Assessment of HIV Service Needs in the Boston Eligible Metropolitan Area

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May 2017

Center for Advancing
Health Policy and Practice

Boston University School of Public Health

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I. Introduction

In 2016, the Boston Public Health Commission (BPHC) sought to determine the HIV care and treatment needs of people living with HIV (PLWH) in the Boston Eligible Metropolitan Area (EMA) by conducting an assessment of service needs study. The goal was to identify barriers that prevent PLWH, both in and out of care, from receiving needed services, engaging in care, and/or adhering to medication regimens.

The needs assessment would culminate in a report intended to serve as a resource for the BPHC and the EMA's Ryan White Planning Council to guide decision-making around the allocation of Ryan White Part A funds. BPHC contracted with Boston University School of Public Health's Center for Advancing Health Policy and Practice (CAHPP) to carry out the design and conduct of the needs assessment, which comprised the following components:

1. A survey of consumers/PLWH regarding their service needs, met and unmet;
2. A survey of HIV primary care providers (medical doctors, nurse practitioners, and physician assistants) regarding service needs and barriers to care for their patients living with HIV;
3. Focus groups of vulnerable subpopulations of consumers (long term survivors, men who have sex with men (MSM) of color, women, and PLWH who are out of care);
4. Focus groups of HIV medical case managers; and
5. Key informant interviews with HIV primary care providers.

The data collection instruments and recruitment plan were developed in the summer and fall of 2016, and surveys were collected from December 2016 through March 2017; interviews and focus groups were conducted concurrently with survey collection. Data were analyzed in March and April of 2017. This report summarizes the findings and provides recommendations on:

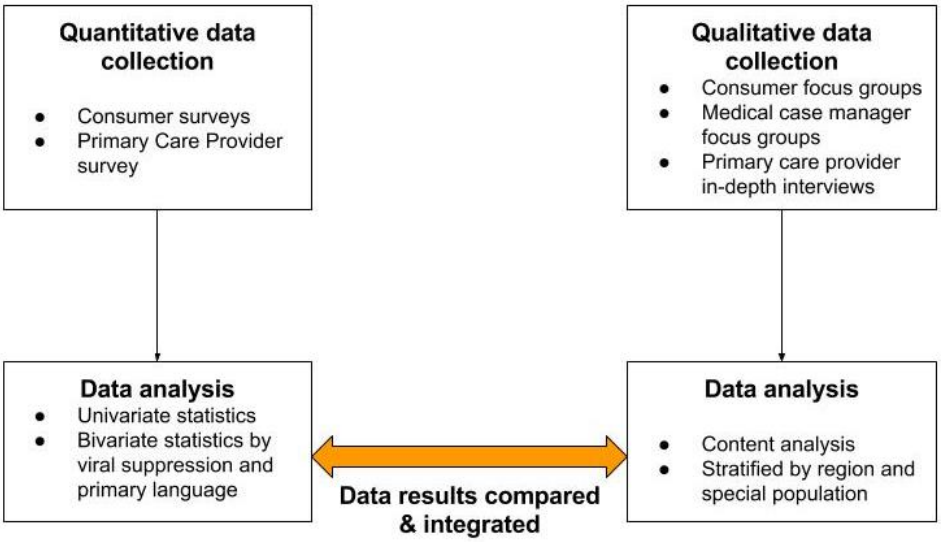
- Barriers to linkage and retention in care and achieving viral suppression for PLWH throughout the EMA and for specific populations; and
- Best practices and models of care that could address these barriers to care and service needs.

II. Methodology

Study Design:

To guide our research and ultimately inform our recommendations, our team employed a mixed-methods research and data collection approach. This method uses both quantitative and qualitative data collection methods in order to corroborate and supplement findings within the investigation[1]. This approach allows us to integrate the findings from both methods during the interpretation phase of analysis, which provides further insight than either method alone. The study was designed to incorporate the perspectives of consumers, HIV case managers, and HIV primary care providers regarding the service needs and gaps, and barriers to care of PLWH in the Boston EMA. The Boston University Medical Center Institutional Review Board approved this study under exempt status. Figure 1 summarizes our study design.

Figure 1. Study Design



Study Recruitment:

Utilizing a convenience sampling strategy across all data collection methods, our team collaborated with the Boston Public Health Commission and the EMA's Ryan White Planning Council (henceforth referred to as "the Planning Council") for all recruitment activities. For the consumer and provider surveys, the Planning Council provided us with a list of 36 BPHC-funded agencies, 5 Massachusetts Department of Public Health (MA DPH) funded agencies, and 7 other non-HIV service agencies to reach out to for recruitment. The Planning Council made an initial contact with HIV program directors at each agency and then a CAHPP staff member followed up regularly with each agency. In total, 18 BPHC-funded agencies and 4 MA DPH-funded agencies participated in the study. None of the other non-HIV service agencies agreed to assist in recruiting for the needs assessment.

[1] Creswell, J.W. (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches.* London: Sage Publications.

Participating agencies assisted in distributing our surveys to both consumers and providers (if applicable) within their agencies. Surveys were either provided by our research team as paper copies, or agencies agreed to print their own paper surveys or distribute using the web-based survey link. We also provided participating agencies with recruitment materials, including letters and fliers, they could send to consumers and providers at their agency to invite them to complete a survey. For their participation, consumers were offered the opportunity to enter a drawing for a $100 gift card. Providers were provided no compensation for their participation. In addition to the list of agencies, the Planning Council also provided a list of 21 HIV providers within the Boston EMA. These providers were contacted directly by our team to request participation in the surveys and in-depth interviews, as well as to refer us to other HIV providers in the EMA.

Finally, recruitment for focus groups with HIV case managers (one in New Hampshire, one in Massachusetts), long-term survivors (LTS), men who have sex with men (MSM) of color, women, and out-of-care consumers was carried out by members of the Planning Council who are familiar with these groups within the EMA. Consumer focus group participants were offered $5 gift cards for their participation and a meal was provided; case managers were not compensated for their participation. Eligibility criteria for participants are included in Table 1.

Table 1. Participant Eligibility Criteria

Participant	Data Collection Method(s)	Eligibility Criteria
Primary Care Providers	Survey, Key informant Interview	1. A provider is defined as a one with prescribing privileges, such as physician, physician's assistant, or nurse practitioner. 2. Provides services to PLWH who live in the Boston EMA.
Medical Case Managers	Focus Groups	1. Ryan White Medical Case Manager 2. Provides services to PLWH in the Boston EMA.
PLWH	Survey	1. HIV-positive. 2. Resides in the Boston EMA. 3. At least 18 years of age.
PLWH Sub-Groups	Focus Groups	1. Meets the three PLWH eligibility criteria listed above. 2. Qualifies as any one of the following: • LTS: defined as someone who was diagnosed in 2006 or earlier. • Out of care: defined as no visits with a PCP and HIV consult in past 12 months • Identifies as a woman • Identifies as a MSM of color

Data Collection:

The primary means of collecting quantitative data for the needs assessment was through a web-based consumer and provider survey, both of which were also available in paper. In addition to being available online, the consumer survey was available in both English and Spanish. Copies of the consumer and provider surveys are available in Appendix B. All consumer surveys were anonymous and coded with a unique ID created by the respondent. The consumer survey included demographic questions (race, ethnicity, gender, etc.) and questions on year of diagnosis, criminal history, insurance coverage status, service needs and barriers, other reasons for non-

adherence, and co-morbidities. The primary care provider survey was also anonymous and included questions on perceived service needs, access to services, and barriers to services for patients. Questions on the primary care provider survey were first asked with regard to patients who are virally suppressed and subsequently asked for patients who are not virally suppressed in order to assess whether perceived service needs, access, and barriers differed by viral suppression status.

All consumer surveys were returned to CAHPP for analysis in one of three ways: 1) by means of pre-paid, self-addressed, return envelope, 2) collected by agencies and then picked up by CAHPP team member, or 3) online through the web-based survey. All provider surveys were submitted to CAHPP through the web-based form. Web-submitted surveys were directly entered into a secure, password-protected Qualtrics database. Paper surveys received were manually entered into the Qualtrics database and then double-entered to ensure accuracy of data entry.

For qualitative data collection, we developed and used semi-structured focus group interview guides for PLWH and for medical case managers. The focus group interview guides included questions regarding service needs and gaps, other barriers to HIV care and treatment adherence, and best practice models to engage PLWH in care and other services. Additionally, focus groups with medical case managers included a ranking exercise in which a list of thirteen services was provided and small groups of participants were asked to sort services into piles based on high, moderate, and low need. In the second part of the exercise participants were asked to rate each type of need from limited to high availability. A one-page form was used to collect demographic and/or background information about individuals who participated in all focus groups (both consumer and case manager). Three of the four focus groups were audio recorded and transcribed. For the fourth focus group, we were unable to obtain consent for recording from all participants and therefore field notes of two team members were used in lieu of transcription for analysis.

In addition to focus group guides, we also conducted key informant interviews with HIV primary care providers. The interview guide included questions regarding best practice models for HIV care, barriers to HIV care services, motivators to engage PLWH in HIV care, and challenges providing services to PLWH. We also collected provider information, such as agency of employment and position title. Trained team members conducted the provider interviews. All eight interviews were audio recorded and transcribed. All qualitative analysis resources can be found in Appendix C.

Data Analysis:

Analysis of the consumer and provider surveys included univariate and bivariate statistics. Descriptive statistics for demographic characteristics, health care status, and service needs among all consumer respondents was conducted and then stratified by viral suppression and primary language. We selected primary language as a factor for analysis because of the high proportion of consumers who indicated a language other than English as their primary language spoken at home (23%, n = 51) and to assess for differences by cultural factors in terms of barriers and service gaps. Consumers who indicated they were bilingual in English and Spanish or English and another language were categorized as primarily English-language speakers.

Finally, we stratified our needs analyses (described in the next paragraph) for location of residency. To do this, we categorized the reported zip codes into two groups, those in Boston and those outside of Boston.

We also analyzed service needs for both "met" and "unmet" needs. A need was defined as a consumer indicating he or she needed a service in the 6 months prior to taking the survey. A service need was considered "met" if it was received within those same 6 months. Alternatively, a service need was considered "unmet" if the needed service was not received within those 6 months. To identify top met and unmet needs, we utilized an 85% and 15% threshold. For each service area, if 85% or more of the respondents who reported a service need were able to receive it, the service was observed as a top met service need. Alternatively, for each service area, if 15% or less of the respondents who reported a service need were not able to receive it, the service was observed as a top unmet need. These thresholds were determined by looking at the distribution of met and unmet service needs. We chose thresholds that would allow us to capture a wide overview of top met and unmet needs.

For the provider surveys, we followed the same analysis procedure as for the consumer survey, except we only examined perceptions of barriers to care and top service needs for people living with HIV and stratified by viral suppression status. The quantitative data analysis for this report was generated using SAS software.[2]

For qualitative analyses, two researchers independently reviewed interview and focus group transcripts to identify core concepts and themes. Using the emerging themes, and guided by our research questions, a coding framework consisting of 35 codes and respective definitions was created. This coding framework was used by two researchers to independently code all of the qualitative data. Then the two researchers came together to address any discrepancies in the narrative data until a consensus was reached. Thematic content analysis overall, by region, and sub-population groups were conducted by reviewing coded passages to identify overall trends. All qualitative data analysis was performed using QSR International's NVivo 8 Software.[3]

[2] Copyright © 2016 SAS Institute Inc. SAS and all other SAS Institute Inc. product or service names are registered trademarks or trademarks of SAS Institute Inc., Cary, NC, USA.
[3] NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 8, 2008.

III. Results

Results from Consumer and Provider Surveys:

A total of 226 consumer surveys and 17 provider surveys were collected from across the Boston Eligible Metropolitan Area (EMA). 48 (21%) consumer surveys were collected online, and 64 (28%) consumer surveys were in Spanish. For consumer surveys submitted by paper the response rate was 18%, representing 178 paper surveys received out of 975 distributed. Nineteen consumer respondents did not indicate their primary zip code of residence, but among respondents that did report their zip code all reside in the Boston EMA. 16% of consumer survey respondents were born outside the United States. Approximately 17% of consumer respondents were from New Hampshire counties and the remainder were from Massachusetts counties. Among the provider surveys, 10 were physicians, 5 were nurse practitioners, and 2 were physician's assistants.

Overview of Survey Sample Demographics:

Appendix A, Table 1 provides a description of demographic characteristics among consumers. The majority of consumers identified as male, Hispanic or black race/ethnicity, and were between the ages of 45 and 64 years. Approximately three quarters of the sample had a high school education or higher and the majority identified as heterosexual. While the majority identified English as their primary language spoken at home, approximately 23% primarily spoke Spanish or another language at home (i.e. French, Creole, Kikuyu, and Kiswahili).

It is important to note that the consumer sample differs from the demographic make-up of the Boston EMA. The consumer sample is over-representative of female consumers (40% in the survey vs. 29% in the EMA), Hispanic consumers (37% in the survey vs. 21% in the EMA), and Boston consumers (43% in the survey vs. 35% in the EMA). However, our sample is relatively representative of the EMA age distribution, with 23% ages 18-44 (24% in the EMA), 68% ages 45-64 (64% in the EMA), and 9% ages 65 or older (11% in the EMA).

