antiretroviral therapy (ART) initiation, as well as the changes in our health care system from Ryan White to the ACA, represent a revolution in how we understand and use HIV treatment and interact with health systems in the United States. Gaps in the treatment cascade will only widen without adequate provision of education and support for people to understand the implications of new treatment indications and their prevention benefits, and of new health care policies and how they affect their lives.

Key Questions:

- 1. What approaches to treatment literacy are most effective in helping patients make and follow through on treatment and prevention decisions? How do these approaches differ by population?
- 2. Does TasP motivate people to seek testing and care?
- 3. What is the role of peers as patient navigators? How can this role be optimized?
- 4. How can messaging and targeted outreach about the prevention benefits of treatment clarify the difference between TasP and preexposure prophylaxis (PrEP)?

Adherence, Retention, and Reengagement in Care

Increasing treatment literacy and providing assistance with health systems navigation are important strategies for increasing adherence and retention in care. But in order to further improve retention and adherence, a better understanding is needed of the triggers for disengagement, especially early attrition. Standards for long-term retention are needed in order to monitor and track patients far downstream after 10 or more years on treatment.

Key Questions:

- 1. What is the package of services that has led to high rates of retention in care for different populations?
- 2. Can a predictive model be developed to identify those most at risk for loss to follow-up? Are different providers more effective at different points in the cascade (e.g., community-based organizations [CBOs] for intensive early support, and health services facilities for longer-term care)?
- 3. How are retention measures calibrated for different populations (e.g., is one visit a year enough for young people and for people at greater risk?)?
- 4. How can electronic media and mobile devices be used more effectively for appointment reminders, lab tracking, and adherence support?

Community Mobilization

Community-based approaches have been the cornerstone of the response to the AIDS epidemic since its inception. In order to successfully implement improved treatment and prevention interventions, there must be renewed community mobilization. The promise of ending AIDS in the United States—through increased use of HIV testing, earlier initiation of treatment, engagement in the full range of prevention options, and increased access to health care through the ACA and Medicaid expansion—is realizable only if communities are engaged and mobilized. Community mobilization is essential to ensuring that health care access is available and of high quality, that human rights are protected, and also to creating and sustaining an environment in which people living with and at risk for HIV can communicate with and support one another.

The impact of community mobilization and the creation of social capital in public health is underresearched, though the history and nature of the AIDS epidemic provide uncommonly rich data that can help us understand how communities can be engaged, and actually lead health responses. The failure to study this impact, and the need to better understand new approaches to community mobilization, now creates a significant challenge to ending HIV/AIDS in the United States.

Key Questions:

- 1. What are the barriers to and motivators for engagement in community mobilization for treatment, prevention, and human rights at this stage of the epidemic?
- 2. How can the ways in which HIV-positive and -negative gay men communicate with each other be improved to create environments that foster support and disclosure and reduce stigmatization?
- 3. How can effective links be established between HIV and other social justice and health movements? What is the effect of such linkage on communities, on health, and on social justice outcomes?
- 4. How can community-based advocacy and service delivery be better aligned? How do funding streams affect the relationship between community-based service provision and advocacy?
- 5. What are the various roles and functions of peer navigators, and what training, supervision, and resources are required for them to assume leadership roles in community mobilization efforts?

Health Care Infrastructure and Financing

The passage of the ACA, Medicaid expansion, and other health care reforms will increase 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 adequate resources; that the experience and expertise of CBOs are well utilized; and that patients can navigate smoothly throughout the new landscape of health care systems.

While the ACA will expand access to care for many, in its present formulation, it will still present numerous challenges. The ACA may serve to make premiums more affordable, but many people will still be left with high deductibles and copayments that they cannot afford and that will lead to inconsistent drug access. ACA guidelines for health plans will not require adequate coverage of substance-use treatment and mental health services. Transportation, case management, and other support services are also not covered. How will Ryan White funding be available to provide these critical enabling services that patients depend on?

The "essential health benefits" package for HIV is likely to vary considerably: geographically, and by public and commercial systems, insured population, insurer, and service-delivery systems (i.e., fee-for-service or managed care). The implementation of health care reforms provides a major opportunity to measure the impact of these reforms on HIV prevention and care.

Key Questions:

- 1. Will there be disparities in retention rates between states that do and do not sign on to Medicaid expansion? How can these best be measured? What about the states that are doing something in between (e.g., expanding Medicaid and using health insurance)?
- 2. How do HIV health outcomes differ between states that have a robust public hospital system and those (like Louisiana) where hospitals are being privatized?
- 3. Which populations affected by HIV stand to benefit the most from ACA implementation? How will co-payments and deductibles affect the increased access to care provided through the ACA? How can the impact of increased co-payments and deductibles on retention in care be measured?

Recommendations for Improving the Research Infrastructure and Enabling Priority Implementation Science to Address the Highest-Priority Questions

- 1. ONAP should spearhead coordination of the HIV implementation science research agenda. This would involve convening the key agencies, researchers, and advocates in the field, developing consensus on the research priorities and preferred methodology, mapping the current efforts, and then determining how to fill the gaps in research.
- 2. ONAP should coordinate efforts to disseminate best-practice findings to the public, affected communities, departments of health, and health care providers.
- ONAP should convene a consultation with academics, agencies, methodologists, people with HIV, and service providers to determine the best way of using nonresearch data from the Health Resources Services Administration (HRSA), the Department of Veterans Affairs (VA), the Kaiser Family Foundation (Kaiser), the Centers for Disease Control and Prevention (CDC), etc., to help frame and answer critical questions.
- 4. Many effective approaches to sustaining long-term engagement in care are captured only anecdotally. The development of case-study methodology to better identify and describe varied service-delivery methods is one potential way of providing additional information.
- 5. Federal coordination is needed to develop treatment and prevention cascades at state and local levels. This coordination can provide funding, standardize methodology, and facilitate access to data.
- 6. Community-based participatory research is an essential component of an implementation science research agenda designed to understand the care and service needs of affected individuals, and to create and sustain the best strategies to meet those needs. A funding stream is needed to strengthen the capacity of community-based organizations to participate in the development and implementation of this research.
- 7. An effort by the National Institute on Drug Abuse (NIDA) to integrate correctional databases with Ryan White databases across states was cited by meeting participants as a good example of research coordination. However, the project faced extensive institutional barriers. Similar projects should be considered to better understand service-delivery flows between correctional and external health- and social service systems.
- 8. Develop community surveillance networks for consumers to report and provide feedback on the impact of ACA implementation on service delivery. One model for this work is the International Treatment Preparedness Coalition (ITPC) Missing the Target project in which community organizations collect and report on health services access and quality using a standardized set of data collection and reporting tools.

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INTRODUCTION

Since the introduction of highly active antiretroviral therapy (ART) in 1996, the annual death rate from HIV/AIDS has dropped in the United States by over two-thirds. The U.S. Centers for Disease Control and Prevention estimates that approximately 1.2 million Americans are living with HIV. More recent data indicate that ART not only prevents progression to AIDS and death, but, when used among serodiscordant heterosexual couples earlier, ART also reduces HIV transmission by 96 percent.³ The enactment of the Affordable Care Act and related expansion of Medicaid will ensure access to health care for millions of Americans living with and at risk for HIV disease. The National HIV/AIDS Strategy, issued in 2010, articulates the government's commitment to addressing the HIV epidemic, and the Obama administration has made ending AIDS a priority both in the United States and around the world.

