Massachusetts and
Southern New Hampshire

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HIV/AIDS Consumer Study

JSI Research & Training Institute, Inc.

Building a Healthy Boston

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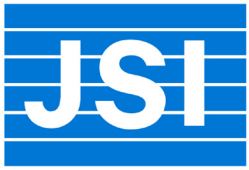

JSI Research & Training Institute, Inc.

Research conducted and report written by:
Jeremy Holman, PhD | Karen Schneider, PhD | Kim Watson, MPH | Jaya Mathur | Amy Flynn

With a funder response written by:
Massachusetts Department of Public Health and Boston Public Health Commission

And a consumer response written by:
Massachusetts Office of HIV/AIDS Statewide Consumer Advisory Board and the
Massachusetts Statewide Consumer Advisory Board and Boston HIV Health Services Planning Council

Building a Healthy Boston

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COMMON ACRONYMS

ADAP	AIDS Drug Assistance Program
APTD	Aid to the Permanently and Totally Disabled
ARV	Antiretroviral (medications)
BPHC	Boston Public Health Commission
CAB	Consumer Advisory Board
DX	Diagnosis or diagnosed
EAEDC	Emergency Aid to Elders, Disabled, and Children
EMA	Eligible Metropolitan Area
HDAP	HIV Drug Assistance Program
HRSA	Health Resources and Services Administration
IDU	Intravenous drug use or user
JSI	JSI Research & Training Institute
MA	Massachusetts
MDPH	Massachusetts Department of Public Health
MH	Mental health
MSM	Men who have sex with men
NH	New Hampshire
OHA	Office of HIV/AIDS
OI	Opportunistic infection
PLWH	People living with HIV/AIDS
STI	Sexually transmitted infection
TAFDC	Transitional Aid to Families with Dependent Children
TANF	Temporary Assistance for Needy Families

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» INTRODUCTION

In early 2008, representatives of Massachusetts Department of Public Health's (MDPH) Office of HIV/AIDS (OHA) and Boston Public Health Commission (BPHC) HIV/AIDS Services Division (HASD) began discussions with JSI Research & Training Institute (JSI) about conducting a comprehensive assessment of the needs of people living with HIV/AIDS (PLWH) in their respective service areas. MDPH OHA receives and administers Ryan White HIV/AIDS Program Part B and MA general revenue funds to provide HIV/AIDS care and support services for PLWH throughout the Commonwealth; BPHC receives and administers Ryan White HIV/AIDS Program Part A funds to provide similar services for PLWH in the Boston eligible metropolitan area (EMA) which includes seven counties in eastern and central Massachusetts and three counties in southern New Hampshire (see map inset). Because of the overlap in geography and populations served, MPDH and BPHC were committed to conducting a collaborative, coordinated assessment that would (1) combine their respective resources and expertise, (2) use those resources efficiently by avoiding duplicative assessment efforts, and (3) gather data that could be used by both organizations for their HIV/AIDS planning efforts.

Over the course of several meetings among MDPH, BPHC, and JSI staff, several common principles were identified and agreed upon that set the foundation for this study. Specifically, MDPH and BPHC agreed that the study should:

- Gather data to assess the service needs of PLWH, as well as a broad range of barriers, challenges, and quality of life issues they face
- Include a large sample of PLWH in MA and southern NH that was reflective of the HIV epidemic
- Be scientifically rigorous and produce data that were valid and objective
- Produce data that could be used to support decision making on issues within their respective purviews
- Represent a true collaboration between MDPH and BPHC that respected their shared and distinct needs as well as those of their stakeholders and constituents
- Involve PLWH from across both service areas, including all of MA and parts of southern NH
- Involve input from PLWH and other stakeholders in the design and implementation

These meeting also enabled JSI to develop an overall "research question" that would ultimately guide the project, the methods, and the data analysis. The research question for this study was:

Among PLWH in MA and the Boston EMA, what are the needs for HIV care and support services, barriers to accessing services, and experiences living with HIV/AIDS, including quality of life, stigma, self-sufficiency, and other challenges?

Based on the above principles and research question, JSI developed a proposed research plan for the study. During the summer of 2008, this plan was revised through ongoing discussions with MDPH and BPHC. By September 2008, MDPH, BPHC, and JSI had agreed on an overall research plan and methodology. Specifically, JSI would implement a broad, two-part survey. Phase I would be intended to reach a large sample of PLWH (goal of 1,650) and gather a limited range of data on service needs, barriers, and demographic characteristics. Phase II would be intended to reach a smaller sample of PLWH (goal of 700) and gather more in-depth data on HIV-related topics. In addition to this methodology, the research plan also proposed complementary research methods (e.g., in-person surveys) to include PLWH who may not be reached by the survey, and proposed the development of an Advisory Group to guide the project and further refine the methods, implementation, and data analysis.

ABOUT THIS REPORT

This report is not intended as the final product of this study, but rather a "milestone" in what we hope will be an ongoing exploration of a rich dataset. Because this study was successful in reaching a large number of PLWH, it has produced a wealth of data that can continue to be analyzed. No single report could answer every question or include all of the possible ways that the data could be explored. The dataset from this study provides opportunities to ask and answer new, more focused research questions, to explore results that point to unique challenges or issues, and/or to focus on specific populations or topics of interest. We anticipate that this study will continue to produce data that can be used by MDPH, BPHC, planning bodies, and other stakeholders for several years to come.

This report provides a summary of the results from this comprehensive study. In the sections that follow, we first describe the research methods, and provide a detailed description of the sample of PLWH who were reached. We then provide a summary of key results of the study, and identify any significant variations that were identified. Lastly, the report concludes with responses from the funders of the project (MDPH and BPHC) and from organizations that represent the needs of PLWH including the Massachusetts Statewide Consumer Advisory Board and Boston HIV Health Services Planning Council. These responses summarize important findings of the study and potential future activities in response.

FOR MORE INFORMATION

Inquiries about this report and/or the potential for the dataset to answer specific research questions should be directed to MDPH's Office of HIV/AIDS or BPHC's HIV/AIDS Services Division. Inquiries about the methods and approach should be directed to JSI Research & Training Institute, Boston, MA.

METHODOLOGY

The methods used in this study were implemented in ways that ensured the confidentiality of research participants. Measures taken to protect the rights and confidentiality of all participants are described in more detail later in the *Confidentiality and Institutional Review Board Approval* sections (see page 8).

APPROACH

Based on the key principles identified above, JSI, MDPH, and BPHC agreed that the primary method for this study would be a survey. In addition, the survey would be made available in four languages—English, Spanish, Portuguese, and Haitian-Creole—to ensure linguistic accessibility. These languages were chosen based on demographic data from MDPH and BPHC on the most common languages spoken among the local population of PLWH. After a thorough consideration of the advantages and disadvantages of various survey administration methods, MDPH, BPHC, and JSI decided to implement a two-phase survey approach. Phase I would use a short-form survey distributed by mail. This survey would be intended to reach a large number of people and gather a limited set of data focused on HIV service needs and barriers. Phase II would be a long-form survey administered to a smaller subset of respondents to the short form, and would delve more deeply into a broad range of topics. This survey would be distributed only to short form respondents who volunteered to take it, and could be taken online or by phone or mail, thus providing opportunities for participation by those with higher and lower language literacy.

The justification for this two-phase approach was driven by two factors. First, JSI had implemented a "consumer satisfaction survey" for BPHC in 2007 that used a one-page (front and back) tool distributed by mail, along with a small upfront incentive ($3 Dunkin Donuts® gift card). This approach was successful and the response rate (~40%) indicated that a large number of people would be wiling to respond to a short survey with a small upfront incentive. Second, it was assumed that a larger incentive would be required to encourage individuals to take a longer survey. Implementing the survey in two phases would allow the team to target the longer and more expensive survey (in terms of reproduction and incentive costs) to those who were most likely to take it and in the format and language they preferred.

JSI established an Advisory Group to assist the team with the study design, survey tool development, survey administration, and data collection and analysis. Members of the Advisory Group included MDPH and BPHC staff, representatives from the Boston EMA HIV Services Planning Council, a representative from MDPHs Office of HIV/AIDS Consumer Office, and the members of JSI's research team.

STAKEHOLDER INPUT

Before a single survey question was drafted, JSI began a process to gather community input. In October and November 2008, members of the JSI research team participated in several regularly-scheduled meetings of local advisory groups and community planning bodies. JSI announced the study and gathered input from key stakeholders about what would make the study most useful for the community. In total, JSI attended and participated in seven meetings of six stakeholder groups including:

- Consumer Committee of Boston EMA HIV Health Services Planning Council[1] (2 meetings)

1. The Boston HIV Health Services Planning Council is a federally-mandated group of local stakeholders, appointed by the Mayor of the City of Boston, that is responsible for planning and setting priorities for Ryan White Part A funds received in the Boston EMA for HIV services.

- Evaluation Committee of the Boston EMA HIV Health Services Planning Council
- Massachusetts HIV Prevention Planning Group (MPPG)
- Massachusetts Office of HIV/AIDS Statewide Consumer Advisory Board[2] (Statewide CAB)
- Service Coordination Collaborative (SCC) Coordinators Group
- Greater Boston/Metrowest SCC Peer Support Working Group

In addition, JSI attended and announced the project at the Boston EMA Research Forum sponsored by BPHC.

SURVEY TOOL DEVELOPMENT

After the community input phase was completed in November 2008, the process to develop and finalize the survey tools began and lasted through May 2009. The Advisory Board met regularly during this time period, providing important input on the survey questions and design, as well as ensuring that relevant stakeholders could review and comment. When possible, questions were borrowed or adapted from other surveys and/or validated scales, but in other cases, new questions were developed to respond to specific data needs or research interests.

In March 2009, draft versions of the Phase I and II survey tools were completed and the English language versions were pilot-tested with 15 PLWH, all of whom were members of either the Planning Council or the Statewide CAB. During the pilot test, JSI staff monitored and timed survey completion, responded to questions and requests for clarification, and facilitated a discussion of respondents' experiences with the survey and suggestions for improvement. The pilot participants provided feedback on the process of completing the surveys, content of the questions, and appropriateness of the amount of the proposed incentives ($3 for Phase I and $25 for Phase II).

In mid-April 2009, JSI convened the project Advisory Group to discuss pilot survey feedback and to finalize the survey tools, including numerous changes based on the piloting process. After receiving MDPH and BPHC's final approval on the tools, the surveys were then translated into Spanish, Portuguese, and Haitian-Creole using a local professional translation company. Next, the translations were reviewed and edited by JSI and MDPH staff who were either fluent or native speakers of these languages to ensure that translations were accurate and appropriate. See *Appendix A and B* for the English language versions of the surveys.

SUPPORTING MATERIALS

Supporting materials were developed for distribution with the Phase I and Phase II surveys. The Phase I survey packets included: the Phase I survey tool; a postage-paid envelope to return the survey; an introductory letter to recipients; survey instructions and participant information sheet; answers to frequently asked questions; a service directory sheet; a $3 Dunkin Donuts® gift card; information on how to volunteer to take the Phase II survey via web, phone or mail; and a postage-paid envelope to return the volunteer form to request a Phase II survey by mail or phone. All materials included in the Phase I packets were in English, Spanish, Portuguese, and Haitian-Creole.

