

# Massachusetts Comprehensive Plan to Eliminate HIV Discrimination, AIDS Related Deaths, and New HIV Infections

A Report of the Massachusetts Getting To Zero Coalition



December 1, 2016

**Massachusetts Comprehensive Plan to Eliminate HIV Discrimination, AIDS Related Deaths, and New HIV Infections**

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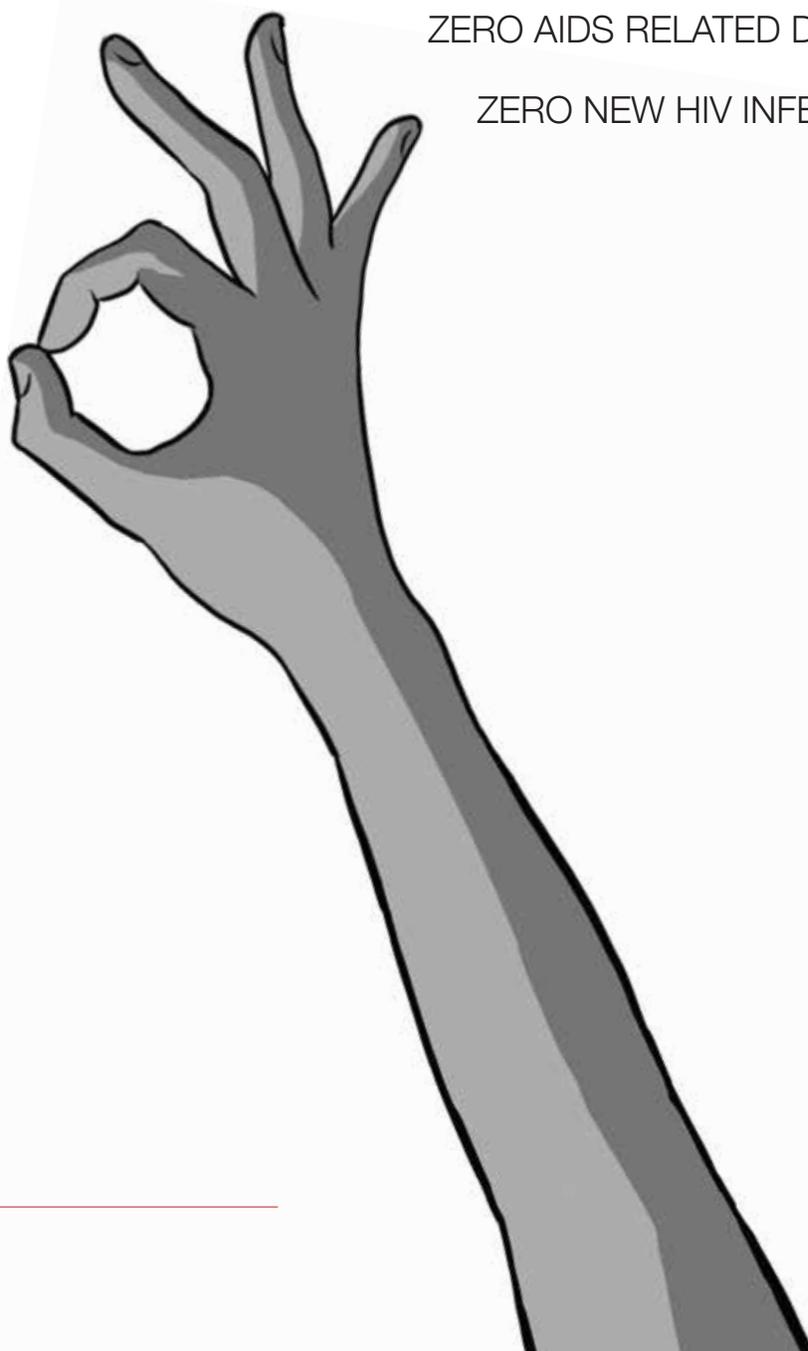
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ZERO DISCRIMINATION

ZERO AIDS RELATED DEATHS

ZERO NEW HIV INFECTIONS





# CONTENTS

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1	Executive Statement
2	HIV/AIDS in Massachusetts
4	Origin of Getting To Zero (GtZ): Applying 90-90-90 by 2020 as a Pathway to Zero
6	The GtZ Coalition: Starting the Conversation in Massachusetts
9	Priority Activities: Meeting the Global Getting To Zero Challenge Locally
11	Identifying Undiagnosed Individuals & Linking to Care
13	Retention in Care & Viral Suppression for PLWHA
15	Initiation of PrEP for Eligible Persons
17	Strengthening of Services for Key Populations
19	Enhancement of Health Surveillance & Data Reporting Systems
21	Adoption of Sexual Health as a Human Right
23	Alignment with External Getting To Zero Efforts
26	Next Steps: How to Address HIV/AIDS and Prioritize Equity in Massachusetts
	Appendix



# Executive Statement

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Whoever you are, you are not alone. If anything, World AIDS Day reminds us of that. December 1st is an important day of observance, remembrance, resilience, and solidarity. For many of us hosting events, attending them, or celebrating on our own; the build up, festivities, and solemn observation of this day can feel like a frantic dash to the finish. Perhaps it is symbolic that today groups around the world, across the nation, and right here in our own state of Massachusetts are having real conversations about putting an end to the HIV/AIDS epidemic. New tools in the fight against HIV have provided an opportunity to complete the work started so many years ago by our lovers and friends. With these tools and technologies we can turn their dream into a reality. The buildup to this opportunity has been dramatic and frantic and we are all anxious to take that final mad dash to get to zero. With the work of this coalition, we are hopeful that the first step of that final fight has begun.

This coalition was established to revitalize and redefine the HIV/AIDS agenda for advocates in the Commonwealth. In the process we found ourselves the ones revitalized, motivated by a new generation of advocates, some of who have been combating HIV for 30 years and have been transformed by the technologies, tools, and energy on the ground today. Sacrifices were made by these passionate and influential advocates. Their efforts brought us where we are today. Now is the time to broaden participation. When we bridge divides and create allies between generations, between racial/ethnic communities, genders, sexual orientations, HIV statuses, and faiths we multiply our strength and expand the scale of our impact.

This document is not the end of the conversation. This is the first step in what we hope is the final chapter of the epidemic. We hope the content of this report will educate, challenge, and inspire individuals to learn more, to take ownership of this cause and to keep talking, keep communicating, and keep working together to make the changes needed real.

You are not alone. We are not alone. We stand together with states and cities across the country and around the world and we will get to *zero* discrimination, *zero* AIDS related deaths, and *zero* new HIV infections.

1 December 2016



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# HIV/AIDS in Massachusetts

The Massachusetts Department of Public Health (MDPH) has been very supportive of the community during this getting to zero research and engagement process. During 2016 MDPH completed a complementary summary report of HIV/AIDS epidemiology and public health priorities in the Commonwealth. The following excerpt from that 2017-21 Massachusetts Integrated Prevention and Care Plan provides a general summary of the state of HIV/AIDS in the Commonwealth today:

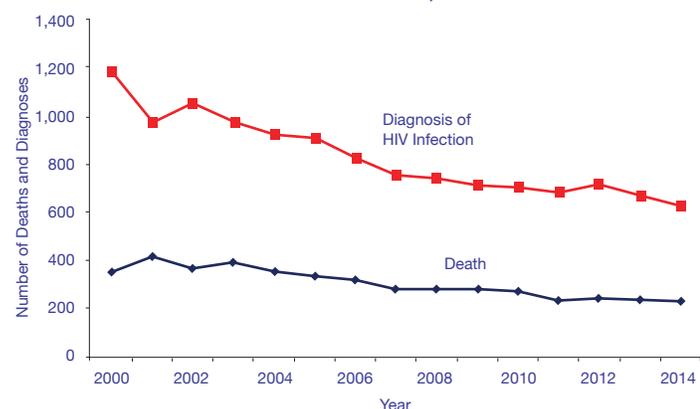
*“As of December 31, 2015, a cumulative total of 34,001 individuals were ever diagnosed with HIV infection and reported in Massachusetts, with or without an AIDS diagnosis, of which 40% (N=13,729) have died and 60% (N=20,272) were living with HIV/AIDS. There are an additional 3,814 people living with HIV/AIDS in Massachusetts who were first diagnosed in another state. Adjusting for residents infected with HIV who do not yet know their status, have not been reported, or were first reported in another state, the MDPH estimates that the total number of residents living with HIV/AIDS in the Commonwealth is between 26,000 and 27,000...”*

*...Since 2000, there are more people living with HIV/AIDS in Massachusetts, with fewer people being diagnosed with HIV infection each year, and fewer people with HIV infection who die. The improvement of health and longevity due to current HIV treatment has resulted in an increase in the number of people living with HIV/AIDS of approximately 3% per year. From 2000 to 2014, the number of people living with HIV/AIDS increased overall by 56%. During the same time period, the number of deaths among people reported with HIV/AIDS decreased by 31% (from 333 to 231). The number of HIV infection diagnoses decreased by 37% from 2000 (N=1,191) to 2008 (N=746), then plateaued at an average of 691 diagnoses each year from 2009 to 2014.”*

This excerpt highlights that the annual number of new HIV diagnoses has plateaued around 700 in recent years. MDPH and the HIV community are working together to understand the nature of that plateau and to identify effective strategies to break through it while striving to provide unfettered access to high quality, life-extending care, free from stigma and discrimination, to all residents. It is worth noting that the most recent data for 2014 is showing signs of a real drop in new diagnoses. This drop is potentially related to the influence of pre-exposure prophylaxis (PrEP) for prevention, which was introduced in 2012.