Overview of Consumer Sample Health Characteristics:

Appendix A, Table 2 provides a description of health characteristics for all consumer respondents. On average, consumers reported living with HIV for 18 years (n = 217) with a standard deviation of 8 years. Twenty (9%) of the consumer survey respondents have been living with HIV for less than or equal to 5 years (n= 217). The majority of survey respondents had seen a provider less than 6 months prior to taking the survey. Nearly all respondents reported having health insurance and the majority reported having Medicaid as their primary insurance. 212 (95%) of consumer survey respondents are currently taking HIV medications to treat their HIV or AIDS, of which 31 (15%) stopped taking the medications for more than one week in the last 6 months. 183 (81%) of the consumer survey respondents reported having a comorbidity in addition to HIV, and 43 (19%) did not. Approximately 68% of those who reported a comorbidity had depression. High blood pressure, back pain and orthopedic disorders, and hepatitis C were also highly prevalent comorbidities reported by consumers with comorbidities. Among those with depression as a comorbidity (n = 124), 30 (24%) had an education of some high school or

less, 52 (42%) had high school and/or technical/vocational school, 41 (33%) had some college or more, and 1 had other unspecified education. Finally, 95% of consumers reported currently taking antiretroviral medications and one-third reported missing doses in the past two weeks.

Overview of Consumer Demographic Characteristics by Viral Suppression Status and Primary Language:

Appendix A, Tables 3a and 3b show the demographic characteristics of consumer survey respondents by viral suppression status and primary language, respectively. Compared to virally suppressed respondents, virally unsuppressed respondents were more often female, uninsured, with a criminal history, and less often college-educated. Compared to respondents who speak primarily English, respondents who speak primarily Spanish or another language were more likely to be Hispanic, born outside the United States or its territories, and virally detectable (17.4% among primarily Spanish or other (n=46) vs. 12.2% among primarily English (n=148); calculated based on Appendix A, Table 3a); on the other hand they were less likely to be high school educated.

Summary of Top Service Needs, Met and Unmet, from Consumer Survey:

1) Top 5 Needed Services Overall

A total of 207 consumers indicated they had a service need in the 6 months prior to taking the survey. Among those consumers, 51% needed mental health services and counseling in the past 6 months, 50% needed dental care, 48% needed help getting connected to primary medical care and health-related services, 47% needed assistance paying for medications, and 46% needed nutrition/food assistance. Table 2a summarizes that information. Appendix A, Table 4a provides a more detailed overview.

Table 2a. Top Needed Services Overall (N = 207)

Percent Needing a Service
1. Mental health services and counseling (51%)
2. Dental care (50%)
3. Help getting connected to primary medical care and health-related services (48%)
4. Assistance paying for medications (47%)
5. Peer support (46%)

2) Top 5 Needed Services by Viral Suppression Status

When stratifying by viral suppression status, those who are virally suppressed have identical needs in comparison to consumers as a whole. Comparatively, those who are virally unsuppressed have similar needs compared to the group as a whole; however, help getting connected to primary medical care and health-related services is most needed (58%) and nutrition/food assistance is a unique top 5 need for this group (42%) that is not a top 5 need for the virally suppressed group. Table 2b summarizes the top 5 needs by viral suppression status. Appendix A, Table 4b provides a more detailed overview.

Table 2b. Top Needs by Viral Suppression Status

Viral Suppression Status	Percent Needing a Service
Virally Suppressed (n = 158)	1. Mental health services and counseling (51%) 2. Dental care (50%) 3. Assistance paying for medications (49%) 4. Help getting connected to primary medical care and health-related services (48%) 5. Peer support (47%)
Virally Unsuppressed (n = 24)	1. Help getting connected to primary medical care and health-related services (58%) 2. Mental health services (50%) 3. Assistance paying for medications (50%) 4. Dental care (46%) 5. Nutrition/food assistance (42%)

3) Top 5 Needed Services by Primary Language

When stratifying by primary language, those who speak primarily English have the same top 5 needs as the consumer group overall. However, nutrition/food assistance appears to be a priority need for this group, whereas it is not for consumers as a whole. Those who speak Spanish or another language as their primary language, in comparison to those who speak English, needed more help getting connected to primary medical care and health-related services (65%), interpreter/translation services (63%), help getting to medical appointments (52%), assistance paying for medications (50%), and peer support (48%). Table 2c summarizes these results. Appendix A, Table 4c provides a more detailed overview.

Table 2c. Top Needs by Primary Language

Primary Language	Percent Needing a Service
English (n = 157)	1. Mental health services and counseling (53%) 2. Dental care (52%) 3. Assistance paying for medications (47%) 4. Nutrition/food assistance (45%) 5. Peer support (45%)
Spanish or other language (n = 48)	1. Help getting connected to primary medical care and health-related services (65%) 2. Interpreter/translation services (63%) 3. Help getting to medical appointments (52%) 4. Assistance paying for medications (50%) 5. Peer support (48%)

4) Top 5 Needed Services by Location of Residency

We stratified needs by location (Boston vs. Outside of Boston). Those who reside in Boston indicated mental health services, counseling, and treatment (58%) and help finding and obtaining housing (45%) as top priority needs. Comparatively, those who lived outside of Boston reported help getting connected to primary medical care and health-related services (56%) and assistance paying for medications (56%) as top priority needs. Table 2d below summarizes these results. Appendix A, Table 4d provides a more detailed overview.

Table 2d. Top Needs by Location of Residency

Boston (n = 83)	1. Mental health services, counseling, and/or treatment (58%) 2. Dental care (49%) 3. Peer support (46%) 4. Help finding and obtaining housing (45%) 5. Nutrition/food assistance (41%)
Outside Boston (n =105)	1. Help getting connected to primary medical care and health-related services (56%) 2. Assistance paying for medications (56%) 3. Nutrition/food assistance (48%) 4. Dental care (46%) 5. Financial assistance (45%)

5) Top 5 Met and Unmet Needed Services by Viral Suppression Status

Table 2e below summarizes the top 5 met and unmet needed services by viral suppression status among consumers. Those who were virally suppressed had more difficulty receiving residential substance use treatment, legal support for a criminal history/record, job training/employment assistance, clothing or other basic needs, and assistance maintaining housing. In comparison, those who were virally unsuppressed had more difficulty receiving job training/employment assistance, help finding and obtaining housing, nutrition/food assistance, financial assistance, and assistance with maintaining housing. Appendix A, Table 4b provides a more detailed overview.

Table 2e. Top 5 Met and Unmet Needed Services by Viral Suppression Status		
	Virally Suppressed	Virally Unsuppressed
Top 5 Met Services (Expressed as Percent of Consumers who Received the Service)	1. Help getting connected to primary medical care and health-related services (97%, n = 59) 2. Assistance paying for medications (95%, n = 66) 3. Other, unspecified (92%, n = 13) 4. Nutrition/food assistance (91%, n = 55) 5. Assistance paying for copays or coinsurance (89%, n = 47)	1. Interpreter/translation services (100%, n = 5) 2. Substance use counseling (100%, n = 3) 3. Support around medication assisted therapy for substance use (100%, n = 2) 4. Residential substance use treatment (100%, n = 1) 5. Legal support for criminal history (100%, n = 2)
Top 5 Unmet Services (Expressed as Percent of Consumers who did not Receive the Service)	1. Residential substance use treatment (44%, n = 16) 2. Legal support for a criminal history/record (41%, n = 22) 3. Job training/employment assistance (39%, n = 28) 4. Help obtaining clothing or other basic needs (29%, n = 31) 5. Assistance maintaining housing (27%, n = 49)	1. Job training/employment assistance (67%, n = 3) 2. Help finding and obtaining housing (50%, n = 8) 3. Nutrition/food assistance (30%, n = 10) 4. Financial assistance (29%, n = 7) 5. Assistance maintaining housing (25%, n = 4)

6) Top Met and Unmet Needs by Primary Language

Table 2f below summarizes the top 5 met and unmet needed services by primary language among consumers. Those who speak English as their primary language had more difficulty receiving legal support for criminal history, job training/employment services, residential substance use treatment, help finding and obtaining housing, and interpreter/translation services. In comparison, those who speak Spanish or another language as their primary language had more difficulty receiving residential substance use treatment, job training/employment assistance, assistance maintaining housing, help obtaining clothing or other basic needs, and legal support for a criminal history. Appendix A, Table 4c provides a more detailed overview of these results.

Table 2f. Top 5 Met and Unmet Needed Services by Primary Language

	English	Spanish or Other Language
Top 5 Met Services (Expressed as Percent of Consumers who Received the Service)	1. Legal support for immigration services (100%, n = 2) 2. Assistance paying for medications (97%, n = 62) 3. Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge (93%, n = 30) 4. Help getting connected to primary medical care and health-related services (93%, n = 56) 5. Assistance connecting with medical specialists (92%, n = 39)	1. Help getting connected to primary medical care and health-related services (100%, n = 21) 2. Support around medication assisted therapy for substance use (100%, n = 5) 3. Other, unspecified (100%, n = 6) 4. Dental care (93%, n = 15) 5. Peer support (89%, n = 19)
Top 5 Unmet Services (Expressed as Percent of Consumers who did not Receive the Service)	1. Legal support for criminal history/record (36%, n = 22) 2. Job training/employment assistance (35%, n = 23) 3. Residential substance use treatment (33%, n = 15) 4. Help finding and obtaining housing (31%, n = 55) 5. Interpreter/translation services (25%, n = 8)	1. Residential substance use treatment (50%, n = 4) 2. Job training/employment assistance (44%, n = 9) 3. Assistance maintaining housing (43%, n = 7) 4. Help obtaining clothing or other basic needs (40%, n = 10) 5. Legal support for a criminal history (33%, n = 6)

7) Top Met and Unmet Needs by Location

Table 2g below summarizes the top met and unmet needed services by location. Those living in Boston had more difficulty receiving legal support for immigration issues, job training/employment assistance, residential substance use treatment, legal support for criminal history/record, and help obtaining clothing or other basic needs. Those living outside of Boston had more difficulty receiving job training/employment assistance, help finding and obtaining housing, residential substance use treatment, legal support for criminal history/record, and mental health services, counseling, and/or treatment. Appendix A, Table 4d provides a more detailed overview of these results.

Table 2g. Top 5 Met and Unmet Needed Services by Location of Residency		
	Boston	Outside Boston
Top 5 Met Services (Expressed as Percent of Consumers who Received the Service)	1. Help getting connected to primary medical care and health-related services (100%, n = 24) 2. Assistance paying for medications (93%, n = 27) 3. Support around medication assisted therapy for substance use (92%, n = 13) 4. Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge (92%, n = 13) 5. Dental care (91%, n = 35)	1. Legal support for immigration issues (100%, n = 2) 2. Other, unspecified (100%, n = 7) 3. Assistance paying for medications (96%, n = 48)) 4. Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge (95%, n = 21) 5. Help getting connected to primary medical care and health-related services (93%, n = 45))
Top 5 Unmet Services (Expressed as Percent of Consumers who did not Receive the Service)	1. Legal support for immigration issues (50%, n = 2) 2. Job training/employment assistance (39%, n = 18) 3. Residential substance use treatment (38%, n = 13) 4. Legal support for criminal history/record (38%, n = 16) 5. Help obtaining clothing or other basic needs (30%, n = 27)	1. Job training/employment assistance (44%, n = 9) 2. Help finding and obtaining housing (33%, n = 27) 3. Residential substance use treatment (33%, n = 3) 4. Legal support for criminal history/record (33%, n = 6) 5. Mental health services, counseling, and/or treatment (30%, n = 44)

Most Important Services for Clients from Perspective of Provider by viral suppression status

We also asked providers to list the 3-5 service needs that were most important to their patients, with separate response fields for virally suppressed patients and virally unsuppressed patients. For both sets of patients, the top three needs were mental health services, substance use treatment, and housing assistance. Among virally suppressed patients, at least half the providers listed housing and mental health services; while among virally unsuppressed patients, at least half listed mental health services and substance use treatment.

One key difference in providers' responses regarding needs of virally suppressed versus virally unsuppressed patients was around medication access and adherence. Roughly one-third of providers cited medication access support, such as HDAP application assistance and pharmacy services, as a top need among virally suppressed patients, and almost as many mentioned medication adherence support and education. For virally unsuppressed patients, none listed medication access support and only 15% mentioned medication adherence support.

Provider-Reported Barriers to HIV care adherence for people living with HIV:

Providers reported similar barriers for their patients by viral suppression. Mental health and substance use other than alcohol were ranked the highest barriers to adherence despite viral suppression. However, for those who were unsuppressed, unstable housing and lack of support

from family and friends were considered key barriers compared to those who were virally suppressed.