2. The Massachusetts Office of HIV/AIDS Statewide Consumer Advisory Board is a group of up to 30 PLWH, who are reflective of the epidemic in MA, that meets monthly to advise senior staff of the MDPH OHA on services and policies affecting the lives of PLWH in the Commonwealth.

The *introductory letter* explained why the recipient had received the packet (including that their name and address had not been shared with the JSI research team; see *Confidentiality* later in this section), the process for returning the surveys, and information about the incentive. The letter also informed recipients that participation in the study was both voluntary and confidential, and indicated that they could ask questions about the survey by calling a toll-free number or sending a message to the project's email address, both of which were established and staffed by members of the JSI research team.

The *instruction sheet* provided information about the study, including standard information required for informed consent. In an effort to anticipate participant questions, the JSI project team also developed answers to a list of *frequently asked questions* that was included in the Phase I survey packets and also posted on the online portal for the web-based survey.

Because distribution of the survey would provide an opportunity to engage a large number of PLWH and because the surveys asked respondents about a variety of sensitive issues, a brief *service directory* was developed and included with the surveys. It contained contact information for a variety of potentially relevant services (e.g., AIDS hotline, suicide hotline, substance abuse treatment services, HDAP, etc.)

Finally, the Phase I survey packets contained a *volunteer form* that Phase I survey respondents could fill out and submit if they were interested in participating in the Phase II survey. To enable participation by a diverse sample of respondents (including those with low literacy), interested individuals could complete the Phase II survey online, by mail or by phone. Participants were also asked to indicate whether they preferred to complete the survey in English, Spanish, Portuguese, or Haitian-Creole. This document also informed participants that those who completed the Phase II survey according to the study guidelines would receive a $25 CVS gift card.

SURVEY DISTRIBUTION

Because the Phase I survey was mail-based but there was no central database of PLWH and their contact information, the Advisory Group recommended that surveys be distributed to PLWH through funded HIV service providers. To reach the largest groups of PLWH, it was decided that 1,676 surveys would be distributed to clients of Massachusetts HDAP (managed and administered by Community Research Initiative of New England), and 3,216 surveys would be distributed to clients of MDPH- and BPHC-funded HIV case management programs.

To ensure participant confidentiality, the HDAP and MDPH/BPHC-funded case management programs were given survey packets and instructed to send them to a random sample of their clients (including only those clients age 18 or older and only those clients who had agreed to receive mail from the provider). To ensure that traditionally underrepresented portions of the state and EMA were included in the sample in sufficient numbers, case management service providers in western Massachusetts were asked to sample at a higher rate (60%) than those in the remainder of the state (45%). Similarly, case management service providers in southern New Hampshire were asked to send the survey to 100% of their clients. Service providers received no incentive or payment for their participation.

Each Phase I survey was printed with a unique survey identification code developed by JSI (not to be confused with the Client Code or Unique Client Identifier used in the MDPH and BPHC service systems). This same survey code was also included on the form to volunteer for the Phase II survey. If a Phase I respondent volunteered to take the Phase II survey online, this code number was required at the start of the survey. For those who

volunteered to take the Phase II survey by phone or mail, the unique code was transcribed on the Phase II survey. This coding system allowed the research team to "link" each respondent's Phase I survey to the same individual's Phase II survey, enabling data analyses across the two survey tools.

SURVEY ADMINISTRATION

Both Phase I and Phase II surveys were designed using Teleform®, a program that allows completed paper surveys to be scanned and verified digitally, and the results exported directly into a database. Each survey was assigned a unique code that allowed responses from the Phase I and Phase II surveys to be linked by respondent.

An online version of the Phase II survey was developed, using SurveyMonkey®, for respondents who wished to complete the survey online. Respondents who completed the Phase I survey and volunteered to complete the Phase II survey were able to go directly to an online version of the survey in their preferred language by using the URL provided on the Phase I survey and entering their unique respondent IDs. All online SurveyMonkey® data were downloaded after the web site was closed and verified by the JSI project team. Respondents were then mailed the $25 gift card.

For the purposes of the phone surveys, the JSI project team determined that the online SurveyMonkey® tool could also be used by the phone interviewer. The web-based Phase II survey was adapted for use via phone and was available in all four languages. JSI employed part-time interviewers, fluent in the survey languages, to schedule and complete the surveys by phone. When calling a participant, the interviewer would open a SurveyMonkey® phone survey link, read the questions to the respondent, and enter the respondents' answers as delivered. As with the online survey, upon completion of all phone surveys, the data were downloaded and verified. Respondents were then mailed the $25 gift card.

JSI staff mailed the surveys, along with postage-paid return envelopes and the service contact information sheet, to participants who volunteered to complete the Phase II survey by mail. Because JSI had projected and budgeted for a maximum of 700 long form respondents, the long form surveys were initially mailed out in "waves" to control for the final sample size. However, upon learning that over 1,500 people had volunteered to take the long form survey and that some willing participants would have to be excluded in order to remain within the budget constraints, MDPH and BPHC expressed a commitment to full participation by interested respondents. MDPH allocated additional resources to enable all interested respondents the opportunity to participate, and additional $25 gift cards were purchased for use at CVS and a variety of supermarkets across Massachusetts and southern New Hampshire.

Based on the distribution method (by mail and via HIV service providers), the Advisory Group recognized that some populations were unlikely to be reached by the survey, including PLWH who were homeless or did not have a permanent address and PLWH who were not engaged in HIV care and support services. In an attempt to respond to these limitations, JSI conducted field research to gather data from these groups. A total of 168 additional surveys were distributed through these methods (described below).

To reach homeless PLWH, JSI worked with Boston Health Care for the Homeless Program (BHCHP), a local organization that provides primary care and other services for individuals who are homeless. BHCHP provided JSI research team members with office space during its weekly HIV "clinics." As BHCHP staff met with clients on those days, they described the survey to them, assessed willingness to participate, and escorted volunteers to

office space to meet JSI staff members and to complete both the Phase I and Phase II surveys. These respondents received both the $3 and $25 gift cards for their participation.

The Advisory Group recommended that JSI work with HIV peer support providers to reach PLWH who were not in care at the time of the survey. JSI contacted these providers and asked them to distribute survey packets to PLWH who they knew or suspected were not in care.

CONFIDENTIALITY

JSI took several precautions to ensure respondent confidentiality and anonymity. Phase I survey packets were prepared by JSI staff, but distributed by providers to their clients, ensuring that JSI research staff had no access to client names or addresses. Phase I survey participants who elected to participate in the Phase II survey either by phone or mail were required to provide a phone number or address, so that JSI could reach them. The information provided by respondents was used only for contacting the potential Phase II survey respondents and for delivering the $25 gift card upon survey completion. All name, address, and phone number information were stored in a secure file and were shredded upon completion of the project.

For the purposes of tracking survey response and gift card dissemination, the JSI project team developed and maintained Microsoft Access databases to store important information. One database, containing respondents' identifying information (such as name, phone number, and address), was located on a secured network drive accessible only by the JSI project team. The other database contained the ID numbers associated with respondents as well as survey response data, but did not contain any identifying information. These data were stored separately, so that no survey response data was linked to individual respondents.

INSTITUTIONAL REVIEW BOARD APPROVAL AND AUTHORIZATION FOR PUBLIC HEALTH RESEARCH

Research involving human subjects and access to confidential information must be reviewed by an Institutional Review Board (IRB) to ensure the protection of the rights and privacy of research participants. In addition, public health-related research in Massachusetts must be approved by the Commissioner of Public Health in accordance with M.G.L. c. 111, §24A. This protects the confidentiality of all information collected or created as part of an approved research study and imposes restrictions on use and disclosure of research data. All of the methods, protocols, procedures, and tools described above for this study were submitted to MDPH's IRB and 24A review process. IRB and 24A approval were received in May 2009.

DATA COLLECTION AND CLEANING

When a completed mail survey was received by JSI, the status was noted by survey ID in the tracking database. Surveys were then scanned and the respondents' answers were digitally registered and stored. JSI staff then verified the data, specifically ensuring that all digital data reflected the marks indicated on the hard copy survey forms and that all open-ended survey responses were accurately interpreted by the program. Teleform® and SurveyMonkey® data were then exported to SAS for monitoring and analysis by JSI staff. Twenty-five dollar gift cards were sent to respondents of the Phase II survey once a month throughout the approximately three-month period of Phase II survey collection. This was noted in the tracking database.

The JSI project team took additional steps to create a uniform data set for the Phase II open-ended response data. Once the deadline for receiving Phase II surveys had passed, the non-English open-ended survey response data were sent to fluent speakers for translation into English. The data sent for translation included only the respondent IDs and the survey data, and, therefore, did not include any confidential or identifying information. For the Phase I survey, the only open-ended responses requested were numerical, such as the respondents' year of birth; as a result, no translation of non-English Phase I survey response data was necessary.

Upon completion of data collection, JSI conducted quality assurance to ensure that the respondent IDs in the Phase I and Phase II survey data sets matched the respondent IDs in the tracking database. Through this process, JSI also made certain that all Phase II survey respondents had received a $25 gift card for their participation.

DATA MONITORING AND ANALYSIS

The survey sample and survey data were monitored throughout the project. Sampling statistics were run regularly to ensure the potential sample of Phase II respondents was representative of the population of PLWH in MA and southern NH. However, after MDPH identified additional resources to ensure that everyone who volunteered for the Phase II survey would be provided an opportunity to respond, this tracking was not necessary. Information from these analyses also helped guide the distribution of field surveys to special populations.

After all surveys were received and the data were cleaned, the final data analysis process began. For continuous variables, JSI calculated the overall mean value and mean values for specific groups of interest in the population (stratified analysis). JSI tested differences between the group means using t-tests if comparing two groups. ANOVA was used to compare means for more than two groups, and Tukey's HSD test pointed to which group-to-group comparisons were significantly different. A p-value of less than 0.05 was considered indicative of a significant difference.

For categorical variables, JSI calculated proportions for the entire population and for specific groups of interest (stratified analysis). JSI also tested differences between proportions using Chi-square statistics. A p-value of less than .05 was considered indicative of a significant difference.

JSI ran stratified analyses by gender, age, race/ethnicity, US vs. non-US born, disease status, exposure mode, income, mode of data collection, region, and other independent variables included on the survey. JSI often had sufficient sample size to produce reliable estimates of differences within these groups.