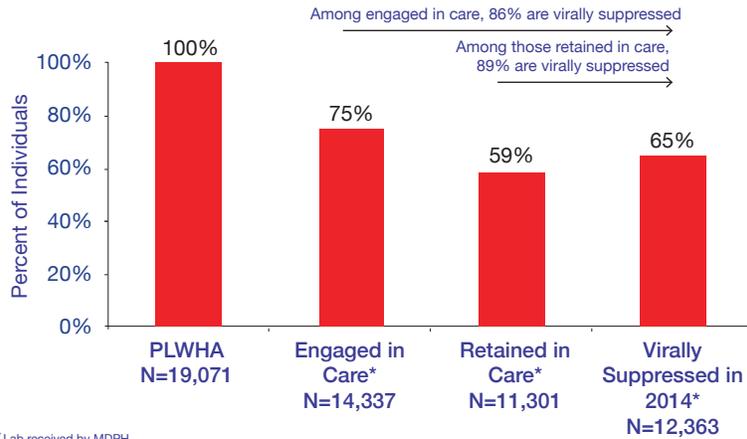
The report also describes state and federal investments in HIV/AIDS prevention, care, and supportive services. These investments are substantial, amounting to between \$450 and \$500 million in FY2016. The financing of these healthcare services is important to the state budget as it provides a positive return on investment. A recent estimate<sup>1</sup> determined that the state will save more than \$1.8 billion in HIV-related health care costs from infections averted in the Commonwealth since 2000.

**Figure 1. Trends in the Number of HIV Infection<sup>1</sup> Diagnoses and Deaths among People Reported with HIV/AIDS: Massachusetts, 2000-2014**



<sup>1</sup>Reflects year of diagnosis for HIV infection among all individuals reported with HIV Infection, with or without an AIDS diagnosis. Data Source: MDPH HIV/AIDS Surveillance Program; Data as of 3/1/16

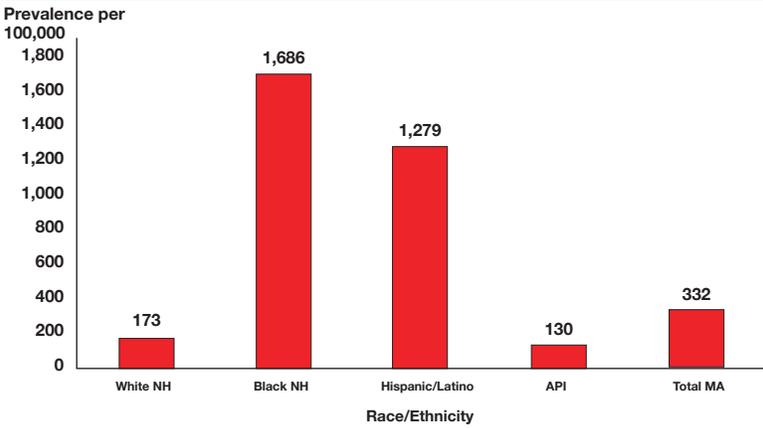
**Figure 2. Stages of HIV Care Among People Living with HIV/AIDS in Massachusetts<sup>1</sup>**



<sup>1</sup> Lab received by MDPH  
<sup>2</sup> Includes Individuals diagnosed through 2013 and living in MA as of 12/31/14, based on last known address, regardless of state of diagnosis  
 Data Source: MDPH HIV/AIDS Surveillance Program, cases reported through 1/1/16

Overall, Massachusetts is fortunate to be performing exceptionally well with regard to moving people along the HIV Care Continuum (Figure 2). Among those persons living with HIV/AIDS who are engaged<sup>1</sup> in care, 80% are virally suppressed and among those who are retained<sup>2</sup> in care, 89% are virally suppressed<sup>3</sup>. When this analysis is limited to only those individuals with evidence of care in Massachusetts in the last five years, the share is even more encouraging at 89% and 77%, respectively.

**Figure 3. Age-Adjusted HIV/AIDS Prevalence Rate per 100,000<sup>1</sup> Population by Race/Ethnicity: Massachusetts, 1/1/16**



<sup>1</sup> Population size for rate calculations are based on 2010 population estimates from the MDPH Bureau of Health Information, Statistics, Research and Evaluation: NH = Non-Hispanic, API = Asian/Pacific Islander  
 Data Source: MDPH HIV/AIDS Surveillance Program, data as of 03/01/16

Probably the most outstanding feature of the HIV/AIDS epidemic today is the state of persistent health disparities borne by minority and vulnerable populations. Deeper analyses of the Care Continuum (Figure 2) reveal disparities of engagement, retention, and viral suppression by race/ethnicity, gender, age, geographic location, and other sub-divisions of the data. A clear example of the health disparities that persist in Massachusetts is highlighted in the introduction of the 2017-21 Massachusetts Integrated Prevention and Care Plan. The introduction states that, “Black non-Hispanic and Hispanic/Latino state residents are affected by HIV/AIDS at levels ten times and seven times that of the White (non-Hispanic) population.” (Figure 3) The figures are even more pronounced when deeper analyses of the data are conducted. The report also outlines additional examples of health disparities in the Commonwealth that affect women of color, young men who have sex with men, transgender individuals, immigrants, and other key populations.

# Origins of Getting To Zero:

## Applying 90-90-90 as a Pathway to Zero

Getting to zero has been a dream of those impacted by HIV/AIDS since the beginning of the epidemic. That vision was turned into a transformative agenda for the global HIV response by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and their partners in 2010 who defined zero to mean zero discrimination, zero AIDS related deaths, and zero new HIV infections.

Since 2010, as the concept evolved and built momentum, an ambitious treatment target was established to end the AIDS epidemic. The target uses the HIV Care Continuum as a point of focus for activities that will contribute to the getting to zero goals and establish a new narrative on HIV treatment. These goals are time bound and ask that by 2020, 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy, and 90% of all people receiving antiretroviral therapy will have viral suppression. Jurisdictions that are able to strengthen their local Care Continuum in this way by 2020 are then projected to achieve 95-95-95 by 2030 and be on the ‘fast-track’ to zero.

In the United States, a few early adopters have led the way in making local commitments to these global goals. The state of New York and city of San Francisco stand out as jurisdictions whose local leadership focused efforts around the 90-90-90 platform as a pathway to achieving the getting to zero goals early. Massachusetts is not far behind, and in comparison is ahead, of these jurisdictions in terms of annual new HIV infections and AIDS related deaths. In terms of leadership, the Massachusetts Department of Public Health has acknowledged and incorporated the 90-90-90 platform into the new integrated state plan’s proposal for improving health outcomes for persons living with HIV. Health disparities persist however and Massachusetts, like the rest of the nation, will need to do more to reach all populations with equitable access to HIV prevention, care, and supportive services moving forward.

Getting To Zero is an excellent opportunity to address these challenges. By recognizing the global call to action, and responding to it, the state can energize communities, mobilize resources, and confront

### THE TREATMENT TARGET<sup>1</sup>



diagnosed



on treatment



virally suppressed

### Revolutionizing the way we think about prevention<sup>2</sup>

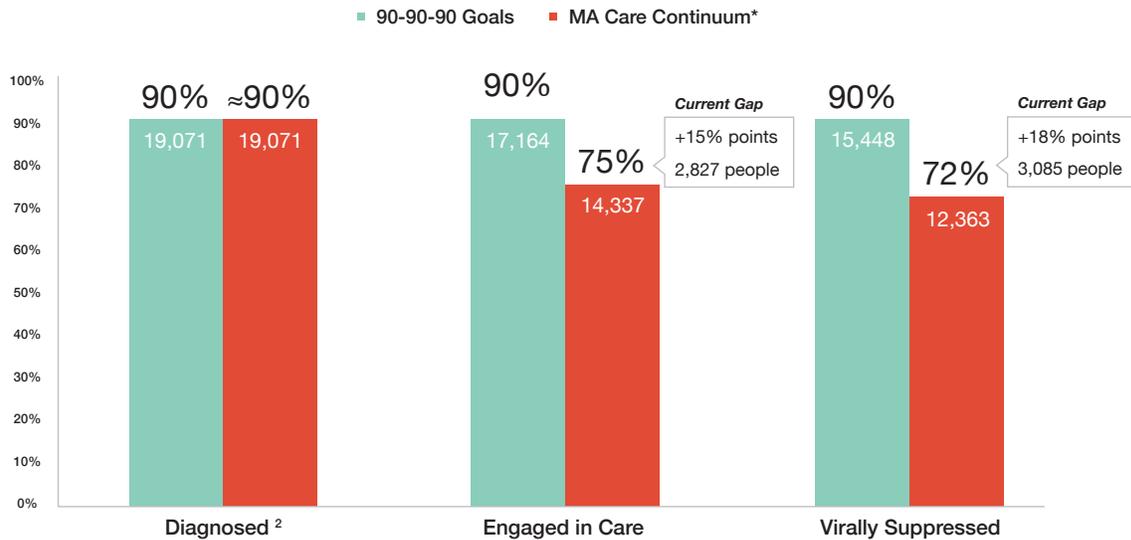
Individual	>>>	Network
Leaflet	>>>	Social Media
Victim	>>>	Actor
Institutions	>>>	Movement
“We know what works”	>>>	“You know what works”
Prevalence	>>>	Incidence
Treatment vs. prevention	>>>	Treatment and prevention
AIDS is exceptional	>>>	AIDS leads the way

challenges that perpetuate a system that is not working equitably for everybody. In addition to 90-90-90, global suggestions have been proposed to revolutionize the way we think about prevention as well. In combination, these strategies have the potential to set the Commonwealth on the pathway to zero. So how close is Massachusetts to the first step on that pathway?