Table 3. Top 5 Provider-Reported Barriers to HIV care adherence by viral suppression status

Virally Suppressed		Virally Unsuppressed	
Barrier	**Mean**	**Barrier**	**Mean**
Mental health disorders	3.4	Mental health disorders	4.0
Substance use other than alcohol	3.3	Substance use other than alcohol	4.0
Alcohol use	3.0	Unstable housing	3.4
Fear of other finding out about HIV	2.2	Alcohol use	3.2
Denial of HIV status	1.5	Lack of support from family/friends	3.0

*Results are based on the question: “In your experience, to what extent do the following barriers impact adherence to HIV care and treatment for your patients who are virally suppressed and NOT virally suppressed?” Providers could respond not at all (0), slightly (1), moderately (2), considerably (3), or extremely (4).

Results from Consumer and Provider Focus Groups and Interviews:

Participant Information

Providers who participated in the key informant interviews (n=8) were predominantly nurses (n=6) and represented multiple regions across the Boston EMA: Boston, Lawrence, Lebanon-Bedford, Plymouth, and Worcester. Medical case manager (MCM) focus groups (n=2) were separated by state of service provision, with 10 MCMs participating in New Hampshire and 11 MCMs in the Massachusetts group. Participants in each MCM focus group reflected a range of regions within the states, representing metropolitan, rural, and suburban areas. We were not able to conduct two of the four consumer focus groups as a result of weather cancellations and low turnout for out of care and women living with HIV, respectively. Demographic information for the consumer focus groups that were conducted with LTS and MSM of color (both in Boston, MA) are available in Table 4.

Table 4. Composition of Consumer Focus Groups (n=2)

	Mean Age	Gender	Sexual Orientation	Race/ Ethnicity	Education	Insurance*
LTS 11 participants	60	100% Men	90% Gay 10% Bisexual	82% White	82% College Grad	64% Private 45% Medicare
MSM of Color 9 participants	36	100% Men	100% Gay	78% PoC	78% Some College	100% MassHealth

** Types of insurance coverage are not mutually exclusive.*

Overall Results

1) Barriers to Care

One of the key barriers to HIV care was the need for services that are situated across fragmented health care and social services systems. From the consumer perspective, having to access to services across multiple locations creates challenges, exacerbated when transportation barriers exist. Beyond the physical barriers to getting needed services, participants (providers, case managers, and consumers) reported major limitations in accessing specialty services needed – most notably mental health care. Based on provider and case management responses it appears that provider time limitations and systematic barriers (e.g. separate EMR systems) do not allow them to communicate regularly with other providers who are serving their patients. It is a struggle to do this and maintain enough time needed to spend with patients. Case managers therefore become the conduit for all communication and coordination of services; given their large caseloads this means that they do not have enough time to dedicate to each client. A New Hampshire-based MCM discussed this in the focus group:

> "*It goes back to coordination of care. If the providers communicate with us and let us know…if it was a team approach, the [patient] would maybe be set up*

more, if we all knew what was happening, so…it depends. When I have a good relationship with a nurse at an ID office it makes a big difference."

Another MCM in the same focus group pointed out how this can affect continuity of mental health care treatment for some of their patients, stating:

"It really comes into play a lot with mental health, but also everything…The seacoast is really fractured. You get your infectious disease care one place and primary another place and dental another place, and …mental health - that's somewhere else. Really hard to have providers coordinate with each other, let alone with us. And so one of the big things when you talk about client willingness for mental health, is that I find no follow-up from primary care or mental health providers when clients stop showing up. And it all comes back to us to try to get them back in there. So that's a big piece."

Providers, case managers, and consumers alike identified difficulty of consumers with navigating systems and managing bureaucracy and paperwork. Strategies suggested by participants in order to address this were: more training for case managers in navigating non-HIV systems, reducing case manager caseloads by hiring and training peer navigators, more outreach and appointment assistance, increased access to computers and to work with high need patients, training for both case managers and peer navigators to help increase patient-involvement and self-efficacy, and increased case management and peer navigators partnerships (formal and informal) with other agencies/organizations.

Another barrier which was described in the consumer focus groups was a lack of both culturally-sensitive and knowledgeable service providers. Based on discussions with these consumers, the cultural sensitivity refers to the recognition that the HIV population is very diverse and that service provider agencies should ensure that their staff and environments are welcoming and inclusive of all, and train staff to avoid stereotyping and clustering all PLWH in one group. The latter refers to the lack of HIV knowledge among non-HIV specialty providers, described by some consumer focus group participants as "out of the loop" with regards to current thinking and approaches to HIV care. Similarly, this lack of information also leads providers to draw on stereotypes and make incorrect assumptions about the needs of PLWH. As a result, there is a lot of uncertainty and concern among PLWH when seeing new specialty providers. One LTS focus groups participant pointed out, "*Whenever I have to see a new specialist I ask if they have experience with HIV."*

Barriers to mental health care and substance use treatment emerged across focus groups and interviews, though there were some differences in what was reported between providers and case managers versus consumers. All of the participants discussed the limited supply and availability of providers (particularly who accept Medicaid) and long wait lists for those who are available. A Boston-based provider discussed this issue in her interview,

"I think we need more treatment beds in the community particularly for substance use disorders, and once we can get people into treatment for their substance use

disorders and their mental illness, we can better connect them to HIV care. There's really a lack of treatment for both those illnesses…"

Consumer participants also discussed the need for more formal mental health assessments by primary care providers as well as more culturally appropriate mental health care provision. One participant pointed out that in attempting to talk to his providers about mental health issues that he is dealing with, some providers have dismissed these as personality differences.

Providers and case managers, on the other hand, spoke about patient readiness as a barrier for some clients to receiving behavioral health services. Providers and case managers noted that they themselves often identify patients who they believe are suffering from mental health or substance use disorders, but reported that it is challenging to identify ways to support these clients to motivate themselves to seek services. A Massachusetts-based MCM observed that: *"The patients don't think they need it…but it is a high need, I would say 90% of our patients could benefit from it."*

2) Priority Service Needs

Consumers and providers reported on the priority needs of PLWH in the EMA. The following were reported as easily-to-reasonably accessible throughout the EMA. Services or vouchers that help obtain food and clothing were identified by case managers in both Massachusetts and New Hampshire as important basic needs. Nearly all case managers reported being able to obtain these services in cases when their clients are in need. Interpretation and translation services were also described as practical needs common across the EMA which are readily met. Furthermore, insurance coverage for primary care was generally accessible and easily obtained in both New Hampshire and Massachusetts.

Providers and consumers discussed several service gaps and offered potential (and often utilized) strategies to address those gaps in services. Both mental health care and substance use treatment, for example, are much needed services for PLWH in the EMA. Based on reports from all participants the services needed are two-fold: first, there must be an increased capacity to provide these services (inpatient and outpatient) – especially those who will accept Medicaid and other insurances that are covering consumers. Integrating such services with primary care was discussed as an effective method to address this systems-level issue by some providers. Secondly, consumers need access to front line staff (e.g. case managers, peers, etc.) who are trained to support clients in moving along the stages of change continuum and address concerns of stigma related to behavioral health illness in a culturally appropriate way.

Another critical need for PLWH was housing. Participants (providers, case managers, and consumers) reported that wait lists for temporary housing are extremely long – there is a critical need for more short-term and emergency assistance options to give people places to stay until they can secure more long term housing.

Additionally, long-term rental assistance voucher programs have long waiting lists because of limited availability (either of vouchers themselves or of landlords who accept such vouchers) and transitional assistance (e.g. rental, utility etc.) is needed to prevent housing

instability and homelessness. One of the Massachusetts-based MCMs stated with certainty, *"I think that the biggest issue by far is housing. We've seen people have Section 8 vouchers that have waited the 10 years and they still can't even find housing…which is just devastating."*

Supporting consumers in increasing self-efficacy is an important need, according to case managers and providers. Not only would such training improve outcomes for their clients, but it would also reduce the amount of time case managers are spending with some of their clients, therefore allowing them to dedicate their energies to more time-consuming tasks that are currently harder to get to. Two types of training to address this emerged in our focus groups and interviews: training for front line staff in providing this kind of self-management support, and consumer trainings that would support them with this (e.g. job training, financial planning).

Lastly, medication support was also a critical need that emerged in discussions across all participants. This includes support in obtaining, organizing, and taking medications. With regards to obtaining medications, assistance is needed with completing regular paperwork in order to maintain coverage (e.g. ADAP), as well as addressing more structural issues such as failure of hospitals and pharmacies to stock needed medications, or challenges to obtain medications when traveling. Some patients also require some assistance with daily reminder, or other systems for addressing barriers for medication adherence. Very few participants in this study provided directly observed therapy though the ones that did found that it is effective with their most complex patients.

Findings by Region

The service needs listed in the previous section were common across regions. There were a few differences in service needs identified by region, however. As described previously, housing was described as a need across several regions by all participants. However, based on case manager accounts there appear to be more barriers to obtaining and maintain housing (and therefore it is an unmet need) in urban areas such as Boston, Worcester, Manchester, as opposed to suburban or rural areas such as Plymouth. Immigration-related issues (e.g. lack of Spanish-speaking providers, need for legal services, inability to access housing due to lack of documentation, etc.) were also identified by case managers and providers as important barriers more common in urban areas (e.g. Boston, Worcester, Manchester), whereas these issues were not raised as primary concerns for providers and case managers in suburban or rural areas. For example, a Massachusetts-based MCM shared,

> *"I do serve mostly the immigrant population. And [they need] legal services, [and] access to basic needs. And sometimes they don't know they qualify for certain things, so sometimes we're the ones to bring them to light…And medical care is at the bottom of the pile in terms of prioritizing things in their own lives."*

On the contrary, while transportation was consistently identified as a barrier to care for patients by case managers and providers, it was reported as a particularly critical need in rural and suburban areas (e.g. Plymouth, Portsmouth, Lebanon-Bedford). In such areas, there appear to be funds designated for this, but it is not always sufficient for the level of need - particularly for areas where hospitals have stopped providing shuttles or other transportation services. This

problem can threaten a patient's continuous engagement in care. A New Hampshire-based provider reported on this, stating:

> *"People's lack of access to reliable transportation - either very old cars or no public transportation - and that coupled with a tight clinical schedule where we don't have– if someone misses an appointment one day – we don't have something to offer them a couple weeks later."*

Additionally, in Boston, although transportation is relatively well-addressed for medical appointments, accessing transportation to other kinds of social services is still a challenge. Table 5 summarizes these regional findings.

Table 5. Needs and Barriers in Urban vs. Suburban and Rural Regions

Urban Regions	Suburban and Rural Regions
Housing Immigration-related issues	Transportation

At the state level, case managers in New Hampshire more often reported barriers with insurance and prescription medication assistance coverage (i.e. ADAP) such as burdensome and repetitive paperwork or refusal to accept such certain types of coverage. New Hampshire case managers also reported that there is a lack of available dental service providers in New Hampshire and that often they have had to refer their clients to such providers in Massachusetts. A MCM from New Hampshire shared,

> *"A lot of people that have the dental program in Boston, but there are not too many dentists over here that take that plan, so we had to bring them into Boston, to Tufts University, to Lowell, or to Lynn Massachusetts which is a lot of time…to bring these people over there."*

On the other hand, availability of dental services providers was not raised by case managers, consumers, or primary care providers as an issue faced in Massachusetts.

Findings by Special Populations

Our sub-group analysis yielded findings for long-term survivors and MSM of color, as reported by these consumers themselves via focus groups, and needs particularly critical to immigrants and non-English speakers as well as people with mental health disorders, as reported by case managers (via focus groups) and providers (via interviews). Table 6 describes the needs and barriers reported by specific populations groups.

Table 6. Sub-Group Needs and Barriers

	LTS*	MSM of color*	Immigrants & non-English speakers**	People with Mental Health Disorders**
HIV-knowledgeable providers	X			
Social support	X	X		
Medical care coordination	X	X		
Mental health service access	X	X		X

Financial planning	X		X	
Housing assistance	X	X	X	
Culturally appropriate service provision		X	X	
Basic needs and practical support			X	X
Legal			X	

** Reported by consumers themselves via focus groups.*
***Reported by case managers and primary care providers in focus groups and in-depth interview, respectively.*

1) Long-Term Survivors

Long-term survivors spoke extensively about limited HIV knowledge among the multitude of specialty providers that they have to see, particularly as they are aging. Because of this, they perceived poorer quality service delivery and a barrier to receiving necessary care outside of the HIV sector. One participant described mistrust going into any appointment with a new specialist – making sure to ask if the provider has had any experience with HIV during their first visit. Another felt that most of his specialty providers are "out of loop about HIV," and as an indicator of health tend to ask about his T-cell count but not his viral load.

Because of their extensive medical care needs, care coordination was also cited as a critical need. These consumers have a high need for care as a result of aging, as well as side effects of long-term (and earlier, more toxic) HIV medications. Few of the participants engage much, if ever, with case managers, as traditional case management has not been adequate in navigating and coordinating care across health systems and agencies, but there was near-unanimous agreement that they need more and better support. As one participant put it, *"On paper we look fine, but we're not. As we age, we become less and less able to self-advocate."* Most participants said they did not know where they could find the kind of medical care coordination they need, if it even exists.