However, despite these advances, there are approximately 56,000 new HIV infections and over 8,000 AIDS deaths each year in the United States.⁴ The racial disparities seen generally in health outcomes are prevalent in HIV. African Americans accounted for 44 percent of new HIV infections diagnosed in 2009, although they constitute only 14 percent of the population.⁵ HIV also disproportionately affects people living in southern states, the states least likely to implement Medicaid expansion where the need is greatest. Ending AIDS in America will take continued advocacy, commitment, and political will.

Changes in health care delivery mechanisms and scientific advances offer real potential to improve the lives of people living with HIV and to reduce infection rates. The possibility of ending the AIDS epidemic in the United States is real. The tools to do so are now within our grasp. But there is still much to do and to learn in order to use these tools effectively. Information about effective methods to improve delivery of HIV treatment and prevention services has not been adequately disseminated and put into practice. And many key questions about how to best provide those services remain unanswered. The development of a new implementation agenda—one that will chart the course for effective HIV treatment and prevention services—is the next essential step toward realizing a United States, and eventually a world, without AIDS.

At the core of this agenda are people living with HIV and those who are most at risk of infection. The communities affected by HIV must take the lead in articulating their needs and priorities in order for health and social services to be effective. To this end, Treatment Action Group (TAG) and the Foundation for AIDS Research (amfAR) sponsored a workshop in Washington, D.C., on June 18–19, 2013, to develop a community-based agenda to improve implementation of effective service-delivery approaches and identify research priorities for improved management of HIV treatment and prevention, with a particular focus on filling the gaps in the United States HIV continuum of care (or *treatment cascade*). This document represents the outcomes from that meeting, attended by representatives from government, academia, and health care systems, along with community-based advocates and service providers.

The meeting agenda was structured around the HIV treatment cascade (see appendix A), with the primary focus on linkage to and retention in care. However, participants also discussed how other factors affect linkage to and retention in care, including HIV prevention and testing, racial disparities in health outcomes, community mobilization, and the impact on HIV care of the implementation of the Affordable Care Act (ACA) and other changes in health care infrastructure. The document provides recommendations and priorities for follow-up.

I. The HIV Treatment Cascade: Mapping Needs and Measuring Progress

The HIV treatment cascade offers a useful tool for understanding the steps from HIV diagnosis through long-term retention in care whose goal is to prevent HIV-related illness and viral transmission. The cascade provides a structure in which to set service-delivery targets and monitor success. In figure 1, below, comparing two versions of the cascade reported in 2011, approximately 20% of people who have HIV remain unaware of their HIV status; approximately 35% have not been linked to care; about 55% have not initiated ART; and almost 70% have not achieved full viral suppression and treatment success. It has been noted that only when each step in the continuum is completed with 90% fidelity would the proportion of viral suppression increase from the current 19–66%.^{6,7}



Figure 1. Gardner and Cohen Treatment Cascades 2011

Treatment cascades are also beginning to be developed for individual cities and states, and for some demographic groups, which provide a critical tool for better prioritizing and monitoring service provision at state and local levels.

Figures 2 and 3, below, present two examples of state-level treatment cascades. One is from Massachusetts compared with national outcomes—and the second from Alabama, illustrating very different outcomes and the need for different strategies. Alabama loses large numbers of patients at each step in the cascade and has a relatively low rate of viral suppression.



Figure 2. Massachusetts Outcomes versus National Outcomes

Source: Holman, J, Schneider, K., Watson, K. Mathur, J, Flynn, A. Massachusetts and Southern New Hampshire HIV/AIDS Consumer Survey. JSI Research and Training, Inc. June 2011.





Source: Mugavero M. Presentation at Filling the Gaps in the HIV Treatment Cascade meeting; 18 June 2013; Washington, D.C.

"I struggle with this technical and managerial approach to the epidemic: monitoring, resource allocation, and so on. There is not enough about the social and political side. How do we measure the impact of our social struggles on treatment cascade outcomes? We have much easier access to metrics like VL [viral load] than things like stigma and incarceration. The dialogue on metrics is sellable to policy makers because it means they can think about resources. Cascade dialogue is incommensurate with community discussions around intimacy and makes me worry about the place of community in the response."

— Daniel Raymond, Harm Reduction Coalition

II. The Limitations of the Treatment Cascade

The value of the treatment cascade is limited by several factors including: 1) the quality of the data that goes into it; 2) varying definitions of indicators; and 3) a simplistic view of service provision that fails to capture the complexity of challenges and needs required to achieve long-term effective retention in care. Each of these is discussed below.

a. Data Quality

Treatment cascades begin with an estimated number of HIV-positive people for the relevant population. The accuracy of these estimates varies widely, and most estimates would benefit from improved surveillance methods.

If the initial estimate is inaccurate, then the remaining estimates within the cascade will be inaccurate as well. Cascades can have different starting points, including the total number of people estimated to be HIV-positive or the total number of people diagnosed with HIV. Cascades often define linkage or retention in care based on locally reported CD4 cell count– and viral-load data, which can underrepresent outcomes. Individuals can be linked to or retained in care and may be virally suppressed, but lab data may not be available or reported. Cascades based on clinic visits will not capture population-based data and, by their nature, will report only on people already in care.

Massachusetts provides a good example of both good outcomes from and the limitations of available data. The state has achieved impressive results in successful engagement in long-term care resulting in reduced AIDS-related morbidity and mortality, lowered HIV incidence, and significant cost savings. New data on viral suppression drawn from 1,000 clinical charts showed sustained suppression in 70 percent of patients in 2011, and in 91 percent of patients at their last visit.⁸ This does not necessarily characterize care for all people with HIV, but it does represent a substantial proportion of the locations providing the majority of care in the state. While the Massachusetts Department of Health stated that this is linked to reduced incidence, it has not published the actual prevalence of HIV, the size of the untested population, the rates or timing of care linkage for the entire HIV-positive population, or the rate of sustained retention in care—nor has it published a recent statewide accounting of people who have been diagnosed with HIV but are not linked to care (known as "community viral load"). Nationwide, there is no consensus on what the overall HIV prevalence or incidence is. For example, the number of undiagnosed black gay men is unknown. New HIV testing technologies, if properly implemented, hold the promise of diagnosing more HIV infections significantly faster, making it possible to intervene in acute HIV infections and break the chain of onward transmission.⁹

In developing state- and local-level cascades, obtaining accurate and comprehensive data is essential but can be difficult to do. At both national and state levels, good data exist, but obtaining access to them is difficult. Even when access is available, communication between multiple databases is extremely challenging. Data on the numbers of people actually taking ART are often incomplete, something that may get even more difficult under the ACA.