<sup>1</sup> Reprinted from: 90-90-90 An ambitious treatment target to help end the AIDS epidemic, 2014, page 1

<sup>2</sup> Reprinted from: Getting to zero: 2011-2015 strategy Joint United Nations Programme on HIV/AIDS (UNAIDS), page 33

**Figure 4. How Close is Massachusetts<sup>1</sup> to the UN/WHO 90-90-90 Goals  
A 2014 Point In Time Estimate to Provoke Discussion**



\* Estimates derived from "2017-2021 Massachusetts Integrated HIV Prevention and Care Plan"  
 1 Includes individuals diagnosed through 2013 and living in MA as of 12/31/14, based on last known address, regardless of state of diagnosis  
 2 Estimation determined using the low estimate for undiagnosed or unreported PLWHA as reported in the 2015 MDPH epidemic at a Glimpse Fact Sheet  
 - Data Source: MDPH HIV/AIDS Surveillance Program, cases reported through 1/1/16

It appears that Massachusetts may already be quite close to achieving the 90-90-90 treatment targets. As a preliminary analysis a coalition data & evaluation working-group looked at publicly available data to construct the table presented in Figure 4 above. This table shows a comparison between the 90-90-90 treatment targets and the 2014 Massachusetts HIV Care Continuum. The table shows Massachusetts to be within twenty percentage points of the three treatment targets, and likely at or very near 90% of all residents living with HIV aware of their HIV status.

According to this analysis, there are approximately 2,287 individuals whose HIV status is already known to them and to the Commonwealth who are not engaged in care. There are approximately 3,085 individuals who do not have a record of having viral suppression. Not all individuals engaged in care necessarily have viral suppression and some persons counted in this projection may have moved permanently out of state and are no longer residents. The projection is very encouraging, lending validity to the concept that in the Commonwealth achieving 90-90-90 by 2020 as the first step on the pathway to zero is not an impractical goal. Details about the data sources, methodology, and limitations can be found in Appendix B.

Looking forward, as the epidemic is further stymied, researchers, program designers, and advocates will be challenged to answer more refined questions at the local level. In this era, answering questions of how the Commonwealth is performing against the cascade will require highly detailed and frequently published reports, striving for biannual reporting, using both prevalence and diagnosis based approaches as recommended by the Centers for Disease Control. Many complex questions are already on the table that require refined analyses of this type to confront, particularly with regard to addressing local health disparities.

The Getting To Zero Coalition's data & evaluation working group is thinking about what is next. One obvious and central discussion is how to develop an advanced methodology for future iterations of the Massachusetts vs. 90-90-90 comparison table in Figure 4. Future iterations will include collaboration with the state Department of Public Health with the goal of responsibly accessing more timely data to create a regularly updated analysis of the Commonwealth's position relative to the 90-90-90 goals.

# The Getting To Zero Coalition:

## Starting the Conversation in Massachusetts

Lots of work has been done to start the getting to zero conversation in Massachusetts, and the conversation is far from over. To provide a framework for the coalition nearly 30 organizational partners were recruited, representing all six health service regions in the state, followed by an announcement at the Massachusetts State House on World AIDS Day 2015. This ceremonial announcement made by organizations signified the start of getting to zero in Massachusetts, but the coalition is much more than organizations. Intentional steps were taken to seed the progression from an institutional structure to a community movement. That work will be expanded upon to include new community partners and advocates in 2017 and beyond.

Throughout the course of 2016, an effort was made to strategically communicate to the local HIV community the global and national momentum building around ending the epidemic and getting to zero. This started with asking the question, “what does getting to zero mean for Massachusetts?” Three working groups were organized with experts and members of the HIV community from across the state focused on areas of prevention, comprehensive care, and data & evaluation. Additionally, regional community forums were hosted in partnership with local community based organizations and health centers in cities representing a high prevalence of HIV/AIDS. For all meetings careful notes were collected from facilitated discussions with community members who consisted of persons living with HIV/AIDS, physicians, case managers, peer staff, local community members, and representation from the state Department of Public Health. Participants were highly diverse by race/ethnicity, gender, age, sexual orientation, and HIV status. A public survey was also provided online to collect concerns, comments, and recommendations related to HIV/AIDS care and services in the Commonwealth as well.

In total, ten community forums and ten working group meetings were hosted, with 286 participants. Input collected during these meetings was used to frame the key priorities outlined in this document. The locations of the community forums are provided in the figure below, and a selection of repeated themes and comments from those forums are listed in the table on the following page.

### CITY AND HOST SITES OF COMMUNITY FORUMS

**Lowell,**  
Lowell Community Health Center

**Lynn,**  
The Lynn Museum

**Worcester,**  
AIDS Project Worcester

**Boston,**  
The Living Center

**Springfield,**  
Baystate Health

**Boston,**  
Codman Square Health Center

**Brockton,**  
BAMSI Cope Center

**Babson Park,**  
Next Step, One Love Project

**New Bedford,**  
Greater New Bedford Community Health Center

**Framingham,**  
JRI Health, Program RISE



## COMMUNITY LISTENING FORUM KEY THEMES AND COMMENTS

### Case Managers

- We feel like we are being asked to do more paperwork and that our one-on-one time with clients is suffering because of it.
- We are frustrated by long wait times or too strict eligibility criteria for ancillary supportive services that limit our ability to make referrals for our clients.
- We find it difficult to keep clients engaged because they want more services than we are empowered to provide.
- In smaller cities, we find it difficult to identify local providers and mental health clinicians who have HIV experience, LGBTQ experience, are non-stigmatizing, and take our clients insurance.

### Outreach Staff

- We used to do more street-level outreach and engagement, and it feels like those programs were scaled back.
- We really liked rapid tests and still have some issues with doing mobile 4th generation testing.
- We need to do outreach and education through social media channels and sexual networking apps to be effective.
- We need to be case managers for high-risk negative clients and be able to offer them supportive services.
- We need to earn community trust, and that often means practically living with people and being able to act quickly when a client decides they are ready to get tested, start PrEP, use emergency nPEP, or get back on therapy after a period of disuse.

### PLWHA

- Most long term survivors with HIV never expected or planned on living this long, we are grateful but concerned about maintaining the services we need to stay healthy another 20 years.
- Unless you go into Boston or another major city there are really limited options to get involved in peer groups and HIV community activities, and that is isolating.
- As young people living with HIV we do not want to be tokenized, but treated with respect.
- As young people living with HIV we may see a cure or vaccine in our lifetime and that is exciting to us, we want to be included and receive clear direction on how to be involved in advocacy.

### Advocates

- People in communities with the highest prevalence or highest rate of HIV infection have community and personal trauma that needs to be tackled to address HIV/AIDS.
- We need community education because there is still stigma and discrimination that makes it uncomfortable for people to disclose their HIV status and sexual behavior, even to their doctors.
- There are lots of local community members already working on tackling root causes of HIV, and they would benefit from support by the medical establishment and HIV allies.
- Engaging new partners like faith groups, including the Black Church and others, and law enforcement to break bread and build community is how we address the heart of this issue.



# Priority Activities:

## Meeting the Global Getting to Zero Challenge Locally

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The following is a set of priority activities, derived from group conversations and individual interviews with the HIV/AIDS community in Massachusetts conducted over the course of 2016. These conversations included people living with HIV/AIDS, people affected by HIV/AIDS, local community members, case managers, peer health navigators, and providers in cities with high HIV/AIDS prevalence and diagnosis rates. Needs and priorities identified by the community during these conversations were analyzed and compared to published resources related to three content areas covering data & evaluation, prevention, and comprehensive care. Issues related to both clinical care and supportive services for persons living with and at-risk-of HIV were considered within each content area.

The resulting recommendations have been categorized into seven priority activities ranked by potential to impact the epidemic. Collectively these will strengthen the HIV Care Continuum and start Massachusetts on the pathway to zero HIV discrimination, zero AIDS related deaths, and zero new HIV infections. The included priority activities are not an exhaustive list of recommendations presented by the community, but after analyzing qualitative trends, resource reports, and state epidemiology the listed priorities capture in brief the most critical components that will contribute to the getting to zero goals.