LTS also participants discussed experiencing chronic depression and other mental health problems. They described the experience of managing HIV and attendant side effects for so long as tiresome, and experience a heavy emotional burden that comes with having witnessed many peers, friends, and loved ones pass away over time from the very illness that they live with. They also shared that they often feel isolated, many of them do not disclose their status publicly and fear the stigma around HIV status and their sexual orientation. They expressed a concern that suicide is a widespread problem among their community for many of these reasons. While these participants made few specific references to mental health services or care, they did express a desire for more structured social support services, including check-in programs for those who struggle with isolation.

A unique challenge of this group was long-term planning around housing and finances. Some participants in the group described financial difficulties as a result of not planning to live as long as they have, now compromising their housing situation as older adults. Others expressed anxieties about entering retirement communities or assisted living facilities because of the stigma of HIV and fear that staff would be ill-equipped to address their needs.

2) MSM of Color

The MSM of color group's primary concerns centered on the importance of social support, medical care and support service coordination, mental health service access, and housing. With regards to social support, they discussed a need for more opportunities for support groups as well as peer support in both formalized and informal ways. They reported feeling isolated as gay men of color because of stigma and ignorance, with many saying they came from communities which were not accepting. At multiple points in the focus group discussion, participants expressed a belief that more service provision by peers (in other words, by MSM of color living with HIV) would be beneficial to their community.

Participants expressed how helpful case management services are, particularly in assisting with paperwork for benefits (e.g. insurance coverage) and medication assistance (e.g. HDAP, ADAP), many of which require resubmission as often as every six months. Case managers were described as important sources of information, as well. Said one participant, *"I could just randomly be ranting, and in the middle of a rant with a case manager they hear me say something and go, 'Oh, he needs this service' - that I didn't even know I needed!"* Conversely, when their case managers are burdened with high volume caseloads, consumers may not learn about available benefits or be able to submit paperwork on their own. The logistical challenges of paperwork and failure to submit on time can lead to lapses in medication adherence or care if the necessary benefits are not renewed.

The MSM of color placed a high priority on case management and support services, but they were clear that these services need to be culturally appropriate. Again, the theme of service provision by peers was emphasized. They believed that reaching people unaware of their status and preventing new infections among younger people would be easier if more HIV-positive MSM of color were professionally involved in the field of HIV services. At minimum, they felt providers needed to be sensitive to the diversity that exists within the HIV community.

Most of these participants described feeling especially vulnerable to chronic depression and other mental health issues as a result of living with HIV and being MSM of color. Social isolation resulting from stigma within their own communities (described above) was cited as one contributing factor, as was the ongoing stress of managing their disease—something which they are constantly reminded of, and what could be described as general minority stress. While most of them agreed that mental health care such as counseling was a high priority for them, they had difficulty accessing it due to inadequate numbers of mental health providers. One participant shared, *"I, um, wanted to go see a therapist--it doesn't even matter where you go. I tried the place downstairs, I tried [another agency], and it's like, a hundred people waitlist."*

Lastly, housing was identified as a critical need which they have faced barriers to obtaining. Participants discussed the cyclical challenges of housing instability –often becoming homeless as a result of their sexuality, but faced with barriers in emergency shelters such as fear of abuse (also due to their sexuality) or restrictive income limitations that do not allow for individuals to maintain a job while in emergency shelter. These adversities do not allow for long-term housing stability – which is exacerbated further by the limited long-term housing availability. Some talked about the problem of housing instability perpetuating risky behavior as well; one participant described a chain of events leading to using casual sex apps or engaging in sex work as a way of finding somewhere to sleep.

3) Immigrants and Non-English Speakers

Immigrants and non-English speakers were discussed as a high-need group among urban areas as compared to suburban and rural areas, as discussed previously. In urban areas, providers and case managers noted that among patients who were immigrants, they observed particularly strong resistance or disinterest in mental health services despite apparent need. Despite disinterest, one case manager shared that *"I would say about 90% of our patients could benefit from [mental health care]."* A self-identified Latino case manager described cultural stigma about mental health care as a barrier, and that it was necessary to invest time into building trust before these patients would consider these services.

Housing was identified as a critical need for immigrant populations, particularly undocumented immigrants, by case managers and providers. The major barriers for this group were limitations in eligibility due to lack of documentation, or in some cases, fear—due to their immigration status—of applying for public services, even though in many cases they would in fact be eligible. Immigrants and non-English speakers also were reported to have higher need for financial planning assistance, legal advising, and assistance with basic needs and practical support (e.g. food assistance) due to particularly severe poverty and difficult navigating social service systems.

The need for culturally appropriate provision of services was also raised by case managers and providers with regards to immigrant and non-English speaking populations. They spoke about the need for providers who speak other languages, especially mental health counselors, explaining that using interpretation services in such contexts would not be appropriate. One case manager also cited a sense of disconnectedness when using interpreter services.

4) People with Mental Illness

Case managers and providers discussed two critical needs for their clients with serious mental health disorders. These are not necessarily comprehensive but they are the ones that emerged in the focus groups and interviews. These patients require assistance in obtaining basic needs and practical support, such as food, clothes, and appointment reminders and accompaniment. Unsurprisingly, they also require mental health care, but experience multiple types of barriers. Access is difficult, with often insufficient availability of clinicians, as well patients with mental illness having difficulty navigating health care systems; and many providers and case managers said they perceived patients with serious mental illness as particularly resistant to receiving treatment.

Overall Motivators to Care and Best Practices

Consumers and providers reported factors and service models which can help to facilitate PLWH engagement in care and treatment. Table 7 illustrates these. Motivators to care were identified across consumer and case manager focus groups and provider interviews; best practice models were discussed in the provider interviews. Motivators to care included factors which

provide support for consumers - socially, emotionally and practically – such as access to peer support, more organized support groups, and front line staff who are able to help navigate multiple systems. Other motivators were focused on the interpersonal factors between consumers and their providers and other support staff (e.g. case managers) – such as building trust with providers, having the opportunity to be involved in their own care plan development, and use of techniques that can facilitate this, such as motivational interviewing. Best practice models recommended by providers include use of interdisciplinary team to provide comprehensive and well-integrated services; key to this is the integration of behavioral health service providers on the health care team and in the suite of available services provided through an agency. Additionally, use of peers to provide support both practical and emotional was recommended not only in order to assist peers but also in order to reduce the burden of such large caseloads for case managers, who can then focus on more tedious tasks such as helping clients with paperwork – as needed. Lastly, the need for front line staff (e.g. peers, case managers, patient navigators) to have outreach capacity (i.e. the ability to go out into the field to locate, visit, and accompany clients) was an important component of an effective service delivery model. In particular, this was critical for engaging patients who have fallen out of care or who are only tenuously connected to care.

Table 7. Motivators to Care and Best Practices

Motivators to Care	Best Practice Models
• Assistance navigating systems • Social support (e.g. peer support, support groups, etc.) • Provider use of motivational interviewing techniques (e.g. active listening) • Provider trust (e.g. relationship building) • Patient involvement in care planning; client-centered care	• Interdisciplinary teams • Comprehensive and integrated services (HIV and behavioral health) • Outreach capacity • Peer support

Summary of Findings:

Our review of the qualitative and quantitative results yielded the following overall findings by consumers and providers about barriers and care and services. Quantitative findings from the consumer and provider surveys reveal that mental health services, dental services, assistance connecting to medical care, paying for medications, and peer support services are highly needed across the entire consumer survey sample, even when adjusting for viral suppression status and primary language. However, among those who speak primarily Spanish or another language, basic needs such as transportation, getting connected to primary medical care, and interpreter services were high priorities. Although these are all top needs among the survey sample, obtaining nutrition services, getting connected to primary medical care, and transportation services were the most easily accessible to consumers.

On the other hand, help obtaining housing, residential substance use treatment, and legal support for criminal history were reported as an unmet need. Those who were virally unsuppressed, similarly to those whom English was not their primary language, also had difficulty obtaining services for clothing and basic needs, finding and maintaining housing and job training. The provider survey revealed similarly that mental health services and substance use

treatment were highly needed by the populations they serve. Providers said they believe key barriers to accessing services include mental health disorders and substance use.

Adherence to treatment continues to be important service need. Approximately 13% of consumers reported being virally unsuppressed and 7% did not know their viral load status. Furthermore approximately 37% reported missing doses in the last 2 weeks and 15% reported stopping taking their medications for more than 1 week in the last 6 months. Among those who stopped taking their HIV medications for more than 12 weeks in the last 6 months (n = 31), 2 (6%) were not virally suppressed, 26 (84%) were virally suppressed, and 3 (10%) did not know their viral suppression status. While some of this may be provider discussion to stop medications, there is a continued need to support taking medications appropriately.

Qualitative findings were generally consistent with the quantitative ones, with some additions. Mental health and substance use treatment were identified as high-need services for which major barriers exist: both in limited availability of qualified providers as well as (for some) patient-readiness to seek services. Housing was also a critical need identified for PLWH in the Boston EMA, though those living in urban regions are likely to encounter more onerous barriers to obtaining needed housing assistance. Transportation was also an identified high-need service, particularly critical in suburban and rural regions, which seems to be a met need – with gaps for non-medical services and in regions where there is no mass transit. Basic needs such as food and clothing also emerged in the qualitative results, with higher need among immigrant populations and those with serious mental illness.

Apart from findings the previously-mentioned qualitative findings, which generally reflect the results yielded from the consumer and provider surveys, another key discovery was the need for assistance navigating and coordinating services across a fragmented health care system (including mental health services and other specialty medical services) as well as systems that fall outside of healthcare – such as social services. Furthermore, more culturally-sensitive and HIV-knowledgeable staff across these services was reported as a need. Support for medication adherence, including support with obtaining, organizing, and taking medications, was also reported across consumers and providers alike. Lastly, improving self-efficacy and self-management, and increasing opportunities to be more involved in their own healthcare planning, were identified as goals among the participants.

IV. Limitations and Challenges

Although we made every effort to use methods that would reduce biases in our results, there are limitations which are important to note. The following issues emerged which may have created bias in the data collected and analyzed, and therefore may affect the accuracy of results that were yielded and limit the populations to which we can generalize these results. This is critical to keep in mind as it is possible that the service needs and barriers for groups who were underrepresented in our study may be different than those presented in this report.

- By comparing demographic information from our consumer survey sample with existing data on the Boston EMA PLWH population we were able to assess how representative our sample was. While our consumer survey sample was reflective of the overall population of PLWH with regard to age distribution, some demographic groups were overrepresented (Hispanic, Boston, and female consumers). Furthermore, because our recruitment efforts to engage out-of-care consumers and PLWH not aware of their status via non-Ryan White and non-HIV care agencies were not successful for a variety of reasons, it is likely that most of the consumers who participated were recruited from HIV care agencies. Therefore it is probable that out-of-care consumers and PLWH who are unaware of their status were underrepresented in our consumer survey sample.

- The survey response rate was low at about 18% for the paper survey. The original intention of this survey was to administer it online to protect anonymity and reach wide distribution of consumers. However, it was quickly realized that a paper survey was more appropriate for the population we were trying to reach. We attempted to address the low response rate by extending the survey period, but there were still challenges obtaining responses.

- All data for the consumer survey was self-reported. It is possible that the respondents to the consumer survey may have answered questions based on social desirability. For example, it was noted to us that many respondents received help from a case manager in completing the survey. Therefore, it is possible that this may have biased the results of the survey favorably toward services provided by case managers. Furthermore, there appeared to be difficulty interpreting questions regarding needed services by respondents who completed the consumer survey on paper. These questions may have been misinterpreted so that those who needed a particular service would report that they did not have that need, when in fact they did and the service was received. As a result, it is possible that there was underreporting of *met* needs via the survey.

- We also calculated and defined met and unmet need based on the distribution of the responses of our consumer sample. Given that these rates are based on PLWH who were willing to complete the survey, the results may not be generalizable to the EMA population overall.

- We were not able to conduct two focus groups: the out-of-care focus group and the women living with HIV focus group. The women's focus group was scheduled with incentives, but the several participants did not show up and thus we were unable to

explore in-depth barriers to care and service needs among women living with HIV. However, this group was overrepresented in our consumer survey sample and therefore we were able to obtain valuable quantitative information about the needs and barriers for this subpopulation, albeit not as extensive in nature. The out-of-care focus group was cancelled due to a snow storm the day prior. Only one person was signed up for the focus group and it was unclear if the person would be able to attend the session. Unfortunately, the out-of-care consumer group is one that we hypothesize is underrepresented in the consumer survey sample. However, we were able to obtain information on this group of consumers via case manager focus groups and provider key informant interviews.

V. Recommendations

Given the results presented in this report, below are recommendations for the Planning Council to address the barriers to linkage and retention in care and service needs of populations in the EMA:

- Nutrition, food assistance, clothing and other basic needs are important services that are needed and are accessible to the population. Support for helping PLWH get connected to medical care, assistance with paying for medications, and substance use counseling are also service needs that are being met for PLWH in the EMA. Continued support for these services are needed as they have been reported as critical services by PLWH despite their viral suppression status.