The cascades have also not yet incorporated current U.S. treatment recommendations into their structures. Based on current guidelines, which recommend ART for all HIV-positive individuals, the number of people on ART should be the same as the number of people who have HIV. In some cases, broad estimates about the number of people linked to care are based on very small data sets. Current cascades offered by the CDC and others are based primarily on models, limited local or regional studies, meta-analyses, and studies based on samples with selection bias, but not on longitudinal data on individuals.

b. Alignment of Indicators

To compare cascades across jurisdictions or populations, indicator definitions and metric reports must be aligned. Currently, indicators have multiple definitions from different sources (HRSA, the IOM, and the Department of Health and Human Services [HHS]), making it difficult to interpret and compare outcomes. This lack of alignment of indicators hinders the ability to build cascades and to compare them with each other.

Measure	Description
Missed visits:	Number of "no show" visits accrued
count	(count measure)
Missed visits:	≥1 "no show" visit
dichotomous	(dichotomous measure, 'no' = retained)
Visit adherence	Proportion of kept visits / (kept + "no-show" visits) (continuous measure, range=0.0-1.0)
4-month constancy	Number of 4-month intervals with at least 1 kept visit (categorical measure, range=0-3)
6-month gap	≥189 days elapsed between sequential kept visits (dichotomous measure, 'no' = retained)
HRSA HAB	2 kept visits separated by ≥90 days (dichotomous measure, 'yes' = retained)

Figure 4. Retention Measures

Source: Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. Ann Intern Med. 2012 Jun 5;156(11):817–33.

Differing definitions of linkage to care are one good example. Varied indicators include evidence of initial viral-load or CD4 testing or office visits within 3, 3–5, 6, or 12 months from receiving a positive HIV test result.

Similarly, the definition of retention in care can vary between evidence of viral-load or CD4 testing or visits at 12 and 24 months. Viral suppression can also be defined as undetectable, <200 copies/mL, or <400 copies/mL. Perhaps most problematic is measuring retention in care.

Figure 4, above, lists a variety of indicators currently being used to measure retention in care. Each indicator has validity, but without consistency it is difficult to compare outcomes. In measuring retention in care, missed visits, appointment adherence, visit constancy, gaps in care, and kept visits are all options, but "missed visits" and "kept visits" may capture different things. Surveillance can only capture kept visits, which are the indicator recommended by the HRSA HIV/AIDS Bureau. However, missed visits may be linked with mortality. In one study, a missed visit in the first year was associated with a threefold risk of mortality, with a bigger impact than age. Nevertheless, both indicators predict viral-load suppression. More than one indicator may be necessary. It is essential to reach agreement on what those indicators should be and then be consistent in their use.

Progress has been in made in the effort to align the definition of indicators. The IOM, for example, has released standardized cascade measures as described in figure 5, below.



The International Association of Physicians in AIDS Care (IAPAC) recently coordinated the development of guidelines to improve linkage to and retention in care; these are published in the *Annals of Internal Medicine*.¹⁰ Additional IAPAC/UNAIDS guidelines on optimizing the HIV treatment cascade are now in preparation for release at the end of 2013. The use of these guidelines as standardized indicators for retention in care will improve the value and comparability of treatment cascade models.

Figure 6. 2012 IAPAC Evidence-Based Guidelines for Linkage, Retention, and Adherence



c. Developing a More Comprehensive View of HIV Service Delivery

The treatment cascade presents a linear view of service delivery and outcomes. But an individual's engagement in care is not always linear. People relocate and change where and how they receive care. People leave care and may reenter at a later stage or in another jurisdiction. These shifts are often not captured in treatment cascade data, making it seem instead as if a person has been lost to follow-up. The reasons why people are unable to sustain their engagement in care are many and complex. HRSA's continuum of care definition recognizes that it is not simply about going into care at one end and being engaged at the other end. It's bidirectional; it's back and forth. Further, the cascade is structured specifically around the use of treatment and virological suppression. But this view fails to take into account the importance of social services including case management, housing, and mental health discussed later in this report.

Developing accurate, detailed, and comprehensive treatment cascades at national, state, and city levels as well as by demographic groups is essential for strategic use of investments, target setting, and monitoring progress. The Office of National AIDS Policy should encourage the development of these cascades. The following recommendations will enable this development and enhance the value of the cascade. ONAP should:

- Encourage adoption of the standardized cascade measures published by the IOM.
- Make funding and technical support available for state- and city-level cascade development.
- Convene a meeting to determine how to improve the overall quality of data for cascade development, with a priority focus on improving estimates of new HIV infections and of people with HIV.
- Spearhead work with the CDC, HRSA, the VA, the CMS, and other relevant agencies to standardize data base definitions, increase access to centralized data, and make data easily available to health departments so they can develop specific and accurate treatment cascades.
- Develop treatment cascades specifically for most-at-risk populations at state and local levels.

III. Identifying Barriers to Sustained Engagement in Care

Sustained engagement in health care is challenging throughout the spectrum of health needs. HIV presents special challenges because of the stigma associated with HIV and the continued discrimination against those most at risk, including gay men, transgender people, people who use drugs, and sex workers. The long asymptomatic stage of HIV disease also presents difficulties, as people will often forego medical care until they feel sick. HIV also affects younger people, who tend to have lower incomes and are less likely to have consistent and adequate health insurance. The failure of many high-prevalence states to adopt Medicaid expansion will make it increasingly difficult for many people living with HIV to get care. The barriers to care are layered, as illustrated in figure 7.



The reasons why patients are unable to sustain engagement in care are often viewed differently by health systems and by patients, as illustrated in figures 8 and 9, below. In figure 9, describing challenges from the patient perspective, a combined 39 percent of patients reported that they did not seek out care because they either did not want to think about being positive or because they felt well. Addressing the needs of asymptomatic patients is a primary challenge.

Figure 8. Programmatic Challenges – A Health Department Perspective



Figure 7. Recursive Cascade Model



Demographic information describing populations and risk factors for poor linkage to and retention in care are listed in figure 10, below. This information can help target research on interventions for those who need them most.



Bhatta, Am J Med Sci 2010; Anthony, AIDS Care 2007; Stein, Am J Public Health 2000; Rodriguez, JAIDS 2007; Sohler, AIDS Patient Care STDs 2009; Keruly, AJPH 2002; Robbins, JAIDS 2007; Giordano, Clin Infect Dis 2007; Mugavero, JAIDS 2009; Metsch, Clin Infect Dis 2008; Hall, JAIDS 2012; Hightow-Weidman, AIDS Pt Care and STDs 2011; Torian, Arch Intern Med 2008; Giordano, HIV Clin Trials 2009; Coleman, AIDS Patient Care STDs 2007; Kempf, AIDS Patient Care STDs 2010; Mugavero, JAIDS 2012; **Slide adapted from C del Rio and M Mugavero**

THE GEORGE

WASHINGTON

UNIVERSITY

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Challenges from the Patient Perspective

Key Questions: Delayed Linkage to Care and Poor Retention

- What incentives and information are needed to encourage asymptomatic patients to enter and remain in care?
- As people with higher CD4 counts and fewer symptoms are offered HIV treatment, what are the determinants of treatment acceptance and adherence, and how can they be optimized?
- How will side effects from first-line regimens affect adherence in asymptomatic patients?
- How does the impact of treatment as prevention (TasP) provide a motivation for people to enter and remain in care?
- What are the particular engagement and retention challenges for HIV-positive youth and other mostat-risk populations, including incarcerated and transgender persons—populations in which little research has been conducted?

a. Stigma, Discrimination, and Criminalization

Thirty years into the epidemic, stigma and discrimination against both PLHIV and those most at risk continue to create significant challenges to accessing and utilizing effective care. The effects of racism, violence, trauma, and criminalization must be carefully considered in the creation of any treatment cascade that can effectively monitor treatment outcomes.