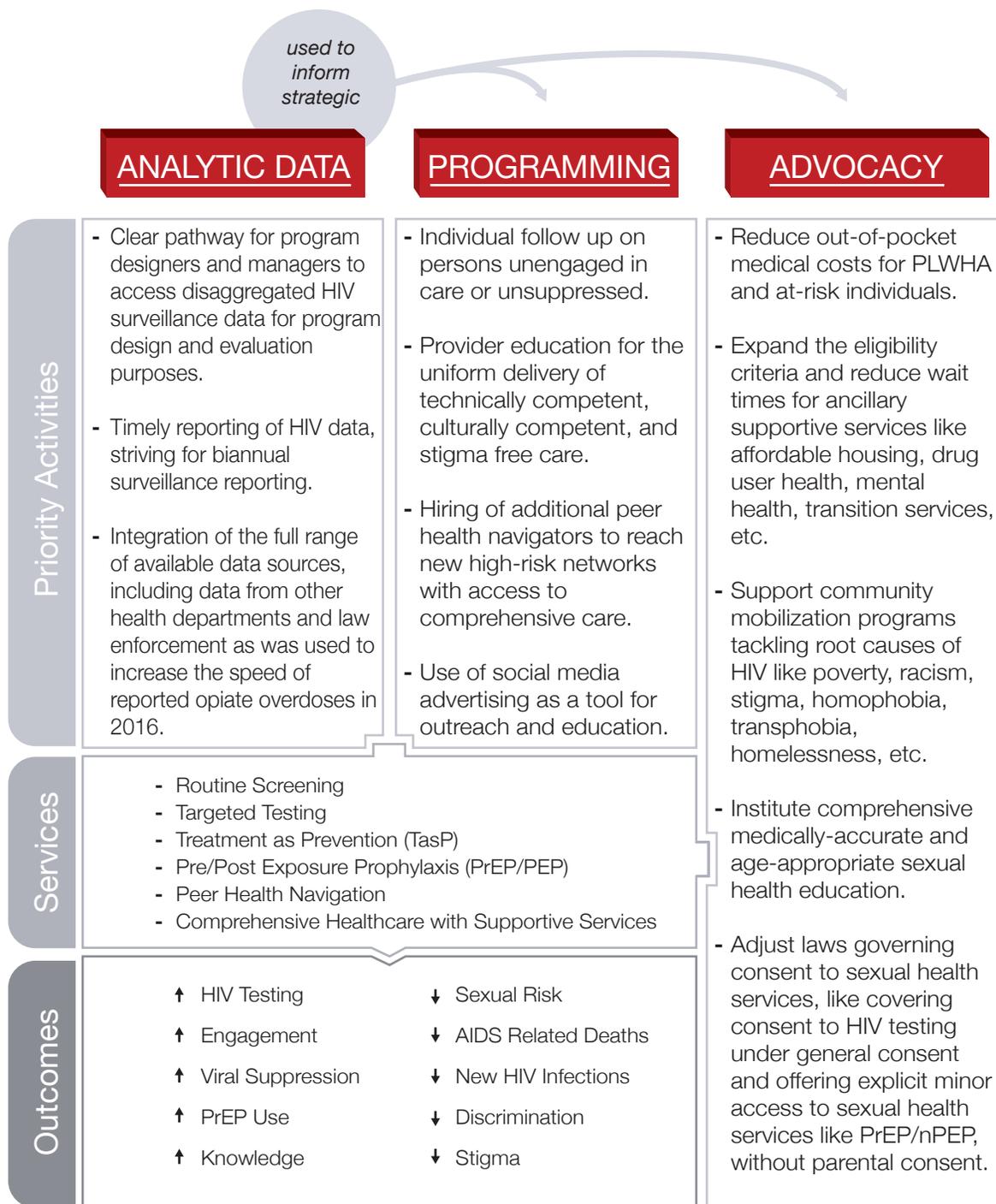
As an advocacy tool and guiding document for change these priority activities should incite controversy, challenge assumptions, and spark conversations among key stakeholders involved in HIV prevention services, and care. Some of the recommended priority activities identify specific entities that should be responsible for their execution, such as recommending the state and cities financially support peer programs to do social media outreach and advertising, including on sexual networking apps. Many recommendations do not specify any particular actor to take responsibility for them, but expect that multiple stakeholders including health facilities, community-based organizations, academic institutes, private industries, advocates, legislators, and elected officials will collaborate to share responsibility for ensuring their implementation and success.

The brevity of this document does not explain in full detail the many ways that each of these recommended activities interact or the way they influence and are influenced by actors in the health care system including patients, providers, and insurers. Many recommendations are presented as a black box, leaving room for interpretation as to where they were derived, how they will be implemented, and by whom. Excellent reference materials are available that provide deeper explanations and implementation strategies for many of the presented priorities. For those interested to learn more select publications are provided in a supplemental reading list (Appendix A).

*“We need to use grassroots tactics to build a movement. Even if we got top down support that would still be the thing we would need to do.”*

- Community Advocate, The Living Center

This document is drafted to build alignment and introduce an ordering of the many components of an effective statewide HIV/AIDS community strategy for Massachusetts. Moving into the next phase of this work specific action steps will be more concretely defined around content areas such as provider training, PrEP awareness and acceptance within communities of color, and community mobilization strategies for advocacy agenda items.



**Figure 8. A Framework for Getting to Zero in Massachusetts**

The table above categorizes selected priority activities showing their relationship to getting to zero HIV discrimination, zero AIDS related deaths, and zero new HIV infections in Massachusetts. The categories include **Analytic Data** derived from HIV/AIDS health surveillance and potentially new sources, **Programming** intended for workforce development as well as client engagement and care, and **Advocacy** for the tools, resources and structural changes necessary to affect the epidemic. These actionable activity areas are linked to the services they support and the population health outcomes they are intended to impact. Arrows are used to indicate the directionality of that impact, either increasing or decreasing.

# Priority Activity One:

## Identifying Undiagnosed Individuals and Linking to Care

The 2017-21 Massachusetts Integrated HIV Prevention and Care Plan estimates that 7-11% of people living with HIV in Massachusetts are undiagnosed. While this is very encouraging, the estimates are based on national samples and may mask inequitable testing rates regionally and among communities of color, women, immigrants, transgender persons, and other sub-populations. Working to enhance testing rates by strengthening routine screening practices, conducting focused testing in key populations, and doing everything possible to reduce barriers or perceived barriers to testing are critical ongoing pieces of HIV/AIDS prevention and care in the state. As more people are tested for HIV there should be a spike in new diagnoses initially because more tests are being conducted. It will become increasingly difficult to locate undiagnosed individuals because there will be fewer of them. This is already the experience in the Massachusetts health care system, which has seen a large drop in new diagnoses since 2000. Technical methods using innovative analytic techniques for strategic in-reach into clinical populations and outreach into new community networks will help to find the last remaining individuals living with HIV and rapidly linking them to clinical care and supportive services.

### Recommended Supporting Activities

#### 1. Train providers on routine HIV screening

Community discussions indicate that although routine HIV screening is recommended in the Commonwealth, individuals and members of the HIV workforce report clients receive inconsistent routine screening or have never been screened for HIV by their primary care provider. A strategic provider training initiative, focused on locations with low reported HIV screening rates or high HIV prevalence should be conducted to enhance routine screening and continually monitor the practice. The strategy should include special consideration for screening in emergency departments and urgent care centers (with appropriate follow up services), which will help to capture populations such as youth transitioning out of pediatric care who have not established a PCP and people who inject drugs using these centers for acute complications of injecting drugs, or, worse, with overdose.

#### 2. Train providers on taking stigma-free sexual histories and behavioral health assessments

Peer navigators and case managers report that clients are not always honest with their providers about their HIV risk behavior and that providers do not always ask the right questions of clients to assess their HIV risk, or do not ask questions in the right way. Provider training on taking stigma-free sexual histories and behavioral health assessments using a trauma informed approach to care should be conducted strategically targeted to areas and communities with high HIV prevalence.

#### 3. Provide guidance from the state on using epidemiologic data and network analysis to identify individuals at risk of HIV infection for HIV testing (i.e. case finding)

While most outreach programs are already employing some form of epidemiologic data analysis to inform community testing strategy, publicly available data is often outdated or too aggregated to give very clear direction on the best local communities or sub-populations to prioritize for strategic outreach and testing. The state can be more instructive on how to focus local population priorities for strategic community testing by providing more clear timely data for program design purposes.

**4. Continue to offer HIV testing to partners of newly diagnosed individuals**

Most sites in Massachusetts offer testing to partners of newly diagnosed individuals as a matter of protocol. Training to reinforce or address any lapses in the practice should continue where they are already employed or be undertaken where the practice is lacking.

**5. Support peer outreach staff in community-based HIV testing settings to use social media for education and outreach**

Social media and sexual networking apps have become ubiquitous in modern LGBTQ culture that these digital marketplaces must be used for advertising and outreach. In order to have an impact this advertising must be paired with a strong online presence and be funded for multi-month campaigns. The state and cities should finance social media advertising and outreach to engage new high-risk communities, particularly young Black and Latino men who have sex with men.

**6. Make it easier for peer outreach staff to do mobile 4th generation testing**

Mobile testing staff in the Commonwealth are performing mobile 4th generation testing. These individuals identified issues that make the process cumbersome such as the state submission form for the tests not being formatted for tablets. The state should seek out any barriers to efficient and effective mobile 4th generation testing and address them as this has the potential to enhance community based testing and replace the rapid tests that are no longer publicly funded in the state.