- Invest in resources to address unmet needs such as job training, assistance with housing subsidies, and rental and utility assistance across the EMA. Strategies could include training case managers and providing resources to them to support PLWH with information about employment and housing resources and support with finding and completing employment and housing applications.

- Transportation is a high-need service need, particularly in rural and suburban regions of the EMA. Therefore, investment in transportation assistance is recommended, which can contribute to service gaps and be continued and augmented in particularly high-need regions.

- Invest in resources toward hiring and building capacity of HIV service staff (including case managers and peers). Strategies include motivational interviewing and promoting self-efficacy among clients for current providers.

- Peer support and case management services were described as critical services by consumer groups with helping them coordinate their care, obtaining their medications, and general support. Consumer groups such as MSM and long term survivors described a need for finding providers who can provide culturally-sensitive and knowledgeable services as critical to reducing stigma and keeping them engaged in care. Hiring more peers and case managers who are culturally aware of the populations they are working with and who have knowledge on the systems needed to be accessed by PLWH could be a strategy to address this need.

- Investing in models of care that provide or train existing staff in managing legal issues for people with a criminal history is critical. PLWH with history of incarceration or recent immigrants continue to need support with connecting to services, primarily housing and job training/employment opportunities. Allocation of resources for short term or emergency housing support is one of the highest priority unmet needs for PLWH by viral suppression status but also for these specific target group of populations.

- Training for peer support and case management staff on financial planning would be beneficial for staff working with long term survivors. Many long term survivors

expressed concerns about their financial well-being in later life, having previously not expected to live so long with HIV. Training areas include how to assess client's financial stability and concerns and identify resources in the community, both legal and financial planning, that could help survivors plan accordingly.

- To address concerns about medication adherence, consider Direct Observed Therapy (DOT) for clients who are particularly high need and need more support with taking their medications.

- Disseminate best practice models across providers in the EMA for integration of mental health and substance use treatment with HIV care. The provider survey and interviews both highlighted that co-occurring mental health and substance use disorders are barriers to care and viral suppression. Although these are major system issues for the EMA both in terms of access and availability of providers that are beyond the scope of Ryan White resources, several best practice models emerged from the data that could be encouraged by the Planning Council. This includes:

    a. Employ a behavioral health staff person (social worker, counselor, etc) as part of the HIV care team. This staff member can provide counseling and support and facilitate access to psychiatric care when necessary.

    b. Provide medication assisted therapy and counseling for substance use treatment and encourage strong relationships with HIV and behavioral health care managers to facilitate access to their treatment.

    c. Formalize relationships with external substance use treatment agencies to prioritize clients when necessary. HIV case managers who had strong relationships with these agencies were successful in connecting their clients to services.

    d. Establish walk-in appointments for mental health services for PLWH. This may take time to build and coordinate care across HIV and mental health departments or agencies. However, having mental health provider readily accessible to talk with PLWH with mental health disorders may reduce the barrier to accessing services or reduce no shows and help activate the person to seek care when a person is ready.

APPENDIX A: DATA TABLES

Table 1. Demographics of Consumer Survey Sample

Gender (N = 225)	**%**
Male	58.22%
Female	40.00%
Transgender and Other	1.78%
Age (N = 217)	
18-44 years	23.04%
45-64 years	67.74%
65+ years	9.22%
Sexual Orientation (N = 221)	
Straight	60.18%
Gay	32.31%
Lesbian	0.90%
Bisexual	5.88%
Pansexual	0.45%
Unsure	0.45%
Race/Ethnicity (N = 222)	
Hispanic	36.94%
White	27.93%
Black	30.63%
Asian/Pacific Islander/Native Hawaiian	0.45%
American Indian/Alaskan Native	0.90%
Multiracial	3.15%
Highest Level of Education (N = 221)	
Some high school or less than high school	26.24%
High school and/or technical/vocational school	41.18%
Some college or more	32.13%
Other (Unspecified)	0.45%
Primary Language (N = 224)	
English	77.23%
Spanish or other (i.e. French, Creole, Kikuyu, and Kiswahili)	22.77%
County of Residence (N = 207)	
Bristol	2.90%
Essex	13.04%
Middlesex	6.28%
Norfolk	3.86%
Plymouth	6.76%
Suffolk	42.51%
Worcester	8.21%
Hillsborough	15.46%
Rockingham	0.97%
Criminal Record History (N = 223)	
No	69.55%
Yes	30.45%
Health Insurance Status (N = 224)	
Insured	97.32%
Uninsured	2.68%

Country of Birth (N = 225)	
USA and Territories	84.00%
Outside USA and Territories	16.00%

Table 2. Consumer Health Characteristics

Years Living with HIV (N = 217)	**%**
0-10 years	21.66%
11-20 years	34.56%
21+ years (diagnosed pre-HAART)	43.78%
Last Time Consumer Saw HIV Medical Provider (N = 220)	
Less than 6 months	88.18%
Between 6 months and 12 months (less than 1 year)	10.00%
Between 1 year and 3 years	0.91%
Between 3 years and 5 years	0.45%
More than 5 years	0.45%
Insurance Type (N = 224)	
Medicaid	58.48%
Medicare	8.04%
Private Insurance	9.82%
Multiple Insurances	20.09%
Uninsured	2.68%
Unspecified	0.89%
Viral Suppression Status (N = 212)	
Virally Suppressed	79.72%
Not Virally Suppressed	12.74%
Don't Know	7.55%
Comorbidities (N = 183)	
Depression	68.31%
High blood pressure	36.61%
Back pain and other orthopedic disorders	36.07%
Hepatitis C	26.23%
Diabetes	20.22%
Osteoporosis, degenerative arthritis	19.13%
Rheumatoid arthritis and other autoimmune disorders	18.03%
Anemia or other blood disease	13.11%
Kidney disease	12.02%
Heart disease and other vascular diseases	11.48%
Gastrointestinal disorders	9.29%
Other liver disease	8.74%
Lung and respiratory diseases	8.20%
Cancer	7.10%
Anxiety, bipolar, and PTSD	3.83%
Neurological disorders	2.73%
Other	2.19%
Other psychiatric disorders	1.64%
Thyroid diseases	1.64%
Skin disease	1.09%
Sexually transmitted diseases	1.09%
Other infectious diseases	1.09%
Lipodystrophy	0.55%
Currently Taking HIV Medications to Treat HIV or AIDS (N = 223)	
Yes	95.07%
No	4.93%

Stopped taking HIV medications for > 7 days in last 6 months (N = 212)	
Yes	15.09%
No	84.91%
Ever Missed a Dose of HIV Medications in Past 2 Weeks (N = 163)	
Never	61.35%
1-2 times	36.81%
3-4 times	1.84%
Reasons Stopped Taking HIV Medications for > 7 Days (N = 30)	
Forgot to take them	46.67%
Felt depressed or overwhelmed	33.33%
Was busy with other things	23.33%
Wanted to avoid side effects	20.00%
Felt too sick	16.67%
Was living on the street or homeless	16.67%
Could not get to a doctor or clinic	13.33%
Had too many pills to take	13.33%
Could not afford a refill	10.00%
Had problems taking pills	6.67%
Administrative problems obtaining medications	6.67%
My medical provider told me to stop	3.33%

Table 3a. Demographics of Consumer Survey Sample Stratified by Viral Suppression Status

	Virally Suppressed	Virally Unsuppressed
Gender		
N	168	27
Male	60.71%	40.74%
Female	36.90%	59.26%
Transgender and Other	2.38%	0.00%
Age		
N	161	27
18-44 years	23.60%	22.22%
45-64 years	66.46%	74.07%
65+ years	9.94%	3.70%
Sexual Orientation		
N	165	27
Straight	57.58%	66.67%
Gay	35.15%	22.22%
Lesbian	1.21%	0.00%
Bisexual	6.06%	7.41%
Pansexual	0.00%	0.00%
Unsure	0.00%	3.70%
Race/Ethnicity		
N	166	27
Hispanic	34.94%	37.04%
White	30.12%	33.33%
Black	30.12%	29.63%
Asian/Pacific Islander/Native Hawaiian	0.60%	0.00%
American Indian/Alaskan Native	0.60%	0.00%
Multiracial	3.61%	0.00%
Highest Level of Education		
N	165	27
Some high school or less than high school	23.03%	37.04%
High school and/or technical/vocational school	40.61%	40.74%
Some college or more	35.76%	22.22%
Other	0.61%	0.00%
Primary Language		
N	168	26
English	77.38%	69.23%
Spanish or other	22.62%	30.77%
County of Residence		
N	155	26
Bristol	3.23%	3.85%
Essex	12.26%	11.54%
Middlesex	3.87%	7.69%
Norfolk	3.87%	3.85%
Plymouth	7.10%	7.69%
Suffolk	42.58%	42.31%
Worcester	10.32%	3.85%
Hillsborough	16.13%	15.38%
Rockingham	0.65%	3.85%

Criminal Record History		
N	166	27
No	72.29%	62.96%
Yes	27.71%	37.04%
Health Insurance Status		
N	168	27
Insured	98.21%	92.59%
Uninsured	1.79%	7.41%
Country of Birth		
N	168	27
USA and Territories	84.52%	85.19%
Outside USA and Territories	15.48%	14.81%

Table 3b. Demographics of Consumer Survey Sample Stratified by Primary Language

	English as Primary Language	Spanish or Other Primary Language
Gender		
N	173	51
Male	57.80%	58.82%
Female	41.04%	37.25%
Transgender and Other	1.16%	3.92%
Age		
N	170	46
18-44 years	24.71%	17.39%
45-64 years	67.06%	69.57%
65+ years	8.24%	13.04%
Sexual Orientation		
N	173	47
Straight	56.65%	74.47%
Gay	35.26%	19.15%
Lesbian	1.16%	0.00%
Bisexual	6.36%	4.26%
Pansexual	0.58%	0.00%
Unsure	0.00%	2.13%
Race/Ethnicity		
N	171	50
Hispanic	20.47%	92.00%
White	36.26%	0.00%
Black	37.43%	8.00%
Asian/Pacific Islander/Native Hawaiian	0.58%	0.00%
American Indian/Alaskan Native	1.17%	0.00%
Multiracial	4.09%	0.00%
Highest Level of Education		
N	170	49
Some high school or less than high school	18.82%	51.02%
High school and/or technical/vocational school	42.35%	38.78%
Some college or more	38.24%	10.20%
Other	0.59%	0.00%
County of Residence		
N	160	46
Bristol	3.75%	0.00%
Essex	8.75%	26.09%
Middlesex	6.88%	4.35%
Norfolk	3.75%	4.35%
Plymouth	8.75%	0.00%
Suffolk	44.38%	36.96%
Worcester	6.88%	13.04%
Hillsborough	15.63%	15.22%
Rockingham	1.25%	0.00%
Criminal Record History		
N	169	49
No	67.46%	75.51%
Yes	32.54%	24.49%

Health Insurance Status		
N	171	51
Insured	97.66%	96.08%
Uninsured	2.34%	3.92%
Country of Birth		
N	173	51
USA and Territories	91.91%	58.82%
Outside USA and Territories	8.09%	41.18%

Table 4a. Top Service Needs Among Consumer Survey Respondents

Top 5 Needs	Total Sample Size	Percent Needing Service
Mental health services and counseling	207	51%
Dental Care	207	50%
Help getting connected to primary medical care and health-related services	207	48%
Assistance paying for medications	207	47%
Nutrition/food assistance	207	46%
Top Met Needs	**Total Sample Size**	**Percent Receiving Needed Service**
Assistance paying for medications	82	95%
Help getting connected to primary medical care and health-related services	78	95%
Other (unspecified)	17	94%
Assistance with understanding HIV/AIDS diagnosis, treatment, HIV knowledge	43	91%
Assistance paying for copays and coinsurance	60	88%
Nutrition/food assistance	77	88%
Assistance connecting with medical specialists	51	88%
Substance use counseling	47	87%
Support around medication assisted therapy for substance use	30	87%
Top Unmet Needs	**Total Sample Size**	**Percent Not Receiving Needed Service**
Job training/employment assistance	34	41%
Residential substance use treatment	19	37%
Legal support for a criminal history/record	28	36%
Help obtaining clothing or other basic needs	43	28%
Helping finding and obtaining housing	70	27%
Assistance maintaining housing	60	27%
Peer support	80	20%
Mental health services, counseling, and/or treatment	93	19%
Financial assistance	76	18%
Interpreter/translation services when attempting to access medical services	30	17%
Legal support for immigration issues	6	17%
Help getting to medical appointments	69	16%
Dental care	89	16%

Table 4b. Top Service Needs Among Consumer Survey Respondents Stratified by Viral Suppression Status