DATA PRESENTATIONS

Prior to publication of this report, members of the JSI research team made numerous presentations of preliminary data to local stakeholders and planning groups. The purpose of these presentations was to make data available more quickly than a final report would allow, and to provide information that could inform ongoing planning efforts, such as identifying needs, setting priorities, or answering specific research questions. JSI presented research results to the following groups:

- Consumer Committee of the Boston EMA HIV Health Services Planning Council (February 2010)
- Evaluation Committee of the Boston EMA HIV Health Services Planning Council (March 2010)
- Service Providers who attended the Ryan White Part A Provider Training (March 2010)

- The Boston EMA HIV Health Services Planning Council (April 2010)
- Staff of MDPH's Office of HIV/AIDS (May 2010)
- Massachusetts HIV Prevention Planning Group (November 2010)
- The Boston EMA HIV Health Services Planning Council (January 2011)
- Consumer Committee of the Boston EMA HIV Health Services Planning Council (January 2011)
- Staff of BPHC's HIV/AIDS Services Division (February 2011)

In addition, data from the survey on HIV-related stigma were presented as posters at two national conferences, including:

- Ryan White Grantee Meeting (August 2010, Washington, DC)
- HIV Prevention Leadership Summit (December 2010, Washington, DC)

LIMITATIONS

The survey methodology posed several limitations. By using providers to disseminate the surveys, respondents were primarily individuals receiving regular medical care and were connected to publicly funded services. PLWH who are homeless or do not have a permanent address and/or who do not use MDPH or BPHC-funded HIV care and support services were underrepresented among the pool of survey respondents. In addition, those not born in the US were underrepresented when compared to the HIV epidemiology in the surveyed region. These limitations should be kept in mind while reviewing the data presented throughout this report.

The JSI project team also encountered unforeseen complications with survey distribution and collection. Through the data monitoring process, JSI realized that a small number of those who completed the Phase II online did not complete and return the Phase I survey. As a result, the linked Phase I and Phase II survey data set (n=1,029) contains fewer records than the dataset with all Phase II surveys (n=1,066).

Lastly, JSI set up bulk postage permit accounts with Boston's Fort Point Post Office with which to pay for outgoing and returning mail project surveys. Early in the survey distribution process, it was discovered that the postage permit printed on the Phase I survey packets sent to providers for distribution would not allow the packets to be mailed from a location other than the Fort Point Post Office. JSI worked with all providers to resolve the situation, including providing stamps to place over the invalid permit and/or paying for transport and drop-off of the surveys at the Fort Point Post Office.

In spite of these limitations, the study was successful and had a very high response rate, reaching the largest sample of PLWH ever obtained in a Massachusetts or Boston EMA assessment of this type. The study also produced a comprehensive, high-quality dataset that provides a wealth of information on PLWH's needs, quality of life, experiences living with HIV/AIDS and other health conditions. In the sections that follow, we describe the sample of respondents and the key results from the Phase I and Phase II surveys.

CHARACTERISTICS OF THE SURVEY SAMPLE

In this section, we provide data on the characteristics of the survey respondents. This information is important not only for describing the survey sample, but also for providing context for understanding and interpreting the data presented later in this report. As noted previously, because of the research methods implemented, respondents were primarily individuals receiving regular medical care. In addition, PLWH who were homeless, not born in the US, and/or who did not use publicly-funded HIV care and support services were underrepresented among the pool of survey respondents. These limitations should be kept in mind while reviewing the data presented throughout this report.

SURVEY SAMPLE

Tables 1 and 2 provide information on the total Phase I and II surveys that were distributed and the total number of completed surveys that were received. Over 5,000 Phase I surveys were distributed, and 1,791 were completed, representing a response rate of 35%. The total Phase I survey distribution is likely to be an overestimate, and thus the actual response rate is likely to have been higher. Some providers reported to the JSI research team that they did not distribute all of the surveys allocated to their agency, and the total distribution estimate was adjusted accordingly. However, it is likely that other providers did not report distributing fewer surveys than they were allocated. In addition, it appears that a very small number of providers did not distribute any

TABLE 1: PHASE I SURVEY DISTRIBUTION AND RESPONSE

PHASE I SURVEY DISTRIBUTION	
Total distribution	**5,060**
Through HDAP	1,676 (33%)
Through HIV case management programs	3,216 (64%)
Through field methods	168 (<1%)
PHASE I SURVEY RESPONSES	
Total received	**1,791**
Within Massachusetts	1,649
Within EMA only	1,339
Response rate	**35%**
Language version of survey	
English	1,548 (86%)
Spanish	204 (11%)
Portuguese	16 (<1%)
Haitian Creole	23 (<1%)

surveys. Because each survey had a unique code number, JSI maintained a database tracking the range of code numbers within each batch of Phase I surveys given to each provider. An analysis of the code numbers on the Phase I surveys returned showed that no surveys were returned from those that were to be distributed by two providers (n=181).

Of the 1,791 respondents to the Phase I surveys, 1,528 volunteered to take the Phase II survey. Of these volunteers, 1,066 completed the Phase II survey, representing a response rate of 70%.

Respondents to both surveys were asked several questions to help construct a profile of the sample, including personal characteristics, HIV history, geography, income, medical care, and health and disability status. A table of complete demographic characteristics is provided in *Appendix C* and key highlights are summarized in the remainder of this section. These data refer to the individuals who completed both the Phase I and Phase II surveys (n=1,029). Note that "n" in each table, which refers to the number of people who answered the related question, may vary.

TABLE 2: PHASE II SURVEY DISTRIBUTION AND RESPONSE

PHASE II SURVEY DISTRIBUTION	
Total distribution	**1,528**
By mail	976 (64%)
By web (online)	263 (17%)
By phone	219 (14%)
By field methods	70 (5%)
PHASE II SURVEY RESPONSES	
Total received	**1,066**
Response rate	**70%**
Total linked to Phase I survey (overall)	**1,029**
Within Massachusetts	958
Within EMA only	763
Language version of surveys linked to Phase I survey	
English	908 (88%)
Spanish	109 (11%)
Portuguese	6 (<1%)
Haitian Creole	6 (<1%)

CHARACTERISTICS OF SURVEY RESPONDENTS

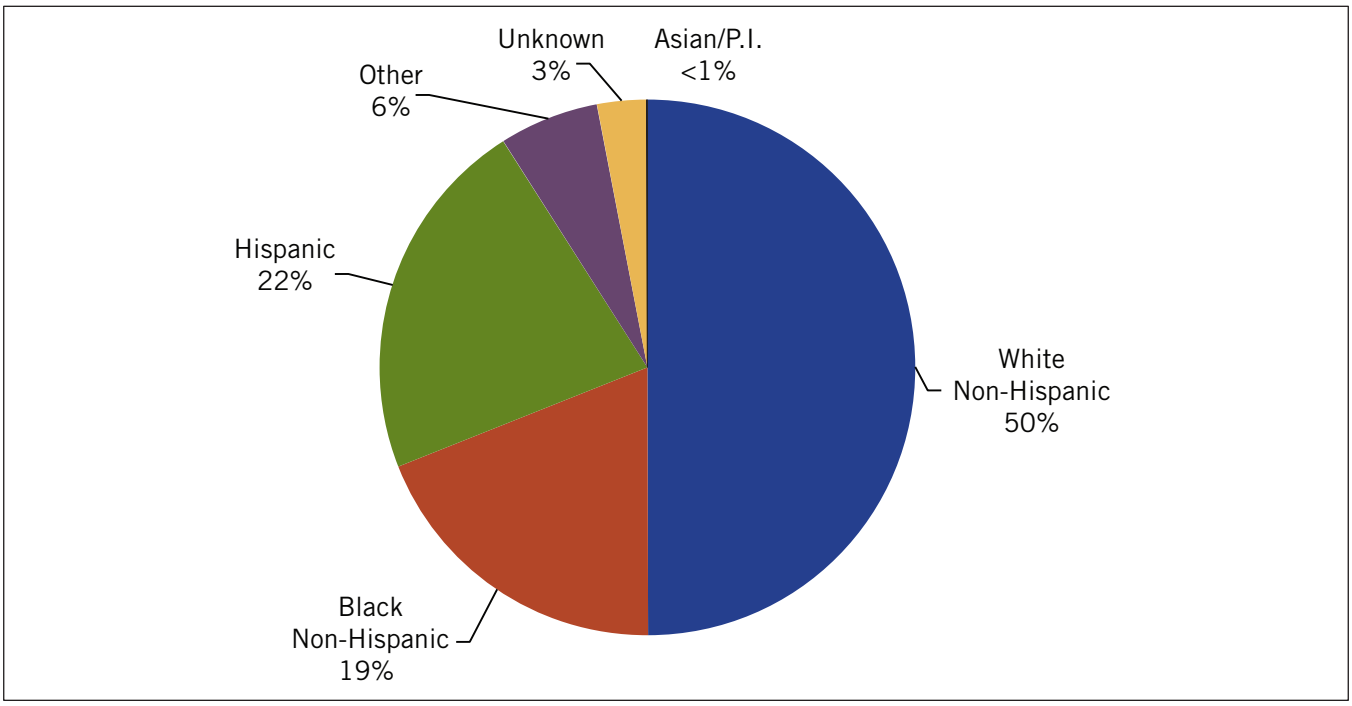
Age. Although PLWH aged 18 and over were eligible to participate in this study, the study sample was largely comprised of older PLWH (See Table 3). The majority of survey respondents (87%) reported their age as 40 years or older. When compared to the MA HIV prevalence, the proportion of respondents age 30 to 39 was slightly lower, while the proportion of respondents 50 to 59 and 60 and over was higher.

TABLE 3: AGE OF SURVEY RESPONDENTS COMPARED TO MA HIV PREVALENCE (2009)

AGE GROUP	HIV PREVALENCE MA (2009)	HIV PREVALENCE EMA (2009)	RESPONDENTS		
			Overall (n=1,027)	MA (n=956)	EMA (n=761)
<20	1%	1%	0%	0%	0%
20-29	5%	6%	2%	2%	2%
30-39	15%	16%	12%	11%	11%
40-49	40%	39%	41%	41%	41%
50-59	29%	38%*	36%	36%	36%
60 and over	9%	NA	10%	10%	10%

*Includes all PLWH 50 and older

FIGURE 1: RACE/ETHNICITY OF SURVEY RESPONDENTS (N=1,029)



Race/Ethnicity. In the Phase I survey, respondents were first asked to indicate if they were of Hispanic/Latino ethnicity, and then to identify their race. Respondents could select as many racial categories as applied. Figure 1 illustrates the racial/ethnic breakdown of all survey respondents. One-half reported their race/ethnicity as non-Hispanic White. Roughly one-fifth of respondents self-identified as non-Hispanic Black (19%), and another one-fifth of respondents indicated their race/ethnicity as Hispanic (22%). The remaining respondents were either Asian/Pacific Islander (<1%); Other, including multiracial (6%); or unknown (3%).

Table 4 summarizes the racial/ethnic composition of the sample in comparison to the MA and EMA HIV epidemic. While the overall breakdown of respondents by race/ethnicity resembles the racial/ethnic epidemiological profile of PLWH in Massachusetts and the EMA, the proportion of non-Hispanic Black respondents is lower than the proportion of this group in the MA and EMA HIV prevalence.