HIV Stigma and Criminalization: Fear of disclosure of HIV status to family and friends and resistance to seeking HIV-related health care for fear of exposing HIV status to the broader community are major barriers to sustained care. Criminalization of HIV strongly discourages people from seeking health care, and recent years have seen increasing instances of such criminalization. The following examples were provided at the meeting by Heidi Nass:

- Ohio 2011: Woman charged with felony assault for <u>spitting</u> and saying she had HIV
- Maryland 2010: Man sentenced to 5 years in prison for <u>spitting</u> on a police officer
- Florida 2009: Man sentenced to 15 years in prison for biting police officer
- Georgia 2009: Man sentenced to 2 years in prison and 8 years probation for <u>consensual sex</u> (in housing complex for people with HIV/AIDS)

"Part of the stigma of HIV is the silence of those who have it in our own families and communities. I think of a person I know who had never talked about his HIV status, had gone into hospital, who died, one of five young gay men under 30 I know who died last year. So when we think of the cascade, we have to be clear that the potential outcome of poor linkage is death, something unacceptable when we have effective treatment." — Cornelius Baker, Black Gay Men's Leadership Coalition

Stigma and discrimination are also prevalent within communities and sexual networks of gay men. Chat rooms used for social and sexual encounters are rife with language that stigmatizes HIV-positive men, reduces the incentive to disclose their HIV status, and hinders condom negotiation.

A wide variety of social determinants affect engagement in health care and HIV care specifically. Incarceration, poverty, access to education, food and environmental security, employment status, mental health, racism, gender inequality, domestic violence, law enforcement, drug policies, and homophobia are all key factors that affect the ability of individuals and communities to respond to HIV and engage in prevention and care. For example, black men die earlier than others in the general population whether they have HIV, diabetes, hypertension, or heart disease; gay men are disproportionately infected, and their health needs are sidelined in the LGBT equality agenda. Black women make up 64 percent of women newly diagnosed with HIV, but only 13 percent of the female population as a whole, and face an increasingly limited range of reproductive health choices. All of these issues are especially pronounced in the U.S. South. Forty-six percent of new HIV diagnoses were given in the South; and Florida, Louisiana, Mississippi, and South Carolina had HIV rates above the national average.

Given the preceding statistics and trends related to discrimination, it is unsurprising that trauma is another prevalent factor in the lives of people living with HIV, with approximately 50 percent having experienced physical or sexual abuse. Meeting participants noted that women living with HIV experience twice the rate of intimate partner violence compared with the general population of women. They also noted that higher numbers of traumatic events are predictive of nonadherence, more emergency room– and hospital visits, unprotected sex, lower reported health and well-being, and higher risk of disease progression.

Health systems may be unable to address all of these issues, but it is critical that the impact of stigma, criminalization, and discrimination on HIV be taken into account in the design of any HIV intervention.

Research regarding the impact of social determinants, racial disparities, and human rights on HIV health outcomes is both undervalued and underfunded.

Key Questions: Reducing Stigma, Discrimination, and Criminalization; Addressing Trauma and Violence; Building Resilience

- How can the extent and effect of HIV-related stigma be monitored? What tools are needed?
- What strategies are effective in reducing stigma in communities facing high HIV risks? How can they be used to facilitate engagement and retention in care?
- How does stigmatization of HIV-positive gay men in sexual and social networks affect engagement in care, disclosure of HIV status, and prevention efforts? What strategies are effective in changing stigmatizing language and behavior?
- What is the impact of criminalization of HIV status and associated behaviors on HIV testing and engagement in care?
- How are trauma and violence considered and addressed in efforts to engage and retain people in care?
- How can HIV programs be more effectively linked to social service- and employment programs?
- What is the role of life skills-building/leadership development for young gay men? What can be learned from various empowerment approaches that have and haven't worked?
- What factors define, predict, strengthen, and maintain individual and community resilience through long-term chronic conditions such as HIV infection?
- Is there a link between law enforcement policy/criminalization (e.g., "Stop and Frisk") and access to health care?

b. Provider Relationships and Lines of Responsibility

The relationships between a patient and his or her health care– and social service providers are another key element that affects engagement in care. Some health care systems have developed dedicated HIV facilities at which staff is well trained in the medical, social, and behavioral aspects of HIV care. However,

many health care providers lack the experience and understanding of affected populations necessary to provide appropriate and non-stigmatizing care. Providers are often reluctant to take sexual histories, may be unfamiliar or uncomfortable working with gay men or transgender people, and may not be up to date on HIV treatment guidelines. People receiving care in a clinic may see a different provider each time they have an appointment, making it difficult to establish the trust of, and in-depth knowledge about, the person seeking care.

The implementation of the ACA may exacerbate these problems as more people receive care through health management organizations (HMOs), coordinated care, or dual-eligible plans. These plans may have 30,000 members, of whom 350 will be living with HIV, so the incentive for the provider to carefully address the particular health and social needs of HIV-positive clients may be limited. While the ACA will ensure access to care for many more people living with HIV, ensuring cultural competencies and proper clinical management within health care settings will become more difficult as more people are distributed across these systems.

Key Questions: Strengthening the Provider-Person with HIV Relationship to Optimize Outcomes along the Care Continuum

- What are effective methods for improving communication between people and providers about sexual and drug-use histories and practices?
- What kind of training for health care workers is needed for treating people who are asymptomatic?
- What is the most useful role for paraprofessionals and peers in health care settings in discussing sexual history and practices?
- What is the impact of community-based service provision on increasing demand for and sustained use of health and social services?
- How can the expertise and experience of AIDS care providers be integrated into changing health care infrastructures?
- How can screening and treatment for post-traumatic stress disorder (PTSD) and other effects of trauma be integrated into care models?
- How can the impact of ACA implementation on quality of HIV care be measured?

IV. Improving Services to Fill the Gaps in the U.S. Treatment Cascade

The evidence base for where we lose people between the first two steps of the treatment cascade (from testing to linkage) is quite robust. Unfortunately, the evidence base for effective service models to fill those gaps is meager. Gathering data about retention, ART initiation, and viral suppression remains a national challenge. In addition to the need for more sophisticated data collection across the cascade, including databases that interact effectively, there is need for an in-depth analysis of why people fall out of the cascade at each step, and for identifying effective and replicable approaches for service delivery.

a. HIV Testing and Counseling

As mentioned above, low levels of testing and knowledge of HIV status are primary barriers to scaling up treatment and therefore crucial areas for increased research. The body of research on testing does not yet make clear whether demand is actually low or whether the myriad barriers to testing prevent people from getting it. Any efforts to increase demand for testing should go hand in hand with systematic attempts to remove barriers to it. Further, testing programs must always be coupled with effective and immediate linkage to care and support, whether the results are positive or negative.