Among the Virally Suppressed		
Top 5 Needs	**Total Sample Size**	**Percent Needing Service**
Mental health services and counseling	158	51%
Dental Care	158	50%
Assistance paying for medications	158	49%
Help getting connected to primary medical care and health-related services	158	48%
Peer support	158	47%
Top Met Needs	**Total Sample Size**	**Percent Receiving Needed Service**
Help getting connected to primary medical care and health-related services	59	97%
Assistance paying for medications	66	95%
Other (unspecified)	13	92%
Nutrition/food assistance	55	91%
Assistance paying for copays and coinsurance	47	89%
Help getting to medical appointments	52	88%
Assistance connecting with medical specialists	41	88%
Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge	32	88%
Dental care	68	87%
Interpreter/translation services	21	86%
Top Unmet Needs	**Total Sample Size**	**Percent Not Receiving Needed Service**
Residential substance use treatment	16	44%
Legal support for a criminal history/record	22	41%
Job training/employment assistance	28	39%
Help obtaining clothing or other basic needs	31	29%
Assistance maintaining housing	49	27%
Help finding and obtaining housing	50	24%
Mental health services and counseling	75	19%
Peer support	65	18%
Support around medication assisted therapy for substance use	22	18%
Legal support for immigration issues	6	17%
Financial assistance	63	16%
Substance use counseling	38	16%
Among the Virally Unsuppressed		
Top 5 Needs	**Total Sample Size**	**Percent Needing Service**
Help getting connected to primary medical care and health-related services	24	58%
Mental health services	24	50%
Assistance paying for medications	24	50%
Dental care	24	46%
Nutrition/food assistance	24	42%

Top Met Needs	Total Sample Size	Percent Receiving Needed Service
Interpreter/translation services	5	100%
Substance use counseling	3	100%
Support around medication assisted therapy for substance use	2	100%
Residential substance use treatment	1	100%
Legal support for criminal history	2	100%
Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge	4	100%
Other (unspecified)	2	100%
Help getting connected to primary medical care and health-related services	13	92%
Dental care	10	90%
Assistance paying for medications	9	89%
Help getting to medical appointments	8	88%
Assistance paying for copays and coinsurance	7	86%
Top Unmet Needs	**Total Sample Size**	**Percent Not Receiving Needed Service**
Job training/employment assistance	3	67%
Help finding and obtaining housing	8	50%
Nutrition/food assistance	10	30%
Financial assistance	7	29%
Assistance maintaining housing	4	25%
Mental health services and counseling	8	25%
Help obtaining clothing or other basic needs	5	20%
Peer support	6	17%
Assistance connecting with medical specialists	6	17%

Table 4c. Top Service Needs Among Consumer Survey Respondents Stratified by Primary Language

Among those who speak primarily English		
Top 5 Needs	**Total Sample Size**	**Percent Needing Service**
Mental health services	157	53%
Dental care	157	52%
Assistance paying for medications	157	47%
Nutrition/food assistance	157	45%
Peer support	157	45%
Top Met Needs	**Total Sample Size**	**Percent Receiving Needed Service**
Legal support for immigration issues	2	100%
Assistance paying for medications	62	97%
Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge	30	93%
Help getting connected to primary medical care and health-related services	56	93%
Assistance connecting with medical specialists	39	92%
Nutrition/food assistance	59	92%
Other (Unspecified)	10	90%
Assistance paying for copays and coinsurance	47	89%
Substance use counseling	37	86%
Top Unmet Needs	**Total Sample Size**	**Percent Not Receiving Needed Service**
Legal support for criminal history/record	22	36%
Job training/employment assistance	23	35%
Residential substance use treatment	15	33%
Help finding and obtaining housing	55	31%
Interpreter/translation services	8	25%
Peer support	60	23%
Assistance maintaining housing	52	23%
Help obtaining clothing or other basic needs	32	22%
Financial assistance	57	21%
Mental health services	73	19%
Dental care	72	17%
Help getting to medical appointments	50	16%
Support around medication assisted therapy for substance use	25	16%
Among those who speak primarily Spanish or another language other than English		
Top 5 Needs	**Total Sample Size**	**Percent Needing Service**
Help getting connected to primary medical care and health-related services	48	65%
Interpreter/translation services	48	63%
Help getting to medical appointments	48	52%
Assistance paying for medications	48	50%
Peer support	48	48%

Top Met Needs	Total Sample Size	Percent Receiving Needed Service
Help getting connected to primary medical care and health-related services	21	100%
Support around medication assisted therapy for substance use	5	100%
Other (Unspecified)	6	100%
Dental care	15	93%
Peer support	19	89%
Assistance paying for medications	19	89%
Help getting connected to medical appointments	18	89%
Financial assistance	18	89%
Substance use counseling	9	89%
Help finding and obtaining housing	15	87%
Interpreter/translation services	21	86%
Top Unmet Needs	**Total Sample Size**	**Percent Not Receiving Needed Service**
Residential substance use treatment	4	50%
Job training/employment assistance	9	44%
Assistance maintaining housing	7	43%
Help obtaining clothing or other basic needs	10	40%
Legal support for a criminal history/record	6	33%
Assistance connecting with medical specialists	11	27%
Legal support for immigration issues	4	25%
Mental health services	19	21%
Nutrition/food assistance	16	19%
Assistance paying for copays and coinsurance	12	17%
Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge	12	17%

Table 4d. Top Service Needs Among Consumer Survey Respondents Stratified by Residence

Among those who live in Boston		
Top 5 Needs	**Total Sample Size**	**Percent Needing Service**
Mental health services, counseling, and/or treatment	83	58%
Dental care	83	49%
Peer support	83	46%
Help finding and obtaining housing	83	45%
Nutrition/food assistance	83	41%
Top Met Needs	**Total Sample Size**	**Percent Receiving Needed Service**
Help getting connected to primary medical care and health-related service	24	100%
Assistance paying for medications (e.g. AIDS Drug Assistance Program)	27	93%
Support around medication assisted therapy for substance use	13	92%
Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge	13	92%
Dental care	35	91%
Substance use counseling	21	90%
Mental health services, counseling, and/or treatment	40	90%
Peer support	32	88%
Assistance paying for copays and coinsurance	20	85%
Assistance connecting with medical specialists	20	85%
Top Unmet Needs	**Total Sample Size**	**Percent Not Receiving Needed Service**
Legal support for immigration issues	2	50%
Job training/employment assistance	18	39%
Residential substance use treatment	13	38%
Legal support for a criminal history/record	16	38%
Help obtaining clothing or other basic needs	27	30%
Assistance maintaining housing	24	29%
Help finding and obtaining housing	33	24%
Financial assistance	28	21%
Help getting to medical appointments	24	21%
Nutrition/food assistance	25	20%
Interpreter/translation services	11	18%
Other	6	17%
Assistance paying for copays and coinsurance	20	15%
Assistance connecting with medical specialists	20	15%
Among those who live outside of Boston		
Top 5 Needs	**Total Sample Size**	**Percent Needing Service**
Help getting connected to primary medical care and health-related services	105	57%
Assistance paying for medications (e.g. AIDS Drug Assistance Program)	105	56%
Nutrition/food assistance	105	48%
Dental care	105	46%

Financial assistance	105	45%
Top Met Needs	**Total Sample Size**	**Percent Receiving Needed Service**
Legal support for immigration issues	2	100%
Other (Unspecified)	7	100%
Assistance paying for medications (e.g. AIDS Drug Assistance Program)	48	96%
Assistance understanding HIV/AIDs diagnosis, treatment, and general HIV/AIDS knowledge	21	95%
Help getting connected to primary medical care and health-related services	45	93%
Nutrition/food assistance	41	93%
Assistance paying for copays and coinsurance	34	91%
Assistance connecting with medical specialists	21	90%
Help getting connected to medical appointments	36	89%
Support around medication assisted therapy for substance use	9	89%
Substance use counseling	17	88%
Top Unmet Needs	**Total Sample Size**	**Percent Not Receiving Needed Service**
Job training/employment assistance	9	44%
Help finding and obtaining housing	27	33%
Residential substance use treatment	3	33%
Legal support for criminal history/record	6	33%
Mental health services, counseling, and/or treatment	44	30%
Peer support	38	24%
Assistance maintaining housing	29	21%
Help obtaining clothing or other basic needs	10	20%
Dental care	41	20%
Financial assistance	38	18%
Interpreter/translation services	13	15%

APPENDIX B: QUANTITATIVE DATA COLLECTION TOOLS

CONSUMER SURVEY

Thank you for agreeing to complete this survey. The Boston University School of Public Health is working with the Boston Public Health Commission on a project to determine the needs of people living with HIV (PLWH) in the Boston metropolitan area (Boston EMA region). As part of this project, this survey is being used to get information from consumers about themselves and the services that are used and needed. We hope the information we collect here will help create better health programs for PLWH.

- ☐ All information you provide in this survey is anonymous.
- ☐ If there are questions you don't feel comfortable answering, you don't have to answer them.
- ☐ Completing this survey takes approximately 20-30 minutes.
- ☐ If you complete and return this survey, you can enter a raffle to win a $100 gift card to Stop & Shop.

By agreeing to participate in this study you are confirming that you are:

- HIV+, and
- 18 years of age or older, and
- Living in the Boston EMA (Massachusetts counties: Bristol, Essex, Middlesex, Norfolk, Plymouth, Suffolk, and Worcester; New Hampshire counties: Hillsborough, Strafford, Rockingham)

To let us know that you have completed this survey, please create a unique code below. Your responses will be linked to your unique code, which is not traced to your name or other information that can identify you. Your responses will be combined with participants from across the Boston EMA with no names attached.

If you have any questions about this project or if you would like assistance in completing this survey, please contact Alexander de Groot at (617) 638-1930.

- ☐ I agree to participate in this survey.
- ☐ I do not agree to participate in this survey.

Please create a unique code using this information: Your mother's initials (first and last name) plus the month you were born in.

EXAMPLE: If my mother's name is Mary Jones, and my birth month is June (06),
Unique code would be: MJ06

Write Unique Code Here: ____ ____ ____ ____

BE SURE TO SUBMIT THIS PAGE WITH YOUR SURVEY

PART 1: DEMOGRAPHIC AND BACKGROUND INFORMATION

1. **How old are you? _____** years

2. **What is your gender?**
   - ☐ Male
   - ☐ Female
   - ☐ Transgender (male to female)
   - ☐ Transgender (female to male)
   - ☐ Other, please specify: _____

3. **What is your sexual orientation?**
   - ☐ Straight
   - ☐ Gay
   - ☐ Lesbian
   - ☐ Bisexual
   - ☐ Other, please specify:_____
   - ☐ Unsure

4. **Are you of Latino/a or Hispanic ethnicity?**
   - ☐ No
   - ☐ Yes

5. **What is your race?** *[Select all that apply]*
   - ☐ American Indian/Alaskan Native
   - ☐ Asian
   - ☐ Black/African American
   - ☐ Native Hawaiian/Pacific Islander
   - ☐ White
   - ☐ Other, please specify: _____

6. **What language do you speak most of the time, with friends and family?**
   - ☐ English
   - ☐ Spanish
   - ☐ Other, please specify:_____

7. **Where were you born?**
   - ☐ USA (not including Puerto Rico or other territories) → Go to 8.
   - ☐ Puerto Rico → Go to 8.
   - ☐ Other → Go to 7A.

   A. If "Other", **how long have you lived in the US? _____** years

8. **What is your current zip code? ___ ___ ___ ___ ___**

9. **What is the highest level of education that you've completed?**
   - ☐ No formal education
   - ☐ Less than high school
   - ☐ High school diploma or GED received
   - ☐ Technical/trade/vocational school
   - ☐ Some college (2- or 4- year college or university)
   - ☐ College graduate (2- or 4-year college or university) or more
   - ☐ Other, please specify:_____

10. **Do you have a criminal record (e.g. CORI)?**
   - ☐ No
   - ☐ Yes

11. **Do you have health insurance?**
   - ☐ No → Go to 12.
   - ☐ Yes → Go to 11A.
   - ☐ I don't know → Go to 12.

   A. If "Yes", **what kind of health insurance do you have?** *[Select all that apply.]*
      - ☐ Medicaid (e.g. Mass Health)
      - ☐ Medicare
      - ☐ Private insurance
      - ☐ CHAMPUS/Veteran's
      - ☐ I don't know
      - ☐ Other (specify): _____

12. **What year did you first test positive for HIV? ___ ___ ___ ___ (yyyy)**

PART 2: SERVICE NEEDS & GAPS

The following questions are about services that you may have needed and used in the past 6 months.

13. **At any time over the last 6 months:**

A. Did you need help getting connected to primary medical care and health-related services (i.e. Peer support, food, housing, transportation, etc.)
   - ☐ No → Go to 13B.
   - ☐ Yes → **Did you receive this service in the last 6 months?**
      - ☐ No → **Why Not?**_____
      - ☐ Yes

B. Did you need nutrition/food assistance (e.g. access to food stamps, WIC, prepared meals, congregate meals, food banks, vouchers, nutritional counseling, or food)?

- ☐ No → Go to 13C.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

C. Did you need help finding and obtaining housing (e.g. permanent, temporary, emergency shelter, residential treatment facilities)?