**7. Ensure that facilities with electronic health record (EHR) technology use HIV screening prompts**

Though providers can develop screen fatigue from too many prompts in an EHR, there is evidence suggesting these prompts increase testing rates and enhance provider compliance delivering quality services that meet the standard of care. Facilities with EHR technology should be encouraged to use HIV screening prompts as reminders to conduct routine screening.

**8. Provide HIV self-testing options with guidance on self-administration of the test and what to do once the result is obtained**

Not everyone wants to receive an HIV test in the same setting. Evidence shows that self-test kits can increase testing rates by increasing the mix of available methods from which people can choose. The state should explore options for providing self-testing paired with guidance on administration and what to do once the result is obtained.

**9. Use case managers and patient navigators to increase linkage to care**

For those persons receiving a positive HIV diagnosis, rapidly linking to care and starting ART as soon as possible is very important. Case managers and patient navigators, particularly those demographically and linguistically representative of their clients, can be very effective at facilitating that linkage. The state should ensure that an adequate number of staff are employed in testing sites throughout the Commonwealth, and that the staff is representative of prioritized populations in that local area.



## **Priority Activity Two:**

# **Retention in Care and Achievement of Viral Suppression for People Living With HIV/AIDS (PLWHA)**

**C**onclusive evidence has been published that demonstrates antiretroviral therapy (ART), when used as prescribed, will suppress the amount of virus present in a person's body and will render that person very unlikely to pass on the virus to another individual. The use of ART for this purpose is called treatment as prevention (TasP), and is a cornerstone of Getting To Zero plans. Additionally, conclusive evidence has also shown that starting antiretroviral therapy earlier in the course of disease, as soon as possible after diagnosis, creates a stronger immune system and provides better long-term health outcomes. The benefits of ART and the simplified recommendation to start therapy immediately following diagnosis make it crucial that all individuals living with HIV know their status, are linked to care, and are supported to achieve and maintain viral suppression. Massachusetts has an excellent record of assisting individuals to achieve viral suppression once they are engaged in care. The groups of people that are most in need of program intervention are those engaged in care that cease to use treatment and those newly diagnosed that delay or avoid treatment. Proactively seeking out individuals known to have unsuppressed virus and engaging them in care as well as having rapid referral systems in place to link newly diagnosed individuals to care immediately following diagnosis will increase the share of persons achieving and maintaining viral suppression.

### **Recommended Supporting Activities**

#### **1. Rapidly link all individuals newly diagnosed with HIV to ART, striving for immediate linkage**

There is substantial evidence that the earlier someone diagnosed with HIV starts treatment, the stronger their immune system is and the less likely they are to pass on the virus to someone else (TasP). Many facilities have strong systems in place to communicate a positive diagnosis and rapidly link persons to ART. A collective goal of all health facilities should be to strive to link newly diagnosed persons to care immediately following receipt of a positive HIV diagnosis.

#### **2. Use clinic databases/surveillance systems for HIV clinical monitoring to support viral suppression and re-engagement in care (i.e. data-to-care)**

Efforts are already underway to help clinical sites, laboratories, and the state surveillance department securely cross-reference patient data to follow patients and ensure they are receiving optimal care. More can be done to increase the efficiency and number of facilities participating in this data-driven patient follow-up strategy. For those patients having difficulty getting annual laboratory tests or maintaining viral suppression, individualized outreach strategies conducted in concert by clinical site staff and state field epidemiologists can be employed to re-engage them in care.

#### **3. Reduce out-of-pocket costs for PLWHA by expanding HDAP to cover all provider fees like co-pays and laboratory fees**

The Massachusetts HIV Drug Assistance Program (HDAP) helps residents who cannot afford to pay the full costs of the HIV-related drugs and health insurance they need. The program reduces cost barriers, but additional costs for co-pays and laboratory fees continue to be a barrier to care for many. Expanding HDAP to also cover these fees will increase access, engagement, and viral suppression for PLWHA.

**4. Use case managers and patient navigators in clinical sites to increase adherence and viral suppression**

During discussions with long term survivors and case managers many issues were identified that result in delaying or stopping the use of ART. These ranged from cultural bias against western medicine or pill taking practices, to concerns over exposure of their status, pill fatigue (exhaustion from taking pills every day for years), and frequent travel to one's home country that disrupts access to medicine. Helping people troubleshoot and overcome these challenges requires having an intimate knowledge of the person and of the insurer, provider, and pharmacy systems at play. In situations where a client is not taking ART, just staying in contact with the client is the only way to keep them engaged. Case managers report that low threshold engagement of this type reduces HIV risk by stabilizing the client, building community, and maintaining a path for rapid linkage to care once the client is ready to initiate or re-initiate ART. This can be challenging because that kind of engagement may not satisfy program reporting requirements, but is very important so the client is not lost to follow-up entirely. The state should ensure case managers are credited for this work and that there are an adequate number of these staff in areas of high need.

**5. Strengthen engagement in care by offering a diverse variety of community programming, particularly in less metropolitan areas**

Rural areas and commuter cities, like Framingham, have limited HIV peer community options and group activities, which was reported to be isolating. In these smaller communities, and even in medium sized cities like Springfield, Lowell, and others PLWHA reported concealing their HIV status and/or limiting disclosure of their sexual orientation due to the threat of community stigma and discrimination. There is often only one community agency delivering HIV services or hosting support groups in these cities. Programs should strive to diversify options for support groups and community engagement to alleviate isolation for PLWHA, should consider innovative online or social media platforms for engagement and the state should financially support these new programs or offer transportation support to individuals that need to travel to participate in peer community activities.

**6. Enhance supportive services by reducing wait times and making eligibility criteria more flexible for key populations to enroll in those services**

Many of the supportive services that key populations need like affordable housing, addiction recovery, and mental health care are provided by the state, however the community reports that long waiting lines, strict eligibility criteria make it difficult for people in need to access them when the need is present and the client is ready to act. In order to better understand these community needs the state is taking action to collect missing information that will guide strategic program design and enhance these services. Community advocacy to ensure that that process is done swiftly and transparently should be undertaken by stakeholders.



## Priority Activity Three: Initiation of Pre-Exposure Prophylaxis (PrEP) for Eligible Persons

*P*re-exposure prophylaxis (PrEP) is the daily use of a single antiretroviral pill that, if taken as prescribed, is safe and effective for the prevention of HIV infection. PrEP does not prevent other sexually transmitted infections, but anyone at elevated risk of HIV can benefit from the use of PrEP to prevent HIV infection. In order to be eligible for PrEP an individual needs to have a recent negative HIV test and receive quarterly screening for HIV, STIs, and other tests to ensure that they are not experiencing any health-related changes from the medication. PrEP is an excellent prevention option for many individuals with elevated HIV risk. There has been a surge of new people using PrEP; however, national reports indicate that this surge is concentrated among White men who have sex with men (MSM). Within communities of color, particularly among young MSM, women, and transgender individuals, PrEP uptake has not been nearly as rapid. For some of these individuals perceived cost, lack of awareness, lack of trust of the medical community, and competing priorities like unstable housing, poverty, stigma, discrimination, and systemic racism are barriers to initiation of PrEP. For some patients their providers neglected to suggest PrEP as an option. In general, provider knowledge and comfort prescribing PrEP is low. This is partly because it is a new intervention and partly because HIV has classically been a specialty field of practice. Inviting providers to participate in PrEP education and engaging key populations with supports to overcome challenges that interfere with PrEP awareness, acceptance, and use will help restore community trust and start people on the road to protecting themselves from HIV infection.

### Recommended Supporting Activities

#### 1. Train providers on Pre-Exposure Prophylaxis (PrEP) for HIV prevention

Individual clients and community-based staff have reported accounts of primary care providers being unfamiliar with PrEP, uncomfortable prescribing it, or unwilling to prescribe PrEP to patients based on assumed sexual risk, even when patients ask for a prescription. Strategically training providers in geographic areas with high HIV transmission rates through PrEP detailing packages, provider-to-provider education, and accredited training courses can help unify the provider approach to PrEP in primary care and specialist settings. The state and local partners should collaborate to see that this training is performed putting emphasis on general practitioner and other family medical providers.

#### 2. Train providers so that they have the skills necessary to provide client centered care

Clients in the Commonwealth report that they often feel uncomfortable sharing details about their sexual behavior with their provider for fear of stigma and that providers often ask questions that are perceived to be insensitive or hetero-normative in narrative. Providers that take unbiased sexual and behavior health assessments and offer stigma-free prevention services will be more capable of providing appropriate prevention services, such as PrEP, to eligible persons including the HIV negative partner in serodiscordant couples. Some sites in Massachusetts have done a lot to carefully integrate PrEP into clinical practice. Training to reinforce or address any lapses in the practice should continue or be undertaken where technical PrEP competency as well as sexual health competency, LGBTQ competency, and/or racial/ethnic competency is lacking.

**3. Reduce out-of-pocket costs for persons on PrEP by expanding PrEP (DAP) to cover all provider fees like co-pays and lab fees**

The Massachusetts PrEP (DAP) pilot program will help HIV negative residents who need assistance paying for PrEP medication to cover any required prescription co-pays and deductibles. Access to this program is limited to a small number of pilot sites and only covers fees associated with the medication, however using PrEP requires quarterly doctor visits and laboratory tests. The program should be eligible to patients receiving a PrEP prescription from any provider in the Commonwealth and should be expanded to include associated provider co-pays and lab fees associated with being on PrEP to defer costs and reduce that additional barrier to equitable access and use of the intervention.