TABLE 4: RACE/ETHNICITY OF SURVEY RESPONDENTS COMPARED TO MA AND EMA HIV PREVALENCE (2009)

RACE/ETHNICITY	HIV PREVALENCE MA (2009)	HIV PREVALENCE EMA (2009)	RESPONDENTS		
			Overall (n=1,029)	MA (n=958)	EMA (n=763)
White, non-Hispanic	45%	47%	50%	49%	52%
Black, non-Hispanic	28%	30%	19%	19%	21%
Hispanic	25%	20%	22%	22%	18%
Asian/Pacific Islander	1%	2%	<1%	<1%	1%
Other (including multi-racial)	1%	<1%	6%	6%	6%
Unknown	N/A	N/A	3%	3%	3%

Gender. As shown in Table 5, nearly two-thirds of survey respondents (65%) were male, and a little over one-third (34%) were female. Less than 1% reported that they were transgender. The distribution of gender among survey respondents resembles the epidemiology in Massachusetts and the EMA, but women are slightly over-represented in the survey sample. HIV prevalence data for the transgender population were not available.

Sexual Orientation. As shown in Figure 2, one-half of respondents identified as heterosexual and the remainder reported homosexual (43%) or bisexual (7%) identity. HIV prevalence data by sexual orientation were not available for comparison.

HIV Transmission Risk. Table 6 illustrates the transmission risk of survey respondents as compared to the MA and EMA HIV prevalence data. Survey respondents were presented a list and asked to select the way they believed they contracted HIV (e.g. sex with a man, sex with a woman, IDU, etc.). The responses were then analyzed based on the gender of the respondent. The largest proportion of respondents (41%) indicated that they

contracted HIV through male-to-male sex, followed by heterosexual sex (33%) and IDU (16%). Compared to HIV transmission prevalence data for MA and the EMA, IDUs were under-represented in the survey sample, while MSM were slightly over-represented.

As indicated in Table 6, MA prevalence data include heterosexual and presumed heterosexual categories. The heterosexual category includes individuals who reported heterosexual sex with a person with, or at increased risk for, HIV infection. The presumed heterosexual risk category includes individuals who reported heterosexual sex but do not report any other behavioral risk or any knowledge of specific HIV risk factors in their sex partners. If these two categories are combined for comparison to the survey sample, the survey sample is reflective of heterosexual risk among PLWH in MA.

TABLE 5: GENDER OF SURVEY RESPONDENTS COMPARED TO MA AND EMA HIV PREVALENCE (2009)

GENDER	HIV PREVALENCE MA (2009)	HIV PREVALENCE EMA (2009)	RESPONDENTS		
			Overall (n=1,029)	MA (n=958)	EMA (n=763)
Male	71%	71%	65%	65%	65%
Female	29%	29%	34%	34%	35%
Transgender (male-to-female)	NA	NA	<1%	<1%	<1%
Transgender (female-to-male)	NA	NA	0%	0%	0%

FIGURE 2: SEXUAL ORIENTATION OF SURVEY RESPONDENTS (N=1,029)

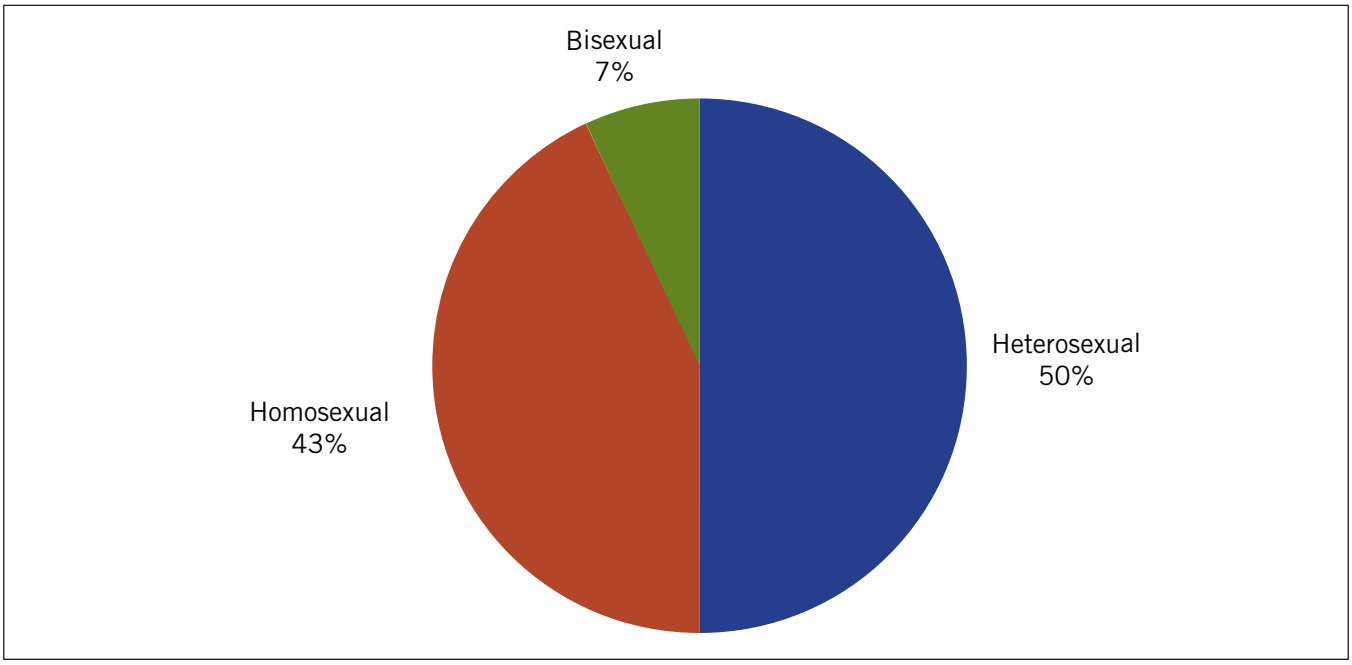
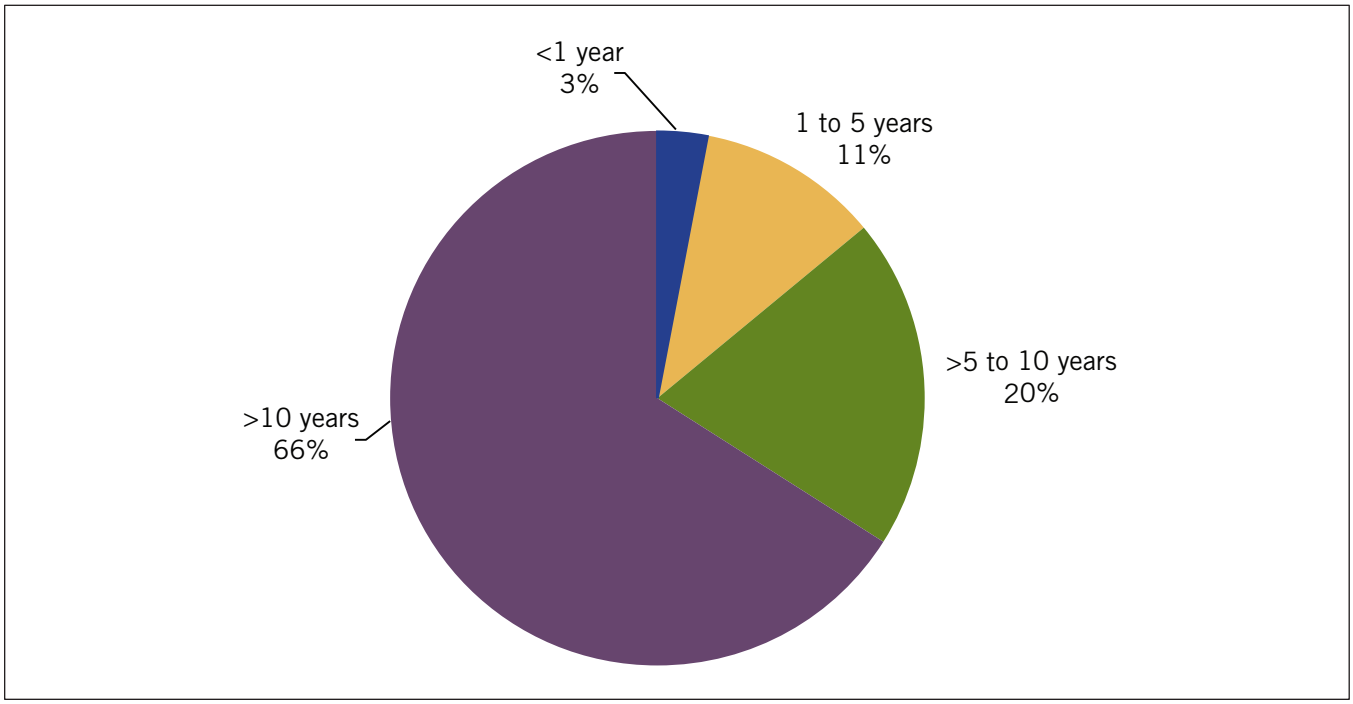


TABLE 6: HIV TRANSMISSION RISK AMONG SURVEY RESPONDENTS COMPARED TO MA AND EMA HIV PREVALENCE (2009)

TRANSMISSION RISK	HIV PREVALENCE MA (2009)	HIV PREVALENCE EMA (2009)	RESPONDENTS		
			Overall (n=1,029)	MA (n=958)	EMA (n=763)
Heterosexual	14%	24%	33%	33%	33%
Presumed heterosexual	16%	NA	NA	NA	NA
IDU	24%	18%	16%	16%	16%
MSM	35%	38%	41%	41%	41%
MSM/IDU	3%	3%	2%	2%	2%
Other	3%	3%	3%	4%	3%
Unknown	6%	14%	5%	5%	4%

FIGURE 3: YEARS LIVING WITH HIV, OVERALL SURVEY RESPONDENTS (N=1,029)



HIV Status and Years Living with HIV. About two-thirds of respondents had been living with HIV/AIDS for more than 10 years at the time of the survey. About 60% of survey respondents had AIDS, determined by responses to questions about ever having a CD4 count less than 200 or ever having an opportunistic infection.

Income. Poverty status of respondents was determined based on reported monthly income and the number of people living in their household. For the purpose of this study, poverty was defined as living at or below the federal poverty level (FPL). Almost half of survey respondents (47%) were living in poverty at the time of the survey.

TABLE 7: POVERTY STATUS OF RESPONDENTS

POVERTY STATUS	OVERALL (N=1,027)	MA (N=956)	EMA (N=761)
Living in poverty	47%	48%	45%
Living above poverty	53%	52%	55%

From a list, survey respondents were asked to select all sources of their income. Table 8 displays the eleven income source options ranked according to response frequency. Over two-thirds of respondents (68%) relied on Social Security for their income. Over one-quarter of respondents (27%) relied on their own employment for income, while 7% indicated their spouse/partner's employment. Five percent of survey respondents received unemployment benefits.

TABLE 8: SOURCE OF INCOME OF RESPONDENTS, RANKED

SOURCE OF INCOME	OVERALL (N=1,012)	MA (N=941)	EMA (N=751)
Social Security (SSI or SSDI)	68%	69%	69%
My own employment	27%	27%	27%
Other*	10%	9%	9%
Spouse/partner's employment	7%	7%	7%
Unemployment benefits	5%	5%	5%
Support from family	4%	4%	5%
TAFDC or TANF	3%	4%	2%
EAEDC or APTD	3%	3%	4%
Support from non-family household members	2%	2%	2%
Child support/alimony	1%	1%	1%
Financial aid from school	<1%	<1%	<1%

* "Other" includes sources written in by respondents; common responses included private long term disability insurance, retirement/pension, food stamps, and veterans benefits.