Theprovider approach to testing can also create barriers and disincentives. Many health facilities now employ routine testing, removing the need to assess risk or carry out targeting testing. But it has been reported that in these settings black men who have sex with men (MSM) believe they are being tested when in fact they are not. One of the reasons for this is that Federally Qualified Health Centers (FQHCs) are reluctant to engage patients in discussions of HIV-related histories and risk factors for fear of being categorized as HIV clinics. In facilities where risk assessments are still used, they tend to be focused on identities (i.e., black gay men) rather than on behaviors, which creates an environment ripe for stigma and discomfort for the client.

Certain populations are particularly neglected in outreach for testing. Young people who inject drugs missed the harm reduction revolution of the 1990s that brought prevalence levels down, and many are unaware of injecting-related HIV risks and harm reduction practices. HIV screening in correctional settings is not routine, and incarcerated and formerly incarcerated people are not made aware of their rights and risks in relation to HIV.

When HIV is bundled with other screenings such as those for sexually transmitted infections (STIs) and pregnancy, women are more likely to get tested, especially when screening is linked to reproductive health care. Yet, integration of HIV and reproductive health care does not happen on a systematic level, lowering the likelihood those women will get tested.

Key Questions: HIV Testing and Counseling

- What strategies are currently working to motivate testing across all populations?
- Are gay men being reached through routine testing?
- Is couples counseling a path to testing?
- What is the role of home testing?
- Is it possible to determine which settings (reproductive health centers, emergency rooms, FQHCs) yield the greatest number of positive diagnoses?
- How effective is HIV testing conducted at social venues and through mobile vans in linking people to health care services?
- How can HIV testing be effectively integrated with other health services including drug treatment and screening for breast cancer, diabetes, HCV, and hypertension?
- Does the prevention impact of treatment provide incentive for increased use of HIV testing? If so, how can we capitalize on this incentive to improve testing rates?
- Can we disaggregate the data collected through HPTN 065 (TLC-Plus: A Study to Evaluate the Feasibility of an Enhanced Test, Link to Care, Plus Treat Approach for HIV Prevention in the United States) by gender and treatment setting?

b. Linkage to Treatment, Care, and Prevention

Low levels of linkage from testing to care result in similarly low levels of ART initiation and severe challenges to achieving viral suppression. As mentioned above, 70 percent of people living with HIV in the United States have unsuppressed viral loads.

Various factors contribute to the disruption of linkages to care, including stigma associated with an HIV diagnosis, discrimination against those most at risk, including in health care settings; the long asymptomatic stage during which people feel healthy and do not seek care; erratic health insurance coverage of young people living with HIV; inability to cover co-pays; comorbidities requiring complex care and treatment interventions at different facilities; and the range of social issues facing those most affected including mental health and trauma, addiction, incarceration and lack of housing.

Lines of responsibility in relation to linkage to care are often unclear. A good example of this is linkage to care. People are tested in a wide variety of circumstances and venues, for example, a community-based organization, a health department testing center, a mobile van outside a night club, in the emergency room, or by using a home test kit. HIV testing normally includes referrals for medical care. But it is unclear who is responsible for making sure that the linkage from testing to health care and prevention services is successful. The structure of funding streams can contribute to this problem. The CDC funds HIV testing. Funding for treatment and medical care are funded from other sources (e.g., private insurance, Ryan White, Medicaid). But neither funding stream is responsible for linkage to care. Without a clear line of responsibility, the success of linkage to care is left to the patient.

The treatment cascade omits linkage to prevention services. The primary outcome of HIV testing should be linkage to treatment and prevention services. Any testing intervention that does not include effective approaches of linkage to care should be considered inadequate, if not unethical. However, more information about how to integrate linkage with prevention services is needed, especially in light of new prevention approaches including PrEP, postexposure prophylaxis (PEP), and TasP.

Key Questions: Linkage to Treatment, Care, and Prevention

- What are the key issues keeping youth from engaging in care?
- Is their sufficient focus on linkage to care in social marketing for testing?
- What is the impact of wait times for test results on linkage to care? Does quicker linkage lead to more sustained engagement?
- What is the role of point-of-care CD4 testing in the United States?
- What are the effects of home testing on linkage to care? (It is hoped that the results of a large CDC study on this issue will help fill some implementation gaps.)
- Where does responsibility lie within health systems for linkage to care at different jurisdictional levels, and which models work best?
- Is there a role for PrEP in low morbidity areas where MSM are the primary population affected by HIV? Or is there a prevalence cutoff where it would not be effective?
- Which behavioral health variables best identify differences in treatment cascade status/outcomes?
- What is the effectiveness of pay-for-service testing (CBOs get paid extra for each posting— each person successfully linked to care) and financial incentives for maintaining people in care?
- How can HIV testing and counseling be effectively linked to assessment for and provision of PrEP?
- How does new information about the prevention impact of treatment affect HIV testing and counseling approaches?
- To what degree does universal treatment access itself contribute to observed viral-suppression rates?
- To what degree does sustained viral suppression contribute to observed incidence reductions at a population level?

c. Health and Treatment Literacy

The data on TasP and early ART initiation and the changes in our health care system from Ryan White to the ACA represent a revolution in how we understand and use HIV treatment and interact with health systems in this country. Gaps in the treatment cascade will only widen if we fail to adequately educate and support patients and clients, and help them understand the implications of new treatment indications and their prevention benefits, and of new health care policies and how they may affect their lives.

It is critical that community-based organizations and networks develop opportunities for their clients and members to improve their understanding of HIV disease and its comorbidities and treatments. These individuals also need help to navigate through the bureaucracy of the ACA and changes to Ryan White. State and local agencies as well as privately funded AIDS service and advocacy organizations take various approaches to treatment literacy and patient navigation. These approaches need to be coordinated, documented, and supported as core components of the continuum of HIV care.

In addition, education departments should be included in discussions about and delivery of health literacy services, especially given the high incidence of HIV among young people.

There are additional challenges that do not fall within the confines of the treatment cascade but clearly have an impact on retention. 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. In addition, comorbidities 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 dealing with complex treatment regimens and toxicity management.

Key Questions: Health and Treatment Literacy

- What approaches to treatment literacy are most effective in helping patients make and follow through on treatment and prevention decisions? How do these approaches differ by population?
- Is TasP a motivator for testing and seeking care?
- Is there different behavioral decision-making around TasP that requires tailored and targeted messaging?
- How can messaging and targeted outreach about the prevention benefits of treatment clarify the difference between TasP and PrEP?
- What are the best models for communicating epidemiological and behavioral data to communities?
- What curricula, methods, and approaches already exist for increasing community understanding of and participation in research? How can they be refined?

d. Adherence, Retention, and Reengagement in Care

Treatment literacy and health systems navigation are important strategies for increasing adherence and retention in care. But in order to further improve retention and adherence, a better understanding is needed of the triggers for disengagement, especially early attrition. Also, standards for long-term retention need to be set in order to monitor and track patients far down stream after 10 or more years on treatment.