**4. Offer ancillary supportive services to persons at an elevated risk of HIV**

For key populations such as young Black (NH) and Latino men who have sex with men, Black and Latina women, transgender individuals, immigrants, sex workers, and migrant workers addressing social drivers of HIV like homelessness, poverty, violence, addiction, and mental health tend to supersede the seeking of HIV prevention. To address these social and structural barriers to HIV prevention, ancillary supportive services and referral networks should be offered to those at an elevated risk of HIV.

**5. Advertise PrEP to communities with the most need, making full use of epidemiologic surveillance data in order to create focused advertising campaigns that are tailored to local communities**

Peer outreach staff across the Commonwealth report feeling that many traditional outreach programs had been defunded or redistributed to enhance clinical programming (infrastructure and clinical staff). To make the most of remaining resources, advertising and education programming needs to be conducted using high quality and up-to-date epidemiologic data and network analysis in order to be done strategically and efficiently. Pilot advertising campaigns of HIV/STI counseling and testing services have demonstrated that using social media and sexual networking app based advertising works to reach certain key populations. For those sub-populations the state should financially support community-based peer staff to develop outreach and advertising campaigns using these channels.

**6. Use clinic databases/surveillance systems for HIV clinical monitoring and systematic monitoring of PrEP candidates within clinical sites, with a focus on equitable PrEP uptake by race/ethnicity**

While CDC guidelines recommend anyone receiving a recent STI diagnosis as a candidate for PrEP, accounts can be found of individuals being treated for multiple STIs in the state and not receiving any PrEP counseling. This may be because they receive services at multiple locations, do not return for follow-up appointments, or receive care from providers who need PrEP training. Similar to the use of secure patient monitoring to support viral suppression and re-engagement for those clients falling out-of-care, secure data-to-care strategies can be used at the site level to confidentially identify likely candidates for PrEP counseling and offer an opportunity for that counseling in a community based or clinic setting. The use of the state's surveillance data should be explored as a resource for this work, but with appropriate privacy safeguards.



## Priority Activity Four: Strengthening of Services for Key Populations

The HIV epidemic has been so well addressed in Massachusetts that the overall number of HIV infection diagnoses and deaths among people reported with HIV/AIDS have been reduced by 47% (from 1,191 to 629) and 35% (from 353 to 231) during the period 2000-2014. There has however been a plateau of HIV diagnoses at an annual average of 691 from 2009-2014, and among those being diagnosed vulnerable populations remain disproportionately impacted by HIV/AIDS. Providing investment and innovative program strategies to prevent new infections and provide HIV care for these vulnerable populations is warranted. Among those populations with the most vulnerability include people who inject drugs, incarcerated or institutionalized individuals, members of high risk sub-populations such as youth, Black and Latino men who have sex with men, Black and Latina women, transgender persons, and non-US born individuals. Investigating circumstances that maintain persistent health inequities is critical to achieving the getting to zero goals. The issues driving HIV in each of these populations are unique and will require custom health system responses to address them. Even with innovative programming collaboration is needed among the state, cities, health care providers, community based organizations, and the communities themselves to make an impact and that is something Massachusetts has a strong legacy of doing well.

### Recommended Supporting Activities

#### 1. Expand drug user health services

Massachusetts recently lifted a ten-site cap on safe syringe program (SSP) sites, which provide clean needles and syringes to people who inject drugs (PWID). These sites provide a clinical environment that takes a harm reduction approach to wellness and incorporates health education, linkage to care, and overdose protection. The opening of strategically placed additional SSP sites should be undertaken by partnerships between the state and local communities in areas of high injection drug prevalence. Additionally strengthening supportive services like reducing wait times to detoxification and rehabilitation services, which SSP staff report as a continued barrier to addiction recovery in Massachusetts, are proactive measures that need to be taken to protect drug user health and prevent potential HIV/HCV outbreaks among injecting networks in the Commonwealth.

#### 2. Strengthen HIV/AIDS services within correctional and institutional settings, including upon entering and exiting these settings

Community based health navigation staff that facilitate HIV counseling, testing, and linkage to care report that individuals in Massachusetts often suffer from lapses in insurance coverage, access to ART, and peer support upon entering and exiting correctional and institutional settings like jails, prisons, addiction recovery programs, housing shelters, mental health settings, and assisted living centers. Strengthening the continuum of services during entry into these settings, while in residence, and when exiting and returning home is a community priority. Additionally, incorporating PrEP awareness and access into these settings will help prevent HIV infections, which the community identified as either being slow to occur or not occurring at all.

### 3. Strengthen HIV/AIDS services for key sub-populations with inequitable rates of infection

Similar to national HIV disparities, in Massachusetts individuals from certain key sub-populations are contracting HIV at rates much higher than their White and/or US-born counterparts. Young Black and Latino men who have sex with men, Black and Latina women, transgender persons, non-US born individuals, sex workers, migrant workers, and homeless populations are included among the most impacted groups. Community health center staff and peer program staff from different areas of the Commonwealth report that programs focusing on these populations have existed for many years but are just now being expanded upon at many sites. A repeated criticism of efforts to reach these populations with services is that the health workforce designing the services are often not demographically and linguistically representative of the communities being served. Additionally, community representatives and clients themselves are not included enough in the process of program research, design, and evaluation. A vigorous effort should be made by all sites to strengthen services for sub-populations with inequitable local rates of infection or disease prevalence and to include representation from those populations in the design of new programming.

### 4. Assess need and develop programs to strengthen supportive services for persons aging with HIV

Getting to zero does not mean there will be zero people living with HIV/AIDS. The roughly 20,000 people living with the virus in the Commonwealth will need to be supported with quality services throughout their life. In community discussions long-term survivors of HIV/AIDS asked to focus attention on the fact that the majority of PLWHA in Massachusetts are over the age of 50. Strategies need to be put in place to prepare for assisting these individuals, and right behind them potentially the last generation to age with HIV, to transition into retirement, assisted living if necessary, and after many years end of life care. New programs may need to be devised to monitor the quality of services for people aging with HIV, to identify new and emerging service needs, and to provide training on HIV, LGBTQ, and racial/ethnic competency in retirement, assisted living, and geriatric settings. These services should include modules focused on recent sexual activity, drug and alcohol use, and behavioral health, which are often reportedly overlooked by primary care physicians treating these populations. In care and institutional settings the people aging with HIV will be their best advocates and should be supported to act as vocal stakeholders and consumers of these services.



## **Priority Activity Five:**

# **Enhancement of Health Surveillance and Data Reporting Systems**

**M**assachusetts is a major technology hub and global leader in research, development, and innovation. The Commonwealth is well positioned to use its creative capacity and analytic resources to inform strategic programming and advocacy work that will contribute to population health outcomes. An essential part of that support is supplying front line staff with the comprehensive and timely information they make strategic programming decisions for their local communities. That programming may be focused on training providers, or may be focused on delivering testing, prevention, linkage, engagement, and adherence services to clients. There are sources of data available that report on quality of care, provider availability, population level epidemiology, and community needs. One issue confronted by staff designing effective programs and interventions or undertaking advocacy is how to access detailed and timely information to inform decision-making in real time. Excellent steps have been taken by the state this past year to consolidate HIV data in the infectious disease surveillance program, to implement refined data capture systems across state-funded programs, and to work with the community to investigate complex questions to better inform regional and local strategic priorities. With focused advocacy these efforts can be expanded upon to reach their full potential and further influence the course of the epidemic.

### **Recommended Supporting Activities**

- 1. Centralize local community and population level data sources to make public, private, and academic data more accessible to local program design and evaluation staff**

Individuals at community based organizations and health centers reported spending large amounts of time searching for or organizing community and population-level clinical/surveillance data in order to design local programs and evaluate their impact. Centralizing these data sources and providing clear guidance on how to use them would enhance the capacity of staff to access relevant information quickly and make informed strategic program decisions for work they are funded to do by the state and cities.

- 2. Increase the frequency of epidemiologic data reporting, striving for biannual surveillance updates**

Program designers and peer outreach workers in the state indicated some frustration in trying to design programs for their local communities based on epidemiologic data from state and city sources. There are systemic factors that limit the speed with which that data can be processed and information released. The Department of Health is taking steps to streamline HIV data collection and reporting while maintaining accuracy so that the data reflects the true epidemic in the Commonwealth. One factor that could help with speeding up the process is timelier reporting from providers to the state surveillance program. Still cleaning, cross-referencing, and analyzing the data is an enormous undertaking, which should be supported by the community. By advocating for a focused effort to increase the frequency of data reporting, striving for biannual updates, we can enhance our information systems and strengthen our program design and evaluation capability at the local level.

**3. Explore innovative data analyses and visualization technologies as new methods for information sharing and strategic program design and evaluation**

Two cutting edge data visualization technologies stand out as real opportunities to enhance analytic capacity and inform more strategic program design and evaluation, geospatial mapping of disease hot spots, and phylogenetic mapping of HIV to understand transmission networks and respond quickly to disease outbreaks. Other innovative technologies may exist and should be explored, but the state should at a minimum provide the resources necessary to implement programs that make strategic use of these established data visualization tools.