Geography. Respondents were asked several questions to assess geographic characteristics such as place of birth, state of residence, and region of residence within the state. These are each described below.

» Country of Birth. Over three-quarters of respondents (78%) reported that they were born in the United States. Another 14% were born in Puerto Rico or another US territory, and about 10% were born outside the US. The most common other country was Haiti, representing less than 2% of respondents. All other countries represented less than 1%. Of those born outside the US, respondents included individuals from 33 countries around the world, representing every continent except Australia/Oceania and Antarctica.

» State of Residence. Of the overall survey sample, 94% of respondents were residents of Massachusetts, 5% were residents of New Hampshire, and 1% were homeless. These data closely mirror the HIV prevalence data for the Boston EMA (95% MA, 5% NH, and 2% homeless).

» Region of Massachusetts. Table 9 illustrates the regions of Massachusetts in which respondents lived at the time of the survey. The southeast and western regions of Massachusetts are over-represented in the survey sample, while Boston and the northeast region are under-represented.

TABLE 9: REGION OF RESIDENCE FOR MA RESPONDENTS

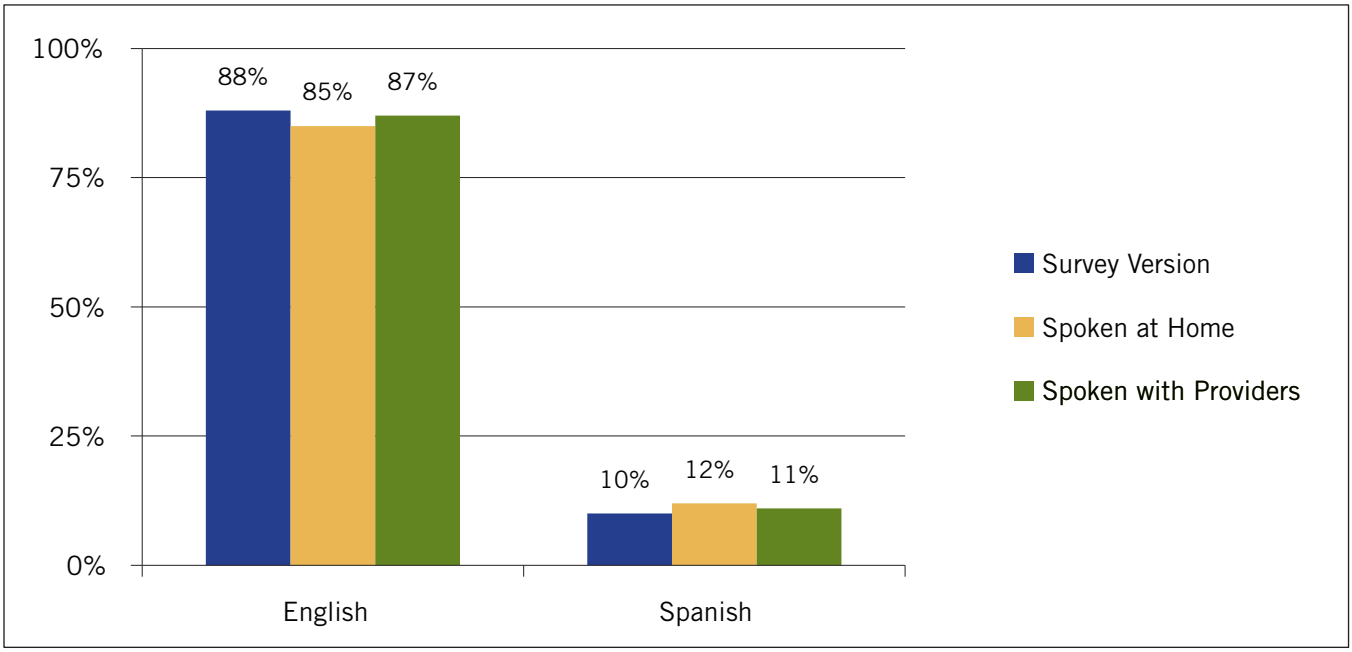
HEALTH SERVICE REGION	HIV PREVALENCE MA (2009)	RESPONDENTS		
		Overall (n=1,029)	MA (n=958)	EMA (n=763)
Boston/Metrowest	45%	34%	36%	45%
Central	9%	11%	11%	15%
Northeast	15%	10%	10%	14%
Southeast	14%	22%	24%	20%
Western	12%	17%	18%	NA

Immigration Status. As noted above, 10% of survey respondents were born outside the US. Of this group, 73% moved to the US 10 years ago or more, and 10% were recent immigrants (moved less than five years ago).

To assess immigration status, respondents were asked to select from a list of the four legal status options. Of those who were born outside the 50 US states and DC, 72% said they were US citizens, 14% were legal permanent residents, 4% were refugees or asylees, and 1% had a student/work/business/tourist visa. About 9% selected the "other" response option.

The survey also asked respondents to indicate the month and year when they first tested positive for HIV and for those who were not born in the US, the year they moved to the US. Using these two variables, 71% of the non-US born respondents tested HIV positive *after* moving to the US, and 16% were diagnosed before immigrating. The remainder indicated that they tested positive during the same year as moving to the US.

FIGURE 4: SURVEY LANGUAGE, LANGUAGE SPOKEN AT HOME, AND LANGUAGE SPOKEN WITH PROVIDERS



Language. The Phase II survey asked respondents which language they speak most of the time at home, as well as which language they prefer to speak with service providers. Nearly 85% of respondents said they speak English at home, 12% said Spanish, and 1% said Haitian-Creole. Fourteen other languages were reported by respondents as the language they speak most often at home, but each represented less than 1% of respondents.

FIGURE 5: HEALTH INSURANCE STATUS

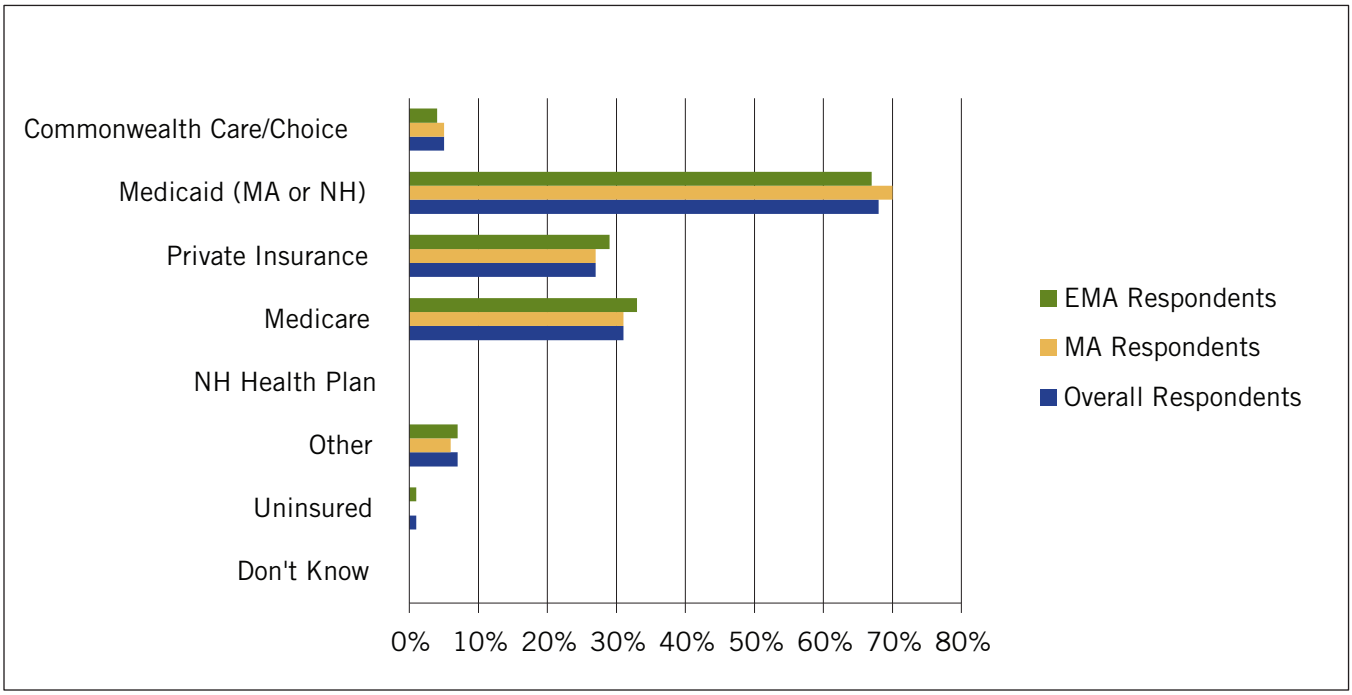


Figure 4 compares the proportions of respondents who said they speak English and Spanish at home and with their providers to the proportion of respondents who took each language version of the surveys. A slightly lower proportion of respondents who speak Spanish at home or with their providers took the survey in Spanish. The proportions for Portuguese and Haitian-Creole were too small for comparison on this chart.

Health Insurance Status. Figure 5 displays the health insurance status of respondents. Because individuals may have health insurance from more than one source, percentages across categories total more than 100%. The majority of this overlap is likely represented by low-income PLWH who are long term disabled and/or over 65 years of age, who have coverage under both Medicare and Medicaid. Survey respondents were asked to select all forms of health insurance that they had. Over two-thirds of respondents (70%) reported having Medicaid as at least one of their health insurance providers and almost one-third of respondents (34%) reported Medicare. A slightly smaller proportion (28%) reported that they were privately insured.

PHASE I SURVEY RESULTS

In this section, we present the results of the Phase I survey (see *Appendix A*). This survey was distributed to 5,060 PLWH in MA and southern NH and was completed by 1,791 individuals. The survey was brief and intended to gather limited data from a broad sample of individuals about their HIV care and support service needs. In addition to a few basic demographic questions, the survey included a list of 19 services and asked respondents to indicate, for the prior six months:

1. Their *need and use* of each service by selecting either "needed and used," "needed but couldn't get," or "didn't need and didn't use"
2. The *role of the service* in their life by selecting either "essential," "not essential, but nice to have" or "no role/not essential"
3. Any *barriers* they experienced in accessing the service by selecting from a list that included 10 different barriers (e.g., "didn't know it existed," "couldn't get there," etc).

The 19 services were described on the survey rather than labeled with a common "short hand" name or phrase. For ease of presentation and discussion, shorter phrases are used in this report for each of these 19 services. Table 10 illustrates the words used in this document and the words that were included on the survey.

NOTE ABOUT THE DATA IN THIS SECTION

The data tables in this section illustrate the results of the Phase I survey for three groups: (1) all respondents (overall), (2) respondents who resided in Massachusetts, and (3) respondents who resided in the Boston EMA. Homeless respondents are only included in the "overall" group since residency could not be established for these individuals.