- ☐ No → Go to 13D.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

D. Did you need assistance maintaining housing (e.g. assistance paying rent or utilities, handling eviction notices)?

- ☐ No → Go to 13E.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

E. Did you need help obtaining clothing or other basic needs?

- ☐ No → Go to 13F.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

F. Did you need help getting to medical appointments (e.g. transportation services, taxi vouchers)?

- ☐ No → Go to 13G.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

G. Did you need financial assistance (e.g. Supplemental Security Income (SSI); Social Security Disability Insurance (SSDI); Emergency Aid to the Elderly, Disabled, and Children (EAEDC), etc.)

- ☐ No → Go to 13H.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

H. Did you need interpreter/translation services when attempting to access medical services?

- ☐ No → Go to 13I.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

I. Did you need peer support (i.e. emotional support or support obtaining services offered by a person living with HIV)?

- ☐ No → Go to 13J.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

J. Did you need substance use counseling (e.g. Alcoholics Anonymous, individual counseling, support groups)?

- ☐ No → Go to 13K.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → Why Not?_____
  - ☐ Yes

K. Did you need support around medication assisted therapy for substance use (e.g. Vivitrol, Naltrexone, Narcan, Naloxone, Methadone, Buprenorphine, Suboxone)?

- ☐ No → Go to 13L.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

L. Did you need residential substance use treatment (e.g. rehab, detox, sober living house, halfway house)?

- ☐ No → Go to 13M.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

M. Did you need mental health services, counseling, and/or treatment?

- ☐ No → Go to 13N.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

N. Did you need legal support for a criminal history/record?

- ☐ No → Go to 13O.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

O. Did you need legal support for immigration issues?

- ☐ No → Go to 13P.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

P. Did you need assistance paying for medications (e.g. AIDS Drug Assistance Program)?

- ☐ No → Go to 13Q.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

Q. Did you need assistance paying for copays and coinsurance?

- ☐ No → Go to 13R.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

R. Did you need job training/employment assistance?

- ☐ No → Go to 13S.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

S. Did you need dental care (e.g. routine exams, cleanings, fillings, treatment for gum disease)?

- ☐ No → Go to 13T.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____
  - ☐ Yes

T. Did you need assistance connecting with medical specialists?

- ☐ No → Go to 13U.
- ☐ Yes → **Did you receive this service in the last 6 months?**
  - ☐ No → **Why Not?**_____

☐ Yes

U. Did you need assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge?

☐ No → Go to 13V.

☐ Yes → **Did you receive this service in the last 6 months?**

☐ No → **Why Not?**_____

☐ Yes

V. Did you need any other service at any time over the last 6 months?

☐ No → Go to 14.

☐ Yes → **Please specify:** _____

↓

If "Yes", **Did you receive this service in the last 6 months?**

☐ No → **Why Not?**_____

☐ Yes

Part 3: Medical Care and Medications

14. Are you currently taking HIV medications (antiretrovirals), prescribed by your HIV medical provider, to treat HIV or AIDS?

☐ No → Go to 16.

☐ Yes → Go to 15.

15. During the past 6 months, have you ever stopped taking your HIV medications for more than a week (7 days in a row)?

☐ No → Go to 15B.

☐ Yes → Go to 15A.

A. If "Yes"**, why?** *[Select all that apply.]*

- ☐ Forgot to take them
- ☐ Wanted to avoid side effects
- ☐ Was busy with other things
- ☐ Had problems taking pills
- ☐ Could not get to a doctor or clinic
- ☐ Felt depressed or overwhelmed
- ☐ Felt too sick
- ☐ Was living on the street or homeless
- ☐ Had too many pills to take
- ☐ Could not afford a refill
- ☐ My medical provider told me to stop
- ☐ Other, please specify: _____

B. If "No", **how often have you missed a dose of any of your HIV medications in the past 2 weeks?**
   - ☐ Never
   - ☐ 1-2 times
   - ☐ 3-4 times
   - ☐ 5 or more times

16. When was the last time (month and year) you had your blood drawn to check your viral load?

___ ___ /___ ___ ___ ___ **(mm/yyyy)** → Go to 16A.

☐ I don't know → Go to 16A.
☐ I have never had a viral load lab drawn → Go to 17.

A. Were you undetectable (less than 200 copies/mL) the last time you had your blood drawn to check your viral load?
   - ☐ No
   - ☐ Yes
   - ☐ I don't know

17. How long ago did you last see your HIV medical provider?
☐ Less than 6 months → Go to 18.
☐ Between 6 months and 12 months (less than 1 year) → Go to 17A.
☐ Between 1 year and 3 years → Go to 17A.
☐ Between 3 and 5 years → Go to 17A.
☐ More than 5 years → Go to 17A.

A. If it has been longer than 6 months since you last saw your HIV medical provider, why haven't you had an appointment in the past 6 months?
   - ☐ I was feeling healthy/not feeling sick
   - ☐ I forgot
   - ☐ I felt that the provider or other staff treated me as inferior because of my HIV status
   - ☐ I felt that the provider or other staff treated me as inferior because of my ethnic/racial background
   - ☐ The provider or other staff at the agency do not speak my primary language
   - ☐ The days and times that the provider is available do not work for my schedule
   - ☐ My HIV medical provider is located in an area that is difficult to get to
   - ☐ Other, please specify: _____

18. How many HIV care appointments have you missed (without rescheduling) in the last year?

☐ None → Go to 19.

☐ At least one time → Please specify the number of times: _____ → Go to 18A.
☐ I don't know → Go to 19.

A. Why did you miss your appointments? _____

19. Which of the following medical problems have you been diagnosed with? *[Select all that apply]*.

☐ Heart disease
☐ High blood pressure
☐ Lung disease
☐ Diabetes
☐ Ulcer or stomach disease
☐ Kidney disease
☐ Hepatitis C
☐ Other liver disease
☐ Anemia or other blood disease
☐ Cancer
☐ Depression
☐ Osteoporosis, degenerative arthritis
☐ Back pain
☐ Rheumatoid arthritis
☐ Other, please specify: _____
☐ I have not been diagnosed with any medical problems other than HIV

20. Have you experienced any other challenges or barriers to receiving HIV primary care services on a consistent basis? If so, please describe them below.

_____
_____
_____
_____

21. Is there anything else you would like to share with the BPHC Planning Council?

_____
_____
_____
_____

END OF SURVEY

Thank you for completing this survey. If you would like to enter the raffle to win a $100 gift card to Stop & Shop, please take the following steps:

1) Write the UNIQUE CODE which you created on Page 1: ___ ___ ___ ___

2) Remove this page and keep for your records.

3) Submit completed survey by using the provided stamped and self-addressed envelope. Please do not include your return address.

4) Email Evey Kane at ekane@bphc.org and provide your unique ID and the best way to reach you (this will not be linked to your survey responses in any way). If you do not have access to email, call (617) 534-2303.

PROVIDER SURVEY

Type of Provider: □ Physician □ Physician's Assistant □ Nurse Practitioner □ Other (please specify): _____

Assessment of Service Needs: Please answer questions A, B, C, and D with regard to your patients who are **VIRALLY SUPPRESSED**.

List of Services	**(A) Do your virally suppressed patients need the listed services?**		**(B) Do your virally suppressed patients have access to the listed services at your agency or at another agency in your area?**		
	Yes	No	Yes	No	Don't Know
1) Services that link clients with primary medical care and health-related support services (i.e. case management)	□	□	□	□	□
2) Preventive dental care (e.g. periodic exams, cleanings, fluoride treatment, etc.)	□	□	□	□	□
3) Restorative dental treatment (e.g. fillings, treatment for gum disease, etc.)	□	□	□	□	□
4) Nutrition (e.g. prepared meals, congregate meals, food banks, vouchers, nutritional counseling)	□	□	□	□	□
5) Help obtaining clothing or other basic needs	□	□	□	□	□
6) Assistance maintaining housing (e.g. assistance paying rent and utilities, handling eviction notices)	□	□	□	□	□
7) Help finding and obtaining housing (e.g. permanent, temporary, emergency shelter, residential treatment facilities)	□	□	□	□	□
8) Peer Support (i.e. emotional support and support obtaining services offered by a person living with HIV)	□	□	□	□	□
9) Support for substance and/or alcohol use (e.g. Alcoholics/Narcotics Anonymous, individual therapy, group therapy, intensive outpatient programs)	□	□	□	□	□
10) Medication-assisted therapy for substance use (e.g. Vivitrol, Naltrexone, Narcan, Naloxone, Methadone, Buprenorphine, Suboxone)	□	□	□	□	□
11) Residential Substance Use Treatment (e.g. Detox, Rehabilitation, sober living, halfway houses)	□	□	□	□	□
12) Mental health counseling and/or treatment	□	□	□	□	□
13) Help getting to medical appointments (e.g. taxi vouchers, public and private transportation services)	□	□	□	□	□

14) Help paying for medications (e.g. AIDS Drug Assistance Program)	□	□	□	□	□
15) Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge	□	□	□	□	□
16) Interpreters and Translation	□	□	□	□	□
17) Assistance finding employment or job training	□	□	□	□	□
18) Assistance paying for copays and coinsurance	□	□	□	□	□
19) Financial Assistance (e.g. SSI/SSDI)	□	□	□	□	□
20) Legal Support – Criminal History/Record	□	□	□	□	□
21) Legal Support – Immigration	□	□	□	□	□
22) Assistance connecting with medical specialists	□	□	□	□	□
23) Other 1:	□	□	□	□	□
24) Other 2:	□	□	□	□	□
(C) Please list the 3-5 services you believe are most important to your patients who are virally suppressed.					
(D) For the services you listed in question C, what are the challenges to getting those services for your patients who are virally suppressed in your area?					

Assessment of Barriers to Services: In your experience, to what extent do the following barriers impact adherence to HIV care and treatment for your patients who are **VIRALLY SUPPRESSED**?

Barrier	**Not at All**	**Slightly**	**Moderately**	**Considerably**	**Extremely**
1) Mental health disorders	□	□	□	□	□
2) Substance use other than alcohol	□	□	□	□	□
3) Alcohol use	□	□	□	□	□
4) Fear of others finding out about HIV status	□	□	□	□	□
5) Denial of HIV status	□	□	□	□	□
6) Not feeling sick	□	□	□	□	□
7) Unstable housing	□	□	□	□	□
8) Limited income	□	□	□	□	□
9) Cost of HIV care and medications	□	□	□	□	□
10) Lack of health insurance	□	□	□	□	□
11) Inadequate insurance coverage	□	□	□	□	□
12) Lack of childcare during medical appointments	□	□	□	□	□
13) Difficulty navigating medical care system	□	□	□	□	□

14) Don't know where to get treatment	□	□	□	□	□
15) Lack of transportation	□	□	□	□	□
16) Lack of support from family/friends	□	□	□	□	□
17) Incarceration	□	□	□	□	□
18) Difficulty accessing medical specialties	□	□	□	□	□
19) Insufficient food	□	□	□	□	□
20) Other priorities than HIV care. Please list:					
a) _____	□	□	□	□	□
b) _____	□	□	□	□	□
c) _____	□	□	□	□	□
Other 1: _____	□	□	□	□	□
Other 2: _____	□	□	□	□	□

<u>Assessment of Service Needs:</u> Please answer questions A, B, C, and D with regard to your patients who are **<u>NOT VIRALLY SUPPRESSED</u>**.

List of Services	**<u>(A)</u> Do your non-virally suppressed patients need the listed services?**		**<u>(B)</u> Do your non-virally suppressed patients have access to the listed services at your agency or at another agency in your area?**		
	Yes	No	Yes	No	Don't Know
1) Services that link clients with primary medical care and health-related support services (i.e. case management)	□	□	□	□	□
2) Preventive dental care (e.g. periodic exams, cleanings, fluoride treatment, etc.)	□	□	□	□	□
3) Restorative dental treatment (e.g. fillings, treatment for gum disease, etc.)	□	□	□	□	□
4) Nutrition (e.g. prepared meals, congregate meals, food banks, vouchers, nutritional counseling)	□	□	□	□	□
5) Help obtaining clothing or other basic needs	□	□	□	□	□
6) Assistance maintaining housing (e.g. assistance paying rent and utilities, handling eviction notices)	□	□	□	□	□
7) Help finding and obtaining housing (e.g. permanent, temporary, emergency shelter, residential treatment facilities)	□	□	□	□	□

8) Peer Support (i.e. emotional support and support obtaining services offered by a person living with HIV)	□	□	□	□	□
9) Support for substance and/or alcohol use (e.g. Alcoholics/Narcotics Anonymous, individual therapy, group therapy, intensive outpatient programs)	□	□	□	□	□
10) Medication-assisted therapy for substance use (e.g. Vivitrol, Naltrexone, Narcan, Naloxone, Methadone, Buprenorphine, Suboxone)	□	□	□	□	□
11) Residential Substance Use Treatment (e.g. Detox, Rehabilitation, sober living, halfway houses)	□	□	□	□	□
12) Mental health counseling and/or treatment	□	□	□	□	□
13) Help getting to medical appointments (e.g. taxi vouchers, public and private transportation services)	□	□	□	□	□
14) Help paying for medications (e.g. AIDS Drug Assistance Program)	□	□	□	□	□
15) Assistance understanding HIV/AIDS diagnosis, treatment, and general HIV/AIDS knowledge	□	□	□	□	□
16) Interpreters and Translation	□	□	□	□	□
17) Assistance finding employment or job training	□	□	□	□	□
18) Assistance paying for copays and coinsurance	□	□	□	□	□
19) Financial Assistance (e.g. SSI/SSDI)	□	□	□	□	□
20) Legal Support – Criminal History/Record	□	□	□	□	□
21) Legal Support – Immigration	□	□	□	□	□
22) Assistance connecting with medical specialists	□	□	□	□	□
23) Other 1:	□	□	□	□	□
24) Other 2:	□	□	□	□	□
(C) Please list the 3-5 services you believe are most important to your patients who are virally suppressed.					
(D) For the services you listed in question C, what are the challenges to getting those services for your patients who are virally suppressed in your area?					