**4. Work with a combination of community partners, program designers, and academic clinicians to continuously refine a set of unique Massachusetts headline and key indicators for Getting To Zero**

In order to have a uniquely Massachusetts perspective and to create an opportunity for the HIV community to play a role in defining priorities and identifying key indicators for quality services and programming, an effort should be made on the part of the coalition to organize the HIV community to annually review state HIV/AIDS indicators and recommend modifications or additions that will address community priorities, including exploring indicators for stigma and discrimination.

**5. Create a digital dashboard with timely reporting of headline and key indicators for the Massachusetts Getting To Zero initiative**

Making the progress towards our collective HIV/AIDS goals publicly visible can be a tool for organizing and disseminating information as well as motivating community participation. This suggestion came up in community forums and other jurisdictions are already making use of digital dashboard of public indicators hosted online. The state of New York and the global Fast Track Cities Initiative are two examples of efforts using dashboards of this type. These platforms can be looked at as models to build a dashboard that is unique to Massachusetts as a tool to organize and share information.



## Priority Activity Six: Adoption of Sexual Health as a Human Right

*H*uman rights are considered a matter of international law and often not explicitly linked to state law and civic culture, but the HIV epidemic has had a uniquely global impact and has galvanized individuals and communities around the world to this common cause. By supporting the ambitious Getting To Zero goals established by the United Nations and elevating our vision for sexual health in Massachusetts to the status of a human right, we can highlight the connection between our local effort and the impact this has on both the global epidemic and the achievement of a liberated, inclusive, and equitable right to sexual health for all. The best way to show a commitment to an ideal such as this is through action. Identifying and undertaking advocacy to address structural barriers to knowledge, self affirming behavior, and social determinants of health will empower the community, start conversations around HIV prevention and care, and support efforts to alleviate other community pressures fueling the epidemic.

### Recommended Supporting Activities

1. **Expand on the minor consent law for HIV and STI treatment without parental consent to also cover preventative treatment, explicitly including PrEP**

State law in Massachusetts allows for providers to determine that a minor is competent to consent to clinical HIV and STI treatment without parental consent when it is in the best interest of the patient. During community discussions it was reported that this minor competency rule is limited in its effectiveness. Education programming to ensure providers and minors are aware of this law should be undertaken. In addition, the language of the law is limited to HIV and STI treatment. PrEP is a therapeutic treatment, but used for prevention purposes. A legislative amendment should be passed to explicitly include not only “treatment” but also “prevention services”, which would include PrEP in the language of this law.

2. **Requiring explanation of benefits (EOB) documents to be sent securely to patients rather than policyholders, when the patient is a minor**

State law in Massachusetts allows for minors to receive treatment for HIV and STIs without parental consent in order to protect the individual’s ability to receive confidential care. The law does not explicitly require that insurance information, such as “explanation of benefits” (EOB) documents, are sent securely to the patient (i.e. young adult or minor) rather than the policy holder (i.e. the parents). This is important when that young person is using parental insurance to support sexual health services. Passing legislation to require EOB documents be sent securely to patients will increase privacy protections for minors receiving sensitive health services.

**3. Modify the Commonwealth's HIV testing consent law to be in full compliance with the CDC-recommendation for opt-out testing**

State law in Massachusetts has two remaining gaps to be in full compliance with the CDC recommendation for opt-out testing. The law currently requires informed verbal consent for HIV testing, and written informed consent for each requested release of HIV test results. The CDC recommends allowing for institutions to incorporate implicit consent to HIV screening under the umbrella of general consent to care, and to allow for two kinds of routine disclosure, one to providers who are assisting in rendering care even if they are outside the institution of licensure, and two to health insurers in day-to-day billing. Legislation should be passed to address both of these gaps in our current law, while maintaining the important privacy protections offered in Massachusetts.

**4. Pass legislation to require all local school districts provide comprehensive, age-appropriate, and medically accurate sex education**

State law in Massachusetts currently allows for school districts to determine if they will have a sexual health component in their local curricula and does not require age-appropriate and medically accurate sexuality education. A state bill called An Act Relative to Healthy Youth is currently before the Massachusetts legislature and would address some of these concerns by requiring those school districts that elect to have sexuality education to use a curriculum that is age-appropriate and medically accurate. This act should be at a minimum passed and enforced in the state.

**5. Advocate for increased investment in promising new research including areas such as cure, vaccine, long-lasting treatment and chemoprophylactic options**

During a facilitated group discussion, youth living with HIV conveyed their excitement about promising areas of research for both prevention and care. It is possible that a sixteen-year-old living with HIV will likely see the advent of long-lasting treatments and pre-exposure prophylactic options, an effective vaccine, and potentially a functional or genuine cure for HIV/AIDS within their lifetime. While in pursuit of the getting to zero goals promising research in these fields should be incorporated as part of the advocacy agenda to inspire participation and keep resources trained on exploring every possible opportunity to impact the epidemic.

**6. Support local community development projects tackling root causes of HIV in neighborhoods with significant new diagnoses and/or high HIV prevalence**

Therapeutic advances and a supportive infrastructure have made living with HIV a manageable chronic infection instead of a crisis situation for most Massachusetts residents. For populations at elevated risk social determinants of health such as poverty, homelessness, violence, lack of access to education, racism, sexism, heterosexism, transphobia, and more have been shown to contribute to HIV infection. Addressing these issues at the structural and community level is beyond the sphere of influence of the medical establishment alone. This work requires multifaceted collaboration. HIV advocates and their allies can identify local grass roots organizations and individuals already working to address drivers of HIV and form allegiances to support one another's work where it exhibits intersectionality.



## Priority Activity Seven: Alignment with External Getting To Zero Efforts

In our increasingly global world with mass migration from commerce and leisure, regional instability, and in the near future from displacement due to climate change, every disease is 24-hours away and on the move. In Massachusetts, about 35% of new diagnoses occur among individuals originally born outside the US, and about 15% of people living with HIV were first diagnosed in another state. Addressing HIV/AIDS requires advanced coordination by many actors, all-working together at the same time in very different contexts towards common goals. Supporting this work will require being intentional about building regional, national, and global partnerships across the many levels of the health care system, supporting other initiatives with intersecting agendas, and being vigilant about changes to the health care system and how they will impact key populations and PLWHA.

### Recommended Supporting Activities

#### 1. Encourage Boston and other major cities in the Commonwealth to become Fast-Track Cities by signing the Paris Declaration

The Fast Track Cities initiative is an international HIV initiative calling on mayors of cities to be local champions of ending the epidemic by striving to achieve the UN/WHO 90-90-90 goals by 2020. Achieving these goals sets cities 'on the fast track' to reaching zero by the year 2030. The initiative was launched on World AIDS Day 2014 in Paris by the International Association of Providers of AIDS Care (IAPAC), the Joint United Nations Programme on HIV/AIDS (UNAIDS), and the United Nations Human Settlements Programme (UN-Habitat). This partnership was consecrated by a compact signed in Paris (*The Paris Declaration*) with the mission of organizing a global movement around the UN/WHO 90-90-90 goals. Originally 26 city mayors signed the Paris Declaration and subsequently additional mayors have been signed, including nine from the United States. Providence is the only New England city so far to make the commitment. Having the mayors of cities in Massachusetts sign onto the Fast Track Initiative will send a signal of support and solidarity for this global cause and provide additional support for efforts here in Massachusetts.

#### 2. Coordinate with other New England Regional Getting To Zero Efforts

New England is an intimate region in North America with small states and high interstate and intercity migration between them. Having a conversation about getting to zero in Massachusetts demands that we coordinate to support the HIV/AIDS needs of our neighboring states and cities throughout all of New England. Many initiatives aligned with Getting To Zero Goals have been started in New England including the Campaign to End AIDS in Maine and On the Road to Zero in Vermont. Providence, Rhode Island is a Fast Track City. Striving to work collaboratively between state and city campaigns will increase the chance of our collective success.

**3. Support the national Act Now: End AIDS coalition**

On September 15, 2016 a national coalition under the name Act Now: End AIDS was announced during a press conference at the United States Conference on AIDS. This community mobilization campaign is building a framework for a collaborative effort to end the AIDS epidemic in the United States. In the press release accompanying the group's formation, Act Now states that this coalition will, "provide technical assistance to individuals and organizations nationwide who are doing work on the city, state, and regional level to address the specific needs of their communities in terms of policy, budget, outreach, and education. They will also facilitate relationships with health departments to share the data necessary to set and achieve benchmarks to ending the epidemic." The Massachusetts Getting To Zero Coalition was signatory as a supporting member of this announcement and has been supportive of this national effort.

**4. Ensure proposed state and federal health system and payment reform changes enhance access to necessary clinical and supportive services**

The United States health care system is going through a turbulent period of transition and reform that will affect federal and state HIV/AIDS prevention, care, and supportive services. It is unclear exactly what changes will be proposed but they may affect the way that services are paid for, the way that people access insurance, and eligibility for certain ancillary supports. The HIV community should stay vigilant of proposed changes in order to undertake advocacy as is necessary to ensure that the needs of populations at risk and PLWHA are equitably addressed. The Massachusetts Getting To Zero Coalition should engage with our local allies working on health reform, such as Health Care For All and the Massachusetts Public Health Association. Nationally, the coalition should work with AIDS United to monitor and advocate for federal changes as warranted.