Sample size. The abbreviation "n" used in the data tables and in the text refers to the number of people who answered each question. The "n" varies depending on which group of respondents being discussed (overall, MA, or EMA), and because some respondents did not answer each question on the survey (or did not have to answer if it wasn't applicable).

Statistically significant differences. Phase I survey data were analyzed by a range of independent variables to determine whether different groups reported different proportions. For example, did men report a higher need than women, or did Whites report a lower need than Blacks? Often, proportions between groups are different, and the key to interpretation is to assess whether these differences are the result of chance or whether they represent a real phenomenon captured by the study. To determine which of these is more likely, a statistical test is conducted (Chi-square), and a statistical value is produced (p-value). If the p-value is less than 0.05, this means we are at least 95% confident that the difference identified is real. This difference is then called "statistically significant." When statistically significant variations were identified between certain groups (e.g., between men and women, or those above or below the poverty level) in our analyses, an "x" symbol is placed in the appropriate column in the tables. To understand these differences, please see the *Data Supplement*[3] that provides more detailed information on the statistically significant variations identified among these groups.

3. The *Data Supplement* is available for download on websites of the BPHC HIV/AIDS Services Division (www.bphc.org/aids) and the MDPH Office of HIV/AIDS (www.mass.gov/dph/aids).

TABLE 10: LANGUAGE USED TO DESCRIBE SERVICES ON THE PHASE I SURVEY

LANGUAGE USED IN THIS REPORT	LANGUAGE USED IN SURVEY
Case Management	Help coordinating and planning for HIV care and other services (case management)
Benefits	Help getting benefits such as health, social security, or disability
Dental	Regular dental care from a dentist or hygienist
Primary care	Regular HIV medical care from a doctor, nurse, or ob/gyn
Drugs	Help paying for or getting drugs for HIV/AIDS and for related health issues
Adherence	Help taking medications regularly and dealing with side-effects
Mental Health	Professional counseling or treatment for a diagnosed mental health issue
Peer Support	Support from other people living with HIV/AIDS (one-on-one or in groups)
Substance Abuse	Services that help deal with alcohol and/or drug use
Housing Search	Help finding a place to live
Rent	Help paying rent
Nutritional Counseling	Help understanding and planning for nutrition needs
Home-Delivered Meals	Meals delivered to my home
Congregate Meals	Group meals served somewhere other than my home
Food Vouchers/Bank	Food vouchers or groceries that can be picked up from a food bank
Legal Assistance	Help with legal issues
Immigration Assistance	Services that help deal with immigration status
Job Help	Help finding and keeping a job
Respite	Help taking care of a partner, parent, or other adult family member

SERVICES THAT PLWH NEEDED AND USED

As shown in Table 11, the top five services most reported as needed and used by PLWH were:

1. **Primary care**
2. **Drugs**
3. **Case management**
4. **Help getting benefits**
5. **Dental services**

The least needed and used services were home-delivered meals, respite support, job help and immigration assistance, all reported by less than 15% of respondents. For any service listed in the table (e.g., primary care at 92%), it is important NOT to interpret that the remaining 8% needed but could not get the service. It is possible that the service was not needed at all. For this reason, Table 11 should be interpreted in the context of Table 12, and Table 13.

It is also important to note that immigration assistance is a service unique to those not born in the US, and there was a small sample of non-US born respondents to the Phase I survey (n=86). For this reason, the low rank of this service may obscure its actual need among this population. Nonetheless, among non-US born respondents, immigration assistance was also among the five least needed and used services, reported by 20% of respondents.

As illustrated in Table 11, a number of statistically significant variations were identified among groups in regard to the services they "needed and used." Variations based on poverty status and race/ethnicity were most prevalent, and several of these are described below. More information about these variations is available in the *Data Supplement*.

- Among the top five needed and used services listed above, the drug service category had several notable variations. The proportion who reported that they needed and used this service was significantly higher among men, those living above poverty, Whites (compared only to Blacks and "other" races), those age 50 and older (EMA only), and those who had been living with HIV for more than 10 years (MA only).
- In general, where statistically significant variations were identified, the proportion who reported that they needed and used a service was significantly higher among those living below poverty and women.
- There were no consistent trends in variations based on race/ethnicity.

TABLE 11: SERVICES NEED AND USED BY PLWH IN THE SIX MONTHS PRIOR TO SURVEY (RANKED) AND SIGNIFICANT VARIATIONS BY SELECTED GROUPS (P<.05)

SERVICE	NEEDED AND USED SERVICE			SIGNIFICANT VARIATIONS AMONG RESPONDENTS								SIGNIFICANT VARIATIONS AMONG RESPONDENTS							
				MA								EMA							
	OVERALL (N=1,791)	MA (N=1,649)	EMA (N=1,339)	Gender	Poverty	Age	Years HIV+	Race/Ethnicity	Country of Birth	Disability	Chronic Condition	Gender	Poverty	Age	Years HIV+	Race/Ethnicity	Country of Birth	Disability	Chronic Condition
Primary Care	92%	92%	92%										x						
Drugs	86%	86%	86%	x	x		x	x				x	x	x		x			
Case Management	77%	77%	77%																
Benefits	66%	66%	66%		x								x						
Dental	64%	65%	63%			x								x					
Mental Health	52%	52%	52%		x			x	x	x	x		x				x	x	x
Adherence	46%	46%	47%	x	x			x				x	x	x		x			
Peer Support	44%	45%	45%		x			x			x	x	x			x			x
Food Vouchers/Bank	46%	45%	45%	x	x			x			x		x			x			
Nutritional Counseling	38%	37%	39%				x	x								x			
Rent	33%	32%	34%	x	x			x		x		x	x						
Housing Search	28%	27%	28%	x	x			x		x			x			x			
Substance Abuse	26%	26%	26%		x		x	x	x	x	x		x		x	x	x		
Congregate Meals	26%	26%	25%		x	x		x			x		x	x	x	x			x
Legal Assistance	25%	25%	24%		x		x	x							x	x			
Home-delivered Meals	14%	15%	15%		x	x		x					x	x		x			
Respite	12%	12%	12%				x	x							x	x			
Job Help	11%	11%	11%				x	x	x			x			x	x	x		
Immigration Assistance	6%	6%	7%				x	x	x						x	x	x		

SERVICES THAT PLWH NEEDED BUT COULD NOT GET

As shown in Table 12, the top five services that PLWH said they needed but could not get (service gaps) were:

1. **Rent**
2. **Food vouchers/food bank**
3. **Dental**
4. **Job help**
5. **Housing search**

As noted above, immigration assistance is a service unique to those not born in the US, and there was a small sample of non-US born respondents to the Phase I survey (n=86). Among this group, immigration assistance was the second highest reported service gap among non-US born respondents; 37% of this group said they needed but could not get this service.

Barriers experienced by those who said they needed but could not get these services are provided later in this section in Table 12. Those services for which the lowest proportion reported that they needed but could not get were primary care, substance abuse, adherence, and drugs.

As illustrated in the table, a number of statistically significant variations were identified among groups in the proportion that reported that they "needed but could not get" a service. Variations based on poverty status, race/ethnicity, and disability status were most prevalent, and several of these are described below. More information about these variations is available in the *Data Supplement*.

» Where variations were identified, the proportion who said they needed but could not get a service was significantly higher among women, those living in poverty, those who were living with HIV for 10 years or less, people of color (non-White respondents), non-US born, those living with a disability or other chronic conditions, and those under age 50.

TABLE 12: SERVICES THAT PLWH NEEDED BUT COULD NOT GET IN THE SIX MONTHS PRIOR TO SURVEY (RANKED) AND SIGNIFICANT VARIATIONS BY SELECTED GROUPS (P<.05)

SERVICE	NEEDED BUT COULD NOT GET			SIGNIFICANT VARIATIONS AMONG RESPONDENTS								SIGNIFICANT VARIATIONS AMONG RESPONDENTS							
				MA								EMA							
	OVERALL (N=1,791)	MA (N=1,649)	EMA (N=1,339)	Gender	Poverty	Age	Years HIV+	Race/Ethnicity	Country of Birth	Disability	Chronic Condition	Gender	Poverty	Age	Years HIV+	Race/Ethnicity	Country of Birth	Disability	Chronic Condition
Rent	25%	25%	25%	x	x	x		x	x			x	x	x		x	x		
Food Vouchers / Bank	21%	21%	21%	x	x	x		x		x			x	x					
Dental	19%	18%	19%			x	x	x						x				x	x
Job Help	17%	17%	18%	x	x	x	x	x	x	x				x	x	x			
Housing Search	16%	16%	16%		x	x	x	x	x	x				x	x	x			
Legal Assistance	15%	15%	15%				x	x	x	x						x		x	
Nutritional Counseling	13%	13%	13%		x	x	x	x		x			x			x		x	
Home-Delivered Meals	12%	12%	13%		x			x	x	x			x			x	x		
Peer Support	11%	11%	12%	x	x			x	x	x							x	x	
Respite	10%	9%	10%		x			x		x						x			
Congregate Meals	9%	9%	9%					x		x						x		x	
Benefits	8%	8%	8%			x	x	x	x					x	x	x			
Mental Health	7%	7%	7%			x	x							x					x
Case Management	6%	6%	7%		x					x			x	x				x	x
Immigration Assistance	6%	6%	6%																
Drugs	5%	5%	5%		x	x	x	x	x			x		x	x	x	x		x
Adherence	5%	5%	5%		x	x				x				x				x	
Substance Abuse	4%	4%	5%		x		x			x			x	x	x				
Primary Care	2%	2%	2%		x			x		x			x					x	

SERVICES THAT WERE ESSENTIAL

As shown in Table 13, the top five services that were essential to PLWH overall health were:

1. **Primary care**
2. **Drugs**
3. **Help with benefits**
4. **Dental services**
5. **Case management**

Among non-US born respondents (n=86), immigration assistance was not among the top five most essential services; it was reported as essential by 59% of respondents and ranked 14 out of 19.

As illustrated in Table 13, a number of statistically significant variations were identified among groups in the proportion that reported that each service was "essential" to their overall health. Variations based on gender, poverty status, and race/ethnicity were most prevalent, and several are described below. More information about these variations is available in the *Data Supplement*.

- Where variations were identified, the proportion who said that the service was essential was significantly higher among women, those living in poverty, people of color, those living with a disability or other chronic conditions, and non-US born.
- Responses to drug reimbursement services were a notable exception to the general trend. Significantly more men than women, and more PLWH living above poverty than below said that medications were essential.