Entry points for improving adherence and retention exist across health and community systems including hospitals, pharmacies, clinics, schools, and community-based service and advocacy organizations. As with treatment literacy and patient navigation, successful private- and public-sector models addressing the specific needs of affected populations need to be carefully documented and studied in order to draw out good practices with the potential to result in suppressed community viral load.



Successful adherence and retention strategies must be dynamic and responsive to changing risk factors and environments for care. For example, in rural settings, increasing use and injection of prescription painkillers requires engagement strategies that focus not only on HIV, but also on HCV and overdose issues. And strategies for engaging patients in care in the pre-ART stage through immediate connections with patient navigators are critical for study, since this is where we find the highest rates of loss to follow-up.

Managed care companies already use predictive models to determine which patients are at high risk of being lost to care by creating individual profiles of who needs extra support and who can manage their own care. These can be expanded and adapted for different settings quite quickly.

Key Questions: Adherence, Retention, and Reengagement in Care

- Are particular providers more effective at different points in the cascade (e.g., CBOs for intensive early support and health service facilities for longer-term care)?
- How can innovative outreach partnerships between clinics, communities, and health departments optimize retention?
- How are retention measures calibrated for different populations (e.g., is one visit a year enough for young people?)?
- What is the added value of seeing a doctor versus visiting a pharmacist?
- What is the relationship between care outcomes and the effects of approaches such as medical case management and peer support?
- Should there be an expanded role for pharmacies for those who are stable on treatment, and can pharmacies feed data on missed prescription pickups into the system?
- What new models are there for long-term care from other diseases such as diabetes?
- Can existing data be used to develop a simple predictive model that would categorize people as low-, medium-, or high risk for loss to follow-up?
- What lessons are there from keeping people in treatment or vaccine studies?

- How can electronic media and mobile devices be used more effectively for appointment reminders, lab tracking, etc.? What are the risks?
- How do we account for healthy, stable patients who reduce their health care use to annual visits? The issue of "doing well" is a confounder in estimating retention and engagement.
- What guidance and infrastructure are needed to support current health care— and social service providers in identifying and describing best practices?
- What is the package of services that has led to high rates of retention in care for key populations?
- Does using a surveillance program—based feedback loop to providers increase viral-load suppression among people living with HIV?
- What is the minimum amount of medical case management, peer support, and other care support necessary to achieve improved treatment outcomes?
- Are the following effective predictors of retention in care?
 - Time frame for linkage
 - Who provided the linkage. Health department versus clinic/test site versus CBO/other
 - How often CD4 count and viral-load testing were conducted to determine viral suppression and immune status
 - Number of appointments over first three to six months
 - Antiretrovirals prescribed
 - Individual-level predictors (stigma, denial, measure of self-efficacy)
 - Type of facility (Ryan White vs. private)
 - Risk group
 - Race
 - Arena/level (city/state health department)

e. Community Mobilization

Community-based approaches have been the cornerstone of the response to the AIDS epidemic since its inception. The community mobilization of the 1980s and '90s created a vast network of community-based HIV service providers, advocates, and support systems. HIV volunteerism and activism provide one the greatest historical examples of community mobilization in the arena of health. In order to successfully implement the promise of improved treatment and prevention interventions, there is a primary need for renewed community mobilization. The promise of ending AIDS in the United States—through increased use of HIV testing, earlier initiation of treatment, engagement in the full range of prevention options, and increased access to health care available through the implementation of the ACA and Medicaid expansion—is realizable only if communities are engaged to ensure that health care access is available and of high quality, that human rights are protected, and that an environment is provided in which people living with and at risk for HIV can communicate with and support one another. Community mobilization is essential to disseminating information about new prevention and treatment approaches and to linking HIV issues with other health and social justice movements. However, the approaches to mobilizing communities in response to HIV must be reevaluated to better meet the needs of a new generation and focus on better use of the tools now available to treat and prevent HIV.

The impact of community mobilization and the creation of social capital in public health is underresearched, though the history and nature of the AIDS epidemic provide uncommonly rich data that can help us better understand how communities can be engaged and actually lead health responses. The failure to study this impact, and the need to better understand new approaches to community mobilization, now creates a significant challenge to ending HIV/AIDS in the United States.

Key Questions: Community Mobilization

- What are the barriers to and motivators for engagement in community mobilization for treatment, prevention, and human rights at this stage of the epidemic? How can motivators for engagement be used to revitalize a movement that reflects the composition of today's epidemic?
- How do new prevention interventions and the nexus between HIV treatment and prevention affect community mobilization efforts?
- How can the ways in which HIV-positive and -negative gay men communicate with each be improved to create environments that foster support and disclosure and reduce stigmatization?
- How can effective links be established between HIV and other health and social justice movements? What is the effect of such linkage on communities, on health, and on social justice outcomes?
- What are the roles of social capital and social status? How do they affect people's behavior regarding their health care?
- How can community members participate in research planning and implementation effectively?
- How can community-based advocacy and service delivery be better aligned? How do funding streams affect the relationship between community-based service provision and advocacy?
- If it can be demonstrated that health literacy has an impact on retention across the cascade, what are the roles of community navigators, leaders, and advocates in creating and sustaining that impact?
- What are the various roles and functions of peer navigators, and what training, supervision, and resources are required for them to assume leadership roles in community mobilization efforts?

f. Health Care Infrastructure and Financing

The passage of the ACA, Medicaid expansion, and other health care reforms will increase 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 are well utilized, and that patients are able to navigate smoothly throughout the new landscape of health care systems.

While the ACA will expand access to care for many, in its present formulation, it will present numerous challenges to people as they try to get care. The ACA may make premiums more affordable, but many individuals will still be left with high deductibles and co-payments that they cannot afford and that could lead to inconsistent access to medications. Substance use treatment and mental health services are often only minimally covered. Transportation, case management, and other support services are also not covered. As we transition away from health services provided through Ryan White–funded clinics, many concerns remain unaddressed. Most existing Ryan White clinics are not prepared or structured to file for and receive insurance payments. 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 fails to provide wraparound services: will Ryan White funding still be available to provide these critical enabling services that patients depend on?

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 living with HIV/AIDS and their family members will need significant help in choosing the insurance plan that best meets their needs.

The "essential health benefits" package for HIV is likely to vary considerably: geographically and by public and commercial systems, insured population, insurer, and service-delivery systems (i.e., 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 lack staff members who are sufficiently credentialed to serve as providers. HIV clinical and support providers must learn to market their services to ensure that they have a role in HIV care delivery. STI, tuberculosis (TB), family planning, and other public health systems will experience significant pressure to integrate into the broader health care financing system.

Measurement of HIV prevention and care outcomes will be key to evaluating the impact of the implementation of new health care reforms.