Assessment of Barriers to Services: In your experience, to what extent do the following barriers impact adherence to HIV care and treatment for your patients who are **NOT VIRALLY SUPPRESSED**?

Barrier	Not at All	Slightly	Moderately	Considerably	Extremely
1) Mental health disorders	□	□	□	□	□
2) Substance use other than alcohol	□	□	□	□	□
3) Alcohol use	□	□	□	□	□

4) Fear of others finding out about HIV status	□	□	□	□	□
5) Denial of HIV status	□	□	□	□	□
6) Not feeling sick	□	□	□	□	□
7) Unstable housing	□	□	□	□	□
8) Limited income	□	□	□	□	□
9) Cost of HIV care and medications	□	□	□	□	□
10) Lack of health insurance	□	□	□	□	□
11) Inadequate insurance coverage	□	□	□	□	□
12) Lack of childcare during medical appointments	□	□	□	□	□
13) Difficulty navigating medical care system	□	□	□	□	□
14) Don't know where to get treatment	□	□	□	□	□
15) Lack of transportation	□	□	□	□	□
16) Lack of support from family/friends	□	□	□	□	□
17) Incarceration	□	□	□	□	□
18) Difficulty accessing medical specialties	□	□	□	□	□
19) Insufficient food	□	□	□	□	□
20) Other priorities than HIV care. Please list:					
a) _____	□	□	□	□	□
b) _____	□	□	□	□	□
c) _____	□	□	□	□	□
Other 1: _____	□	□	□	□	□
Other 2: _____	□	□	□	□	□

APPENDIX C: QUALITATIVE DATA COLLECTION TOOLS

Boston EMA Assessment of Service Needs for PLWH
Semi-Structured Focus Group Guide for Long-Term Survivors

Introductory Script

Thank you for taking the time to speak with us. Under contract by the Boston Public Health Commission, and in collaboration with the Boston EMA Ryan White Planning Council, we are conducting an assessment of service needs for people living with HIV (PLWH) in the Boston EMA. The objective of this work is to identify 1) facilitators to engagement in care and treatment adherence and 2) barriers that prevent PLWH both in and out of care from receiving needed services or from continuing in care and treatment. The information gathered as part of this assessment will be used by the Planning Council 1) to identify which services are needed, which are being provided, and which service gaps remain for PLW in the Boston EMA and 2) to plan for future funding allocation accordingly.

Everything that we discuss in this focus group will is confidential. Some of the questions that we ask or topics that may emerge as a result of our discussions may be sensitive. If a question or topic makes you feel uncomfortable, you don't have to answer them. Your participation is voluntary and you can leave at any time. Because some of the things we discuss today may be sensitive information, please do not share the responses of others outside of this focus group.

In order to capture your responses accurately, we would like your permission to audio record this discussion. Do I have your permission to record?

Background

1. How long have you been living with HIV?
2. Can you please talk a bit about your experience living with HIV and how it has changed over time?

Service Needs

3. As your time living with HIV has passed, can you please describe if and how your needs have changed?
    - **a.** What services are you in need of now that you didn't need in the past?
    - **b.** Which services do you no longer need, if any?

Service Gaps Remaining

4. Have you been able to obtain services that you did not need before? Why or why not?
    - **a.** Can you please describe some instances when you were able to successfully get a new service you needed?
    - **b.** Can you please describe some instances when you have not been able to get a new service that you needed?

        Probes: Do you lack access to these services (availability in their area, financial means to pay for services)? Are you unaware of whether these

services exist or how you would get connected to them? Are there other priorities that are more concerning?

Other Barriers to Care or Adherence

5. As the time has passed, have you encountered new challenges to taking your HIV medications as recommended by your HIV care provider? If so, can you please describe them? What would help or has helped to overcome these challenges?

6. As the time has passed, have you encountered new challenges to keeping up with your HIV primary care appointments? If so, can you please describe them? What would help or has helped to overcome these challenges?

7. If you were previously out of care, what motivators keep you in care now?

Boston EMA Assessment of Service Needs for PLWH
Semi-Structured Focus Group Guide for MSM of Color

Introductory Script

Thank you for taking the time to speak with us. Under contract by the Boston Public Health Commission, and in collaboration with the Boston EMA Ryan White Planning Council, we are conducting an assessment of service needs for people living with HIV (PLWH) in the Boston EMA. The objective of this work is to identify 1) facilitators to engagement in care and treatment adherence and 2) barriers that prevent PLWH both in and out of care from receiving needed services or from continuing in care and treatment. The information gathered as part of this assessment will be used by the Planning Council 1) to identify which services are needed, which are being provided, and which service gaps remain for PLWH in the Boston EMA and 2) to plan for future funding allocation accordingly.

In order to capture your responses accurately, we would like your permission to audio record this discussion. Do I have your permission to record?

Background

8. How long have you been living with HIV?
9. What issues or challenges do MSM of color living with HIV deal with as opposed to other people living with HIV?

Service Needs

10. What services do you consider most important that you receive in your life right now?

Facilitator note*: Can provide this list on a board or news print to give participants ideas if they are having a hard time brainstorming:*

- HIV primary medical care
- Other types of medical assistance (e.g. OB/GYN, etc.)
- Food assistance
- Assistance obtaining (e.g. permanent, temporary, emergency shelter, residential treatment facilities)
- Assistance maintaining housing (e.g. eviction notices)
- Clothing or other basic needs
- Transportation assistance
- Financial assistance
- Interpreter/translation
- Assistance obtaining outpatient substance abuse treatment
- Assistance obtaining inpatient substance abuse treatment
- Assistance obtaining medication-assisted treatments for substance use (e.g. methadone, buprenorphine, vivitrol, naltrexone)
- Assistance with getting into a rehab or detox program for substance use
- Assistance getting into halfway home or sober house

- Assistance getting other substance use support services (e.g. AA, NA, counseling, support groups)
- Assistance with obtaining mental health appointment, counseling, and/or treatment
- Legal assistance
- Medication assistance (paying for drugs, help with prescriptions)
- Job training/Employment assistance
- Assistance with dental care
- Assistance with benefits

11. Of these services, which of these do are you generally able to receive?

Service Gaps Remaining

12. Of the services that you need but aren't able to get – can you give some examples of why you were not able to get these services?

    Probes: Do you lack access to these services (availability in their area, financial means to pay for services)? Are you unaware of whether these services exist or how you would get connected to them? Are there other priorities that are more concerning?

Other Barriers to Care or Adherence

13. Can you describe any challenges you encounter to taking your HIV medications as recommended by your HIV care provider? What would help or has helped to overcome these challenges?

14. Can you describe any challenges you encounter to missing HIV care appointments? What would help or has helped to overcome these challenges?

15. If you were previously out of care, what motivates you to stay in care now?

Boston EMA Assessment of Service Needs for PLWH
Semi-Structured Focus Group Guide for Medical Case Managers

Introductory Script

Thank you for taking the time to speak with us. Under contract by the Boston Public Health Commission, and in collaboration with the Boston EMA Ryan White Planning Council, we are conducting an assessment of service needs for people living with HIV (PLWH) in the Boston EMA. The objective of this work is to identify 1) facilitators to engagement in care and treatment adherence and 2) barriers that prevent PLWH both in and out of care from receiving needed services or from continuing in care and treatment. The information gathered as part of this assessment will be used by the Planning Council 1) to identify which services are needed, which are being provided, and which service gaps remain for PLWH in the Boston EMA and 2) to plan for future funding allocation accordingly.

Background

16. How long have you worked in the field of HIV?
17. How long have you worked as a Medical Case Manager?
18. What kind of experience (professional, educational, or personal) do you feel prepared you for this kind of work?

Service Needs of Clients

19. Please rank the following services based on your client level of need/demand (highest to lowest):
    - Food assistance
    - Assistance obtaining housing (e.g. permanent, temporary, emergency shelter, residential treatment facilities)
    - Assistance maintaining housing (e.g. eviction notices)
    - Clothing assistance
    - Transportation assistance
    - Financial assistance
    - Interpreter/translation
    - Assistance obtaining outpatient substance abuse treatment
    - Assistance obtaining inpatient substance abuse treatment
    - Assistance obtaining medication-assisted treatments for substance use (e.g. methadone, buprenorphine, vivitrol, naltrexone)
    - Assistance with getting into a rehab or detox program for substance use
    - Assistance getting into halfway home or sober house
    - Assistance getting other substance use support services (e.g. AA, NA, counseling, support groups)
    - Assistance with obtaining mental health appointment, counseling, and/or treatment
    - Legal assistance
    - Medication assistance (paying for drugs, help with prescriptions)
    - Job training/Employment assistance

- Assistance with dental care
- Assistance with benefits

Facilitator note: *This is an interactive activity – use newsprint or board to have participants list ranked services and then compare. Probe participants to discuss why they have chosen to rank the services in the way that they have – ask for examples. In particular if there are discrepancies between how participants have ranked needed services – ask if these rankings are specific to certain kinds of patients or certain populations.*

20. What are other services not on this list that are needed by your clients?

21. How do service needs vary by specific group of clients (e.g. homeless, LGBT, racial/ethnic groups, etc.)?

22. Of the needed services you have identified, which of these do they usually receive?

Service Gaps Remaining

23. Of the needed services you have identified, 1) which are the services that clients have the most difficulty receiving in your area and 2) what are the reasons that they do not receive these services?
    a. Probes: Do they lack access to these services (availability in their area, financial means to pay for services)? Do they lack information about these services? Do they lack skills necessary to obtain these services? Are they not interested in seeking these services (and why not)? Do they have other priorities that they are more concerned with?

Other Barriers to Care or Adherence

24. For clients who are not consistently adherent to their medications – can you please give some examples you have encountered of why clients are not adherent to their recommended treatment plans?

25. For clients who are not consistently in care or who regularly miss appointments – can you please give some examples of why they are not consistently in care?

26. For clients who have completely fallen out of care, what do you believe are the reasons for this?
    a. How are these clients different from those who are in care (consistently or inconsistently)?

27. If clients eventually return to care – what are the things that bring them back into care?

28. For clients who were previously out of care, what do you do to motivate them to stay in care?

Boston EMA Ryan White Part A Assessment of Service Needs for PLWH

Semi-Structured Interview Guide for HIV Primary Care Providers

Introductory Script

Thank you for taking the time to speak with us. Under contract by the Boston Public Health Commission, and in collaboration with the Boston EMA Ryan White Planning Council, we are conducting an assessment of service needs for people living with HIV (PLWH) in the Boston EMA. The objective of this work is to identify 1) facilitators to engagement in care and treatment adherence and 2) barriers that prevent PLWH both in and out of care from receiving needed services or from continuing in care and treatment. The information gathered as part of this assessment will be used by the Planning Council to 1) identify which services are needed, which are being provided, and which service gaps remain for PLWH in the Boston EMA, and 2) to plan for future funding allocation accordingly.

Your answers are confidential. Your responses will not be shared with others within the organization. You will not receive compensation for your time.

Do we have your consent to participate in this study? *Yes* *No*

Do we have your permission to record this interview? *Yes* *No*

Background

1. Position/Title: _____
2. Agency: _____
3. Length of time working with agency: _____

Barriers to HIV Care Services

1. In your experience working with PLWH at this clinic, what do you recognize as the greatest barrier or barriers to accessing the HIV care services provided here?
2. How do the barriers to HIV care services differ among your clients who are virally suppressed versus not virally suppressed?

Challenges to Providing Services to PLWH

1. For clients who do come in for HIV care, what challenges do you experience providing services?

Best Practice Models for Providing HIV Care

1. Can you explain the system your clinic has in place for providing HIV care to PLWH?

2. How is HIV care provided at this clinic different for those who are virally suppressed versus not?

3. How do you work with the client to identify their needs/goals for HIV care?

Motivators to Engage PLWH into HIV Care

1. As a provider, what strategies to do you use to involve clients in their HIV care?

2. In your experience, what motivates clients to continue engaging in their HIV care?

3. Do the motivators you use differ for those who are virally suppressed versus not virally suppressed?