TABLE 13: SERVICES THAT WERE ESSENTIAL TO PLWH IN THE SIX MONTHS PRIOR TO SURVEY (RANKED) AND SIGNIFICANT VARIATIONS BY SELECTED GROUPS (P<.05)

SERVICE	ESSENTIAL			SIGNIFICANT VARIATIONS AMONG RESPONDENTS								SIGNIFICANT VARIATIONS AMONG RESPONDENTS							
				MA								EMA							
	OVERALL (N=1,791)	MA (N=1,649)	EMA (N=1,339)	Gender	Poverty	Age	Years HIV+	Race/Ethnicity	Country of Birth	Disability	Chronic Condition	Gender	Poverty	Age	Years HIV+	Race/Ethnicity	Country of Birth	Disability	Chronic Condition
Primary Care	94%	94%	94%								x								x
Drugs	92%	92%	91%	x	x							x	x						x
Benefits	83%	83%	82%																
Dental	83%	83%	82%											x				x	
Case Management	82%	81%	80%		x			x		x						x	x	x	
Mental Health	66%	66%	67%	x	x					x		x				x		x	x
Food Vouchers/Bank	66%	66%	67%	x	x			x		x	x	x	x			x		x	x
Rent	65%	65%	66%	x	x			x	x			x	x			x	x		
Housing Search	61%	61%	62%	x	x	x		x	x	x		x	x	x		x	x	x	x
Adherence	59%	59%	58%	x	x			x				x	x			x			
Nutritional Counseling	57%	57%	58%	x	x			x	x		x	x	x			x			x
Legal Assistance	54%	55%	55%		x			x		x			x			x		x	
Peer Support	54%	54%	54%	x	x			x	x			x	x			x			
Substance Abuse	48%	49%	48%	x	x			x					x			x			
Job Help	38%	39%	40%	x	x	x	x	x	x			x	x	x	x	x	x		
Respite	38%	38%	37%	x	x			x					x			x	x	x	
Congregate Meals	34%	34%	33%		x			x					x			x			
Home-Delivered Meals	33%	34%	33%		x			x			x		x						x
Immigration Assistance	23%	23%	23%	x	x	x	x	x	x				x	x		x	x		

» LESS ESSENTIAL SERVICES

SERVICES THAT WERE LEAST ESSENTIAL

As shown in Table 14, the top five services that PLWH said had "none, or no role" in their overall health were:

1. **Immigration assistance**
2. **Respite**
3. **Job help**
4. **Home-delivered meals**
5. **Congregate meals**

Among the non-US born respondents (n=86), immigration assistance was still among the top five least essential services. It was reported as having "none, no role" by 28% of these respondents, and was the fifth least essential service.

As illustrated in Table 14, a number of statistically significant variations were identified among groups in the proportion that reported that each service had "none, or no role" in their overall health. Variations based on poverty status and race/ethnicity were most prevalent and several are described below. See More information about these variations is available in the *Data Supplement*.

- The proportion of respondents who said that a service had "none, no role" in their life was significantly higher among men, those living above poverty, those age 50 and older, Whites, those who were not living with a disability, and US born.
- Responses to drug reimbursement services were a notable except to the general trend. Significantly more women than men, and more PLWH living below poverty said that drugs had "none, no role" in their lives.

LESS ESSENTIAL SERVICES

TABLE 14: SERVICES THAT WERE NOT ESSENTIAL TO PLWH IN THE SIX MONTHS PRIOR TO SURVEY (RANKED) AND SIGNIFICANT VARIATIONS BY SELECTED GROUPS (P<.05)

SERVICE	NOT ESSENTIAL ("NONE" OR "NO ROLE" IN OVERALL HEALTH)			SIGNIFICANT VARIATIONS AMONG RESPONDENTS								SIGNIFICANT VARIATIONS AMONG RESPONDENTS							
				MA								EMA							
	OVERALL (N=1,791)	MA (N=1,649)	EMA (N=1,339)	Gender	Poverty	Age	Years HIV+	Race/Ethnicity	Country of Birth	Disability	Chronic Condition	Gender	Poverty	Age	Years HIV+	Race/Ethnicity	Country of Birth	Disability	Chronic Condition
Immigration Assistance	66%	66%	66%	x	x	x	x	x	x			x	x		x	x	x		
Respite	48%	48%	48%		x	x		x	x				x			x	x		
Job Help	45%	44%	43%		x	x		x	x				x	x		x	x		
Home-Delivered Meals	43%	42%	42%	x	x			x					x			x			
Congregate Meals	40%	39%	41%		x			x					x			x			
Substance Abuse	37%	36%	36%		x	x		x		x			x			x		x	
Housing Search	28%	28%	27%	x	x	x		x	x	x	x		x	x		x	x	x	
Legal Assistance	28%	27%	27%		x			x					x			x			
Rent	22%	23%	21%	x	x	x		x	x	x		x	x	x		x	x	x	
Adherence	21%	21%	20%	x	x			x				x	x			x			
Food Vouchers/Bank	20%	20%	20%	x	x			x		x	x	x	x			x		x	
Nutritional Counseling	19%	19%	19%	x	x			x		x	x	x	x			x			x
Mental Health	19%	19%	19%		x			x		x			x			x		x	
Peer Support	18%	18%	17%		x		x	x	x				x		x	x			
Benefits	10%	10%	11%					x		x		x							
Dental	8%	8%	9%					x											
Case Management	6%	6%	6%		x								x				x		
Drugs	4%	4%	4%	x	x							x	x					x	
Primary Care	3%	3%	3%		x														

SERVICE BARRIERS

Table 15 includes the top barriers for each of the top 10 services that PLWH said they needed but could not get. For all 10 services, the most common barrier was "didn't know it existed or how to get it."

As noted previously, immigration assistance was second highest in the list of services that non-US born PLWH (n=86) said they needed, but could not get. Among those who said they needed but couldn't get the service and also reported a barrier (n=19), the most common were "didn't know it existed/how to get" (68%) and "other" (26%).

TABLE 15: MOST COMMON BARRIERS FOR TOP 10 SERVICES PLWH SAID THEY NEEDED BUT COULD NOT GET

SERVICE	MOST COMMON BARRIERS	MA %	EMA %	MA n	EMA n
Rent	Didn't know it existed or how to get it	47%	47%	365	298
	Told not eligible	20%	20%		
Food Voucher/Bank	Didn't know existed or how to get it	50%	50%	303	253
	Told not eligible	17%	16%		
Dental	Didn't know it existed or how to get it	30%	33%	268	228
	Don't have enough money	19%	20%		
Job Help	Didn't know existed or how to get it	44%	46%	250	213
	Transportation problems	15%	-		
	Other	-	16%		
Housing Search	Didn't know existed or how to get it	36%	34%	230	192
	Don't have enough money	24%	20%		
Legal Assistance	Didn't know existed or how to get it	43%	44%	223	182
	Other	18%	18%		
Nutritional Counseling	Didn't know existed or how to get it	43%	40%	184	152
	Not available near my area	12%	13%		
Home Delivered Meals	Didn't know existed or how to get it	51%	50%	179	149
	Told not eligible	13%	13%		
Peer Support	Didn't know existed or how to get it	37%	39%	162	140
	Not available near my area	23%	24%		
Respite	Didn't know existed or how to get it	43%	45%	135	121
	Other	22%	20%		

» PHASE II SURVEY RESULTS

In this section, we present the results of the Phase II survey (see *Appendix B*). This survey was distributed to 1,528 PLWH in MA and southern NH who completed the Phase I survey and volunteered to take the Phase II survey. The survey was long and was intended to gather more comprehensive data from a smaller sample of PLWH. In addition to more in-depth demographic questions, the survey included a range of questions on topics such as:

- Access to care and support
- Aging
- Co-morbidities
- Education and employment
- Health knowledge/literacy
- Health status
- HIV diagnosis
- HIV medications & adherence
- Housing status
- Mental health
- Positive prevention
- Primary care
- Stigma and disclosure
- Substance use

NOTE ON TERMINOLOGY

For purposes of this survey, the term "HIV medical provider" was defined as "your main doctor, nurse practitioner, nurse, or physician's assistant who manages your HIV care. If you have more than one medical provider, think about the one you see most of the time."

For help with acronyms used in this section, see *Common Acronyms* on page vii. For assistance with the definition of specific terms, see the Glossary on page 95.

NOTE ABOUT THE DATA IN THIS SECTION

The data tables in this section illustrate the results of the Phase II survey for three groups: (1) all respondents (overall), (2) respondents who resided in Massachusetts, and (3) respondents who resided in the Boston EMA. Homeless respondents are only included in the "overall" group since residency could not be established for these individuals. Proportions cited in the text refer to the "overall" sample only; readers should refer to the tables for proportions for the other two groups.

Sample size. The abbreviation "n" used in the data tables and in the text refers to the number of people who answered each question. The "n" varies depending on which group of respondents being discussed (overall, MA, or EMA), and because some respondents did not answer each question on the survey (or did not have to answer if it wasn't applicable).

Statistically significant differences. Much of the Phase II survey data were also analyzed by a range of independent variables to determine whether different groups responded differently. Often, proportions between groups are different, and the key to interpretation is assessing whether these differences are the result of chance, or whether they represent a real phenomenon captured by the study. To determine which of these is more likely, a statistical test is conducted (Chi-Square), and a statistical variable is produced (p-value). If the p-value is less than 0.05, this means we can be at least 95% confident that the difference identified is real. This difference is then called "statistically significant." When statistically significant variations were identified between certain groups, these differences are identified in the text. All variations were significant at the 0.05 level, unless otherwise noted.

LOCATION

The largest proportion of respondents indicated that they learned their HIV status when they were tested at a hospital or hospital clinic (31%), a private doctor's office (23%), or a community health center or clinic (21%). Smaller proportions reported that they learned in jail/prison or at an HIV counseling, testing, and referral sites.

TABLE 16: FACILITY WHERE RESPONDENTS TESTED POSITIVE

TESTING FACILITY	OVERALL (N=1,014)	MA (N=943)	EMA (N=751)
Hospital/hospital clinic	31%	32%	34%
Private doctor's office	23%	23%	23%
Community health center or clinic	21%	21%	21%
Jail/prison	5%	6%	6%
HIV counseling/testing/referral site	5%	5%	5%

The location where respondents were tested and learned they were HIV positive varied significantly for several populations, described below.

- A significantly higher proportion of MSM than non-MSM tested positive at private doctors' offices (32% vs. 18%) and at community health centers or clinics (26% vs. 18% MA; 25% vs. 18% EMA).
- A significantly higher proportion of women than men tested positive at a hospital or hospital clinic (38% vs. 30%).

Because the survey sample included a large proportion of individuals who had been living with HIV for more than 10 years, HIV testing location information was analyzed to determine whether there was any difference between those tested earlier in the epidemic compared to those tested more recently. A significantly greater proportion of EMA respondents diagnosed more than 10 years ago tested positive at a community health center than those diagnosed more recently (24% vs. 17%). No other statistically significant differences were identified.

The location where individuals tested HIV positive also varied significantly by geography in MA, and likely reflects the distribution and concentration of certain types of facilities throughout the state. For example, a greater proportion of respondents living in the Cape or Island regions of MA reported that they tested positive for HIV at a community health center or clinic (when compared to other regions of the state). Conversely, a smaller proportion of respondents living in the Cape or Island regions reported that they tested positive at a hospital or hospital clinic.