# Next Steps:

## How to Address HIV/AIDS & Prioritize Equity in Massachusetts

After soliciting community input over the course of nine months a couple features that stand out are the resilience and strength of the community participants. Whether in the Western, Central, Northeast, Metrowest, Southeast, or Greater Boston region of the Commonwealth there is a unifying camaraderie felt for and by everyone living with or affected by HIV/AIDS and a proud enthusiasm for writing the final chapter of the epidemic in the Commonwealth. Confronting issues around racial and social justice and addressing health disparities must be the foundation of this work. Taking a movement mentality, the coalition must communicate with and be expanded on by allies in local communities impacted by HIV/AIDS whose areas of focus intersect with the getting to zero goals. These include areas such as education, employment, affordable housing, health literacy, social justice, freedom, equity, de-stigmatization, and non-discrimination. By acting in solidarity with these allies and developing a dialogue around HIV/AIDS, communities will be empowered to adopt and take ownership of this important public health crisis at a local level.

There is cause to be both hopeful and to stay vigilant of change during this era of American health care reform. Necessary health services for HIV/AIDS will need to be protected and strengthened to capitalize on the opportunity to achieve the getting to zero goals. These services will emphasize strengthening the HIV Care Continuum and developing an integrated primary and secondary HIV prevention approach practiced by both infectious disease and primary care physicians<sup>1</sup>. This report is released at an optimal time to gather feedback and identify early anxieties and concerns about proposed and potential changes to services in 2017 and beyond. While the first phase of this initiative has been basic education and information gathering, the next phase will include more structured program design to help address some of the needs, gaps, and barriers identified in this report and the complementary 2017-21 Massachusetts Integrated HIV/AIDS Prevention and Care Plan.

Moving into Phase II of this initiative, the coalition will transition from a broad categorization of priority activities to a structured list of strategic initiatives. These initiatives will be determined by the impact that they are projected to have on a set of public indicators developed through a community engagement process and reported on at regular intervals, striving for biannual reporting. These initiatives will have implementation proposals including clear, specific, and time bound milestones that define the responsibilities and expectations of stakeholders working collaboratively to achieve our collective goals.

### NEXT STEPS

#### Near-Term

- Gather and analyze feedback from the community after the release of this comprehensive report
- Establish working groups focused on defining concrete implementation pathways to deliver on key priorities defined in the report and community input

#### Mid-Term

- Partner with ProjectABLE and others to develop a state lobbying campaign to ensure HIV/AIDS funding
- Formally define a set of public indicators that will be used to evaluate Getting To Zero in Massachusetts
- Expand the getting to zero conversation to new community partners and allies whose work intersects with the key priorities and getting to zero goals

#### Long-Term

- Evaluate progress against the 90-90-90 and other public indicators, and revise priorities as needed

# Supplemental Reading

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Following is a supplemental reading list of reports, publications, and strategic proposals that have informed this report, which elaborate on many of the elements included. These resources can be useful for local program design and evaluation strategy to enhance HIV/AIDS prevention, care, and supportive services across the Commonwealth.

2015 Blueprint for achieving the goal set forth by Governor Cuomo to end the epidemic in New York State by the end of 2020. 2015 | New York State Department of Health

90-90-90 An ambitious treatment target to help end the AIDS epidemic, 2014 | Joint United Nations Programme on HIV/AIDS (UNAIDS)

Black Lives Matter: What's PrEP got to do with it? The State of AIDS in Black America. 2016 | Black AIDS Institute, Annual Report

Connections: From Health Informatics to Improved HIV Outcomes. 2016 | National Alliance of State and Territorial AIDS Directors (NASTAD)

Defining Quality of HIV Services for MSM and Transgender Women: Results of a Systematic Review. July 2016 | MEASURE Evaluation and United States Agency for International Development

Department of Public Health. Bureau of Infectious Disease. HIV/AIDS Surveillance, Surveillance Reports, Epidemiologic Profiles and Research Reports. 2009-2016 | Massachusetts Department of Public Health

Getting to zero: 2011-2015 Strategy. 2010 | Joint United Nations Programme on HIV/AIDS (UNAIDS)

HRS/HAB B, in+care and Other Non-HAB Performance Measurement Results In Massachusetts Clinics, 2010 to 2011. HIV/AIDS Clinical Care Quality Assurance Project. June 2013 | JSI Research & Training Institute, Inc.

Health of Boston 2014-2015: Boston Public Health Commission Research and Evaluation Office. 2015 | Boston Public Health Commission

IAPAC Guidelines for Optimizing the HIV Care Continuum for Adults and Adolescents. 2015 | J Int Assoc Provid AIDS Care

Massachusetts Integrated HIV/AIDS Prevention and Care Plan, HIV/AIDS Services in the Commonwealth: 2017-2021. 2016 | Office of HIV/AIDS Bureau of Infectious Diseases and Laboratory Sciences, Massachusetts Department of Public Health.

New England AIDS Education and Training Center (NEAETC) Needs Assessment Report June 2016. | Prepared for HIV Education Branch, Division of Domestic HIV Programs, Office of Training and Capacity Development, HIV/AIDS Bureau Health Resources and Services Administration

The Lifetime Medical Cost Savings from Preventing HIV in the United States. 2015 | Medical care. Schackman BR, Fleishman JA, Su AE, et al.

Towards an integrated primary and secondary HIV prevention continuum for the United States: a cyclical process model. 2016 | Journal of the International AIDS Society

What Is Required to End the AIDS Epidemic as a Public Health Threat by 2030? The Cost and Impact of the Fast-Track Approach. 2016 | PLoS ONE. Stover J, Bollinger L, Izazola JA, Loures L, DeLay P, Ghys PD, et al.

White House. National HIV/AIDS Strategy. July 2015 | The Office of National AIDS Policy (ONAP)

World Health Organization. Sexual health, human rights and the law. 2015 | Geneva: World Health Organization

# Derived Comparison to 90-90-90

There are limitations to the data available for deriving a comparison of Massachusetts's Care Continuum relative to the 90-90-90 Goals. The following methodology was used to derive the table depicted in Figure 4 on page five of this document.

The Care Continuum depicted in Figure 3 was selected as the baseline year for this comparison, which includes data on individuals diagnosed through 2013 and living in MA as of 12/31/14, based on last known address, regardless of state of diagnosis. This is the most vetted Care Continuum data publicly available by the state surveillance program and depicts the number of persons diagnosed, engaged, and virally suppressed. Two calculations were made based on this estimate to fill in the remaining gaps.

First, in order to calculate an estimate for the total number of people living with HIV, including those undiagnosed or unreported to the Commonwealth, an additional 10 percent was added to the estimated total number of people living with HIV/AIDS (PLWHA). For this estimation the low figure from the range of total people reportedly living with HIV/AIDS from the 2016 Epidemic at a Glance Fact Sheet was applied. The estimated range correlated with CDC estimates used in previous years to approximate the total number of PLWHA in the Commonwealth. The range from those CDC estimates is roughly between 10-15%. Though it is not as conservative as possible, for simplicity the low estimate of 10% was selected as the figure to add to generate the projected total number of PLWHA in this calculation (.9 = 20,272/22,500). With the 19,071 PLWHA who are diagnosed and current residents of Massachusetts regardless of state of diagnoses from figure 3, plus an additional 10% as derived from the 2016 Epidemic at a Glance Fact Sheet, the figure for the total number of PLWHA in Massachusetts as of the close of 2014 was estimated to be 21,190.

Second, those additional 2,119 individuals added to generate the estimated total number of PLWHA were distributed to the goals for the number of people engaged in care and virally suppressed. With these figures in place the following comparison was calculated to show a point in time estimation of how close Massachusetts is to the UN/WHO 90-90-90 goals, which are in effect 90% of total PLWHA diagnosed, 81% of total PLWHA engaged, and 73% of total PLWHA virally suppressed.

		Percent of Goal
Projected total number of PLWHA, assuming 19,071 is 90% of the total	21,190	100%
Reported total number of PLWHA (2017-21 Integrated Plan, Figure 20)	19071	
Estimated number of individuals to meet 90-90-90 goals for HIV diagnoses	19,071	90%
Reported number of persons engaged in care (2017-21 Integrated Plan, Figure 20)	14,337	75%
Estimated number of individuals need to meet 90-90-90 goals for engagement in care	17,164	90%
Gap between state baseline estimate and the 90-90-90 goal	2,827	
Reported number of persons virally suppressed (2017-21 Integrated Plan, Figure 20)	12,363	72%
Estimated number of individuals needed to meet 90-90-90 goals for viral suppression	15,448	90%
Gap between state baseline estimate and 90-90-90 goal	3,085	



# COALITION LEADERSHIP

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AIDS Action Committee

Kenneth H. Mayer, MD  
Medical Research Director  
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AIDS Action Committee

Oscar Guevara-Perez  
Macro Field Placement Intern  
AIDS Action Committee

# COALITION MEMBERS



Plus numerous individuals, volunteers, and community members who make this work possible everyday. *Thank You!*