Key Questions: Health Care Infrastructure and Financing

- Will there be disparities in retention rates between states that do and do not sign on to Medicaid expansion? How can these best be measured? What about the states that are doing something in between (e.g., expanding Medicaid and using health insurance)?
- What is the difference in HIV health outcomes between states that have a robust hospital system and those (like Louisiana) that are being privatized?
- Which populations affected by HIV stand to benefit from ACA implementation? How will co-payments and deductibles undermine the increased access to care provided through the ACA? How can the impact of increased co-pays and deductibles on retention in care be measured?
- How will ACA implementation affect access to and retention in HIV care for undocumented people?
- Legal recognition of transgender men and women: can they get their names changed on Medicaid cards? Is there an impact on retention of (poor) coverage of hormones or reassignment surgery?
- Can bundling payments for services be compared across insurance exchanges with various payers?
- There is a need and an opportunity to conduct comparative analyses of differentials in health outcomes across HIV-positive patient populations based on type of coverage, with a focus on linkage, retention, reengagement, and viral-load changes. These comparisons would include Medicaid versus exchanges versus private/employer-based insurance. How can these studies be developed and funded?

g. Improving the Research Infrastructure

A robust and diverse research infrastructure is needed to address the many issues described above. Currently, there are several programs producing research to better understand the barriers to and improve delivery of HIV treatment, care, and prevention services, some of which are described below. No single agency is responsible for oversight and coordination of the HIV implementation science agenda. Although the NIH is involved in some of this work through NIAID, NIDA, and particularly NIMH, implementation science has not traditionally been seen as the purview of the NIH overall. However, the just-referenced programs are vital and should be sustained. The CDC, SAMHSA, the CMS, and HRSA also have important roles to play in this research. But the entity responsible for overall coordination of this research effort remains unclear. Such coordination is essential, not only to manage research investments across multiple federal agencies, but to ensure engagement of state and local health departments, academia, foundations, and advocacy groups. There is also an urgent need to strengthen the ability to conduct research within real-world service-delivery settings and build research capacity to examine integrated approaches to health care– and social service delivery.

Recommendations for Improving the Research Infrastructure and Enabling Priority Implementation Science to Address the Highest-Priority Questions

- ONAP should spearhead coordination of the HIV implementation science research agenda. This would involve convening the key agencies, researchers, and advocates in the field, developing consensus on research priorities and preferred methodology, mapping the current efforts, and then determining how to fill the gaps in research.
- The development of case study methodology to better identify and describe varied service-delivery methods is one potential way of providing additional information. Many effective approaches to sustaining long-term engagement in care are only captured anecdotally.
- Federal coordination is needed to develop treatment and prevention cascades at state and local levels. This coordination can provide funding, standardize methodology, and facilitate access to data.
- A funding stream is needed to build the capacity of community-based organizations to participate in the development and implementation of this research. Community-based participatory research is an essential component of an implementation science research agenda designed to understand the care and service needs of affected individuals, as well as to create and implement the best strategies to meet those needs.
- An effort by NIDA to integrate correctional databases with Ryan White databases across states was cited as a good example of research coordination. However, the project faced extensive institutional barriers. Similar projects should be considered to better understand service-delivery flows between correctional and external health care— and social service systems.
- Develop community surveillance networks for consumers to report and provide feedback on the impact of ACA implementation on service delivery. One model for this work is the ITPC Missing the Target project, in which community organizations collect and report on health-services access and quality using a standardized set of data collection and reporting tools.
- Meetings should also be held with methodologists to determine best way of using nonresearch data from HRSA, the VA, Kaiser, the CDC, etc., to answer critical questions.

V. Conclusion

In September 2013, ONAP held two webinars to gather input from HIV community advocates about how to improve the U.S. response to HIV. ONAP asked participants the following questions:

- 1. What structural, policy, and programmatic actions could be taken to improve care continuum outcomes?
- 2. What actions could be taken so that evidence-based interventions focusing on the care continuum are further integrated into other proven approaches to addressing HIV (e.g., housing, substance-use treatment)?
- 3. What are the research gaps, including implementation research gaps, along the care continuum?
- 4. What actions are needed so that care continuum data are used effectively to monitor outcomes and drive real-time change across programs?

Through this report, TAG and amfAR have sought to provide comprehensive answers to these questions. The actions needed to improve implementation of HIV prevention and treatment services, as well as the necessary research called for in this report, require coordination and cooperation among multiple federal and state agencies, academia, and civil-society organizations. ONAP needs to provide leadership and coordination to ensure progress, and should take responsibility for articulating and gaining consensus for the research agenda, identifying funding streams, assigning responsibilities, and monitoring progress. Only by doing so will the Obama administration—and the nation—meet the goals of the National HIV/AIDS Strategy.

APPENDIX A. MEETING AGENDA

FILLING THE GAPS IN THE U.S. HIV TREATMENT CASCADE:

Developing a Community-Driven Research Agenda

District Architecture Center 421 7th Street NW Washington, D.C. June 18–19, 2013

<u>DAY ONE</u> <u>JUNE 18, 2013</u>

9:00-9:15 a.m.	Welcome and	Introductions:	Goals and	Agenda	Review
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	Chris Collins – Director of Policy, amfAR			
	Mark Harrington – Executive Director, Treatment Action Group			
	Grant Colfax – Director, Office of U.S. National AIDS Policy			
	 To identify clear action steps, both in implementing current knowledge, and, primarily, creating a research agenda. 			
	 A focus on 1) integration of HIV testing and counseling and linkage to care; and (2) improving retention and reengagement in care. 			
	• A focus on delivery and research needs and priorities for different populations and settings, e.g., young gay men in the South.			
9:15-10:00	Opening Presentations: Improving Treatment Cascade Outcomes through			
	Evidence-Based Research and Implementation Science			
	 HIV Treatment Cascades: Two Examples Addressing the Gaps in Effective Utilization of Services – Massachusetts and Florida 			
	Kevin Cranston – Massachusetts Department of Public Health			
	 The Challenges of Identifying and Implementing Evidence-Based Approaches to Improve Treatment Cascade Outcomes 			
	Alan Greenberg – George Washington University School of Public Health and Health Services			
	The Role of Affected Communities in Improving Treatment Cascade Outcomes			
	Cornelius Baker – Black Gay Men's Leadership Coalition			
10:00-11:00	Full group discussion			
11:00-11:15	Break			
11:15-12:15	Background Presentations			
	 Testing/Linkage to Care and Retention and Reengagement in Care: Current Evidence and Gaps in Knowledge 			
	Michael Mugavero – University of Alabama, Birmingham			
	• What Do We Need to Know to Better Link and Retain People in Care?			
	Heidi Nass – AIDS Treatment Action Coalition			
12:15-1:15	Panel: Improving Uptake of Evidenced-Based Service Delivery			
	Cynthia Grossman, U.S. National Institute of Mental Health			
	Dazon Dixon Diallo – SisterLove, Atlanta			
	David Purcell – U.S. Centers for Disease Control and Prevention			
	Robert Greenwald – Harvard Law School			
	Daniel Raymond – Harm Reduction Coalition			

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Work groups: Defining key research questions to improve retention or		
reengagement in HIV care. Groups consider different approaches for different		
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APPENDIX B. MEETING PARTICIPANTS

Filling the Gaps in the U.S. HIV Treatment Cascade: Developing a Community-Driven Research Agenda

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APPENDIX C. EXECUTIVE ORDER – HIV CARE CONTINUUM INITIATIVE – JULY 15, 2013

EXECUTIVE ORDER

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ACCELERATING IMPROVEMENTS IN HIV PREVENTION AND CARE IN THE UNITED STATES THROUGH THE HIV CARE CONTINUUM INITIATIVE

By the authority vested in me as President by the Constitution and the laws of the United States of America, and in order to further strengthen the capacity of the Federal Government to effectively respond to the ongoing domestic HIV epidemic, it is hereby ordered as follows:

<u>Section 1. Policy</u>. Addressing the domestic HIV epidemic is a priority of my Administration. In 2010, the White House released the first comprehensive National HIV/AIDS Strategy (Strategy), setting quantitative goals for reducing new HIV infections, improving health outcomes for people living with HIV, and reducing HIV-related health disparities. The Strategy will continue to serve as the blueprint for our national response to the domestic epidemic. It has increased coordination, collaboration, and accountability across executive departments and agencies (agencies) with regard to addressing the epidemic. It has also focused our Nation's collective efforts on increasing the use of evidence-based approaches to prevention and care among populations and in regions where HIV is most concentrated.

Since the release of the Strategy, additional scientific discoveries have greatly enhanced our understanding of how to prevent and treat HIV. Accordingly, further Federal action is appropriate in response to these new developments. For example, a breakthrough research trial supported by the National Institutes of Health showed that initiating HIV treatment when the immune system was relatively healthy reduced HIV transmission by 96 percent. In addition, evidence suggests that early treatment may reduce HIV-related complications. These findings highlight the importance of prompt HIV diagnosis, and because of recent advances in HIV testing technology, HIV can be detected sooner and more rapidly than ever before.

Based on these and other data, recommendations for HIV testing and treatment have changed. The U.S. Preventive Services Task Force now recommends that clinicians screen all individuals ages 15 to 65 years for HIV, and the Department of Health and Human Services Guidelines for Use of Antiretroviral Agents now recommends offering treatment to all adolescents and adults diagnosed with HIV.

Furthermore, ongoing implementation of the Affordable Care Act provides a historic opportunity for Americans to access affordable, quality health care. The Act is expanding access to recommended preventive services with no out-of-pocket costs, including HIV testing, and, beginning in 2014, insurance companies will not be able to deny coverage based on pre-existing conditions, including HIV. Starting October 1, 2013, Americans can select the coverage that best suits them through the new Health Insurance Marketplace, and coverage will begin January 1, 2014.

Despite progress in combating HIV, important work remains. Since the publication of the Strategy, data released by the Centers for Disease Control and Prevention show that there are significant gaps along the HIV care continuum — the sequential stages of care from being diagnosed to receiving optimal treatment. Nearly one-fifth of the estimated 1.1 million people living with HIV in the United States are undiagnosed; one-third are not linked to medical care; nearly two-thirds are not engaged in ongoing care; and only one-quarter have the virus effectively controlled, which is necessary to maintain long-term health and reduce risk of transmission to others.

In light of these data, we must further clarify and focus our national efforts to prevent and treat HIV infection. It is the policy of my Administration that agencies implementing the Strategy prioritize addressing the continuum of HIV care, including by accelerating efforts to increase HIV testing, services, and treatment along the continuum. This acceleration will enable us to meet the goals of the Strategy and move closer to an AIDS-free generation.

<u>Sec. 2. Establishment of the HIV Care Continuum Initiative</u>. There is established the HIV Care Continuum Initiative (Initiative), to be overseen by the Director of the Office of National AIDS Policy. The Initiative will mobilize and coordinate Federal efforts in response to recent advances regarding how to prevent and treat HIV infection. The Initiative will support further integration of HIV prevention and care efforts; promote expansion of successful HIV testing and service delivery models; encourage innovative approaches to addressing barriers to accessing testing and treatment; and ensure that Federal resources are appropriately focused on implementing evidence-based interventions that improve outcomes along the HIV care continuum.

Sec. 3. Establishment of the HIV Care Continuum Working Group. There is established the HIV Care Continuum Working Group (Working Group) to support the Initiative. The Working Group shall coordinate Federal efforts to improve outcomes nationally across the HIV care continuum.

(a) <u>Membership</u>. The Working Group shall be co-chaired by the Director of the Office of National AIDS Policy and the Secretary of Health and Human Services or designee (Co-Chairs). In addition to the Co-Chairs, the Working Group shall consist of representatives from:

- (i) the Department of Justice;
- (ii) the Department of Labor;
- (iii) the Department of Health and Human Services;
- (iv) the Department of Housing and Urban Development;
- (v) the Department of Veterans Affairs;
- (vi) the Office of Management and Budget; and
- (vii) other agencies and offices, as designated by the Co-Chairs.

(b) <u>Consultation</u>. The Working Group shall consult with the Presidential Advisory Council on HIV/AIDS, as appropriate.

(c) <u>Functions</u>. As part of the Initiative, the Working Group shall:

(i) request and review information from agencies describing efforts to improve testing, care, and treatment outcomes, and determine if there is appropriate emphasis on addressing the HIV care continuum in relation to other work concerning the domestic epidemic;

(ii) review research on improving outcomes along the HIV care continuum;

(iii) obtain input from Federal grantees, affected communities, and other stakeholders to inform strategies to improve outcomes along the HIV care continuum;

(iv) identify potential impediments to improving outcomes along the HIV care continuum, including for

populations at greatest risk for HIV infection, based on the efforts undertaken pursuant to paragraphs (i), (ii), and (iii) of this subsection;

(v) identify opportunities to address issues identified pursuant to paragraph (iv) of this subsection, and thereby improve outcomes along the HIV care continuum;

(vi) recommend ways to integrate efforts to improve outcomes along the HIV care continuum with other evidence-based strategies to combat HIV; and

(vii) specify how to better align and coordinate Federal efforts, both within and across agencies, to improve outcomes along the HIV care continuum.

(d) <u>Reporting</u>.

(i) Within 180 days of the date of this order, the Working Group shall provide recommendations to the President on actions that agencies can take to improve outcomes along the HIV care continuum.

(ii) Thereafter, the Director of the Office of National AIDS Policy shall include, as part of the annual report to the President pursuant to section 1(b) of my memorandum of July 13, 2010 (Implementation of the National HIV/AIDS Strategy), a report prepared by the Working Group on

Government-wide progress in implementing this order. This report shall include a quantification of progress made in improving outcomes along the HIV care continuum.

Sec. 4. General Provisions. (a) Nothing in this order shall be construed to impair or otherwise affect:

(i) the authority granted by law to an executive department, agency, or the head thereof; or

(ii) the functions of the Director of the Office of Management and Budget relating to budgetary, administrative, or legislative proposals.

(b) This order shall be implemented consistent with applicable law and subject to the availability of appropriations.

(c) This order is not intended to, and does not, create any right or benefit, substantive or procedural, enforceable at law or in equity by any party against the United States, its departments, agencies, or entities, its officers, employees, or agents, or any other person.

Signed by: Barack Obama

This document is available at: http://www.whitehouse.gov/the-press-office/2013/07/15/executive-order-hiv-care-continuum-initiative.

ENDNOTES

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