The Health Resources and Services Administration (HRSA) and the Ryan White Program legislation have encouraged grantees to understand better why PLWH who know their status are not in care and to develop strategies to bring them into care. Although there are a number of potential strategies for assessing the needs of people not in care, it was anticipated that this assessment would not reach a large number of them, based on the methodology and overall objectives.

Nonetheless, all respondents were asked a series of questions about when they tested positive for HIV, how quickly they sought care and support services, who or what helped them access services, and what could have helped them access services sooner. The responses of those who indicated that they delayed accessing care could serve as imperfect proxies for the experiences of PLWH who are not in care.

As illustrated in Table 17, more than three-quarters of respondents indicated that they accessed HIV medical care soon after testing HIV positive; 59% said they got care immediately (within 30 days) and another 18% said they waited one to six months. An additional 16% said they waited longer than a year to access medical care, with very few having not yet accessed care at the time of the survey.

Respondents indicated that they waited longer after testing HIV positive to access services other than medical care, with over one-half (57%) accessing HIV services within six months (including 35% within 30 days). About one-third of respondents waited a year or longer to access HIV services, with 4% reporting that they had not yet accessed HIV services other than medical care.

TABLE 17: LENGTH OF TIME BETWEEN HIV DIAGNOSIS AND ENGAGEMENT IN HIV MEDICAL CARE AND OTHER HIV SERVICES

TIME AFTER DIAGNOSIS	HIV MEDICAL CARE			OTHER HIV SERVICES		
	Overall (n=1,017)	MA (n=946)	EMA (n=754)	Overall (n=1,015)	MA (n=944)	EMA (n=753)
Did not wait (<30 days)	59%	59%	58%	35%	36%	34%
1 - 6 months	18%	18%	19%	22%	22%	23%
6 – 12 months	7%	6%	6%	10%	10%	11%
1-3 years	7%	7%	8%	13%	12%	12%
3-5 years	3%	3%	3%	6%	6%	6%
More than 5 years	5%	6%	5%	10%	10%	10%
Not yet	1%	1%	1%	4%	4%	5%

Respondents were asked to identify what supports would have helped (or would help them now) get medical care sooner. The top responses **for those who waited a year or more** (n=168) to access HIV medical care are included in Table 18. As shown, the two most common responses were "needed more time to deal with diagnosis" (24%)

and "nothing" (17%). Given the intense federal focus on activities to increase the number of people who know their status and are in medical care, these results suggest potential barriers to such efforts. It is important to note, however, that nearly all of the sample population was engaged in care and services at the time of the survey, and therefore, the views of those not in care at the time of the survey are not reflected in these data. In addition, since the majority of participants received their diagnosis more than ten years prior to the survey, it is possible that some respondents may not have immediately recalled any barriers they experienced.

TABLE 18: POTENTIAL FACILITATORS FOR ACCESSING HIV MEDICAL CARE SOONER AFTER HIV DIAGNOSIS AMONG RESPONDENTS WHO WAITED ONE YEAR OR MORE TO ACCESS CARE

WHAT WOULD HAVE HELPED YOU GET HIV MEDICAL CARE SOONER?	OVERALL (N=168)	MA (N=156)	EMA (N=125)
Needed time to deal with diagnosis	24%	24%	28%
Nothing	17%	17%	18%
Help dealing with drug or alcohol issues	10%	10%	10%
More information about what might happen if I did not get it	10%	10%	7%
Other	10%	10%	10%

Table includes only those response categories with ≥10% of responses.

TABLE 19: POTENTIAL FACILITATORS FOR ACCESSING OTHER HIV SERVICES SOONER AFTER HIV DIAGNOSIS AMONG RESPONDENTS WHO WAITED ONE YEAR OR MORE TO ACCESS SERVICES

WHAT WOULD HAVE HELPED YOU GET OTHER HIV SERVICES SOONER?	OVERALL (N=333)	MA (N=310)	EMA (N=245)
More information about where to go to get services	36%	37%	38%
Needed time to deal with diagnosis	29%	27%	31%
Information about free or low cost services	27%	27%	27%
Talk or counseling when I got my diagnosis	21%	20%	22%
Someone with HIV to help me talk about or deal with the diagnosis	19%	19%	20%
Help dealing with drug or alcohol issues	18%	17%	20%
Nothing	17%	17%	18%
More information about what might happen if I did not get it	16%	16%	17%
Other	10%	10%	11%

Table includes only those response categories with ≥10% of responses.

In addition to HIV medical care, respondents were also asked to identify what would have helped (or would help them now) get **other HIV services** sooner. The top responses **for those who waited a year or more** to access such services are included in Table 19. Unlike the responses for HIV medical care, the responses to this question indicate that access to information about services and where to get them is important. As shown in Table 19, the most common responses were "more information about where to go to get services" (36%), "need time to deal with diagnosis" (29%), and "information about free or low cost services" (27%).

As shown in Table 20, respondents reported that their medical providers and case managers were the most helpful to them for getting HIV medical care or other services after testing positive, with 38% indicating the former, and 16% the latter. Further analysis indicated that those who tested positive in a private doctor's office were significantly more likely to enter care sooner than those who tested positive elsewhere. Specifically, 83% of those who tested in a private doctor's office entered care within six months, compared to 75% of those who tested positive in other sites.

TABLE 20: MOST HELPFUL PEOPLE FOR LINKING CLIENTS TO HIV MEDICAL CARE OR OTHER SERVICES

	OVERALL (N=1,013)	MA (N=943)	EMA (N=749)
Medical provider	38%	39%	39%
Case manager	16%	15%	15%
Family member	8%	7%	8%
Spouse/significant other	7%	7%	8%
Friend	7%	8%	7%
No one	6%	6%	6%
Another person with HIV	5%	5%	5%
Person who gave test result	4%	4%	4%
Other	4%	4%	4%
Outreach worker	3%	4%	3%

Comparisons of data on the short and long form surveys suggest that those who waited to access other HIV-related services for a year or more after their HIV diagnosis continue to experience barriers to accessing services. For 14 of 19 services on the short form survey, a significantly higher proportion of those who waited a year or more to access other HIV services than those who waited less time reported (1) a barrier to accessing services in the six months prior to the survey and (2) to have needed but could not get dental care (overall and EMA only), support from other people with HIV/AIDS, and help finding a place to live (EMA only).

Respondents were also asked to select from a list what was most difficult (in general) about using HIV services. Table 21 lists all of the survey response options and the proportion of respondents who selected each. As illustrated, over half of respondents answered "nothing," and the next most common response was "too much paperwork," reported by nearly one-quarter of respondents.

TABLE 21: MOST DIFFICULT ASPECTS OF ACCESSING HIV SERVICES

ASPECTS OF ACCESSING SERVICES	OVERALL (N=1,002)	MA (N=933)	EMA (N=745)
Nothing	54%	54%	54%
Too much paperwork	24%	25%	25%
Having to go to different places to get services	20%	20%	20%
Getting to and from appointments	17%	16%	17%
Finding providers that understand needs of PLWH	14%	14%	15%
Feeling uncomfortable or unwelcome at some service providers	13%	13%	15%
Don't want people to see me getting services	13%	13%	13%
Dealing with all the things my different providers ask of me	11%	11%	11%
Finding time to go to appointments	11%	11%	11%
Getting services because of my immigration status	2%	2%	2%

Respondents could select more than one option.

For several of the options in Table 21, respondent characteristics were analyzed to assess any possible commonalities among those that reported a particular difficulty. Mental health issues and age of respondents were identified as common themes among certain response options. For example, among those who said getting to and from appointments was most difficult (n=166), 67% also reported that they had been diagnosed with a mental health condition in the prior three months, and 92% reported experiencing mental health symptoms in the prior 30 days. Among those who said they felt uncomfortable or unwelcome at some service providers (n=134), 50% reported that they had been diagnosed with a mental health condition in the prior three months, and 95% reported experiencing mental health symptoms in the prior 30 days. In addition, 66% of these respondents were under age 50. Lastly, among those who said they did not want people to see them getting services (n=130), 54% reported that they had been diagnosed with a mental health condition in the prior three months, and 88% reported experiencing mental health symptoms in the prior 30 days. Among this group, 70% were under age 50.

When asked where they usually got HIV medical care, most respondents reported a hospital/hospital clinic (42%), a community health center or clinic (30%), or a private doctor's office (28%). As highlighted in Table 22, a higher proportion of respondents in the Boston EMA than those in MA or the overall sample reported that they got HIV medical care at a hospital/hospital clinic. Similarly, fewer respondents in the Boston EMA reported that they get care at community health centers.

Respondents were also asked whether they kept their last HIV medical appointment. The vast majority (95%) said that they had kept their last appointment. Among the small proportion who did not keep their last appointment, the most common reasons are provided in Table 23.

TABLE 22: FACILITIES USED FOR HIV MEDICAL CARE

FACILITY	OVERALL (N=1,029)	MA (N=930)	EMA (N=763)
Hospital/hospital clinic	42%	42%	47%
Community health center or clinic	30%	32%	28%
Private doctor's office	28%	27%	26%
Other	1%	1%	1%
VA hospital/clinic	1%	<1%	1%
Emergency room	<1%	<1%	<1%

TABLE 23: MOST COMMON REASONS FOR MISSING HIV MEDICAL APPOINTMENT (AMONG THOSE WHO MISSED MOST RECENT APPOINTMENT)

REASONS	OVERALL (N=49)	MA (N=45)	EMA (N=32)
Unable to get there	47%	49%	34%
Feeling well or didn't think it was necessary	18%	18%	19%
Too sick to go	12%	13%	9%
Unable to take time off work	8%	9%	13%
No child care	2%	2%	0%

PLWH WHO ARE NOT IN CARE

HRSA, which administers the federal Ryan White HIV/AIDS Program, has focused for a number of years on PLWH who are not in care. HRSA considers PLWH not to be in care if they have not seen a medical provider in the past

six months (nor received a CD4 and/or viral load test). Because of the methodology used for this study (distribution to PLWH through case managers and ADAP, with some outreach to not-in-care through peer support programs), it was expected that a large proportion of respondents were likely to be "in care."

Nonetheless, the survey included several questions to assess whether respondents were "in care" including when they last saw their medical provider and whether they were taking HIV medications. Date of last CD4 or

TABLE 24: EXPERIENCES WITH HIV MEDICAL PROVIDER

	ALWAYS		SOMETIMES		NEVER		N	
MY MEDICAL PROVIDER . . .	MA	EMA	MA	EMA	MA	EMA	MA	EMA
Spends enough time with me during visits	83%	81%	15%	17%	2%	2%	935	746
Listens to me during visits	88%	87%	12%	13%	1%	1%	939	748
Is easy to reach when I need to	65%	66%	30%	29%	5%	6%	932	745
Is easy to schedule an appointment with	77%	77%	21%	21%	2%	2%	927	743
Encourages me to participate in my own care	84%	83%	12%	12%	4%	5%	932	743
Makes sure I get the care I need, including referrals to specialty care	89%	88%	10%	11%	1%	1%	934	744
Seems to understand the needs of people my age	84%	84%	14%	15%	1%	1%	932	742
Seems to understand my culture or community	81%	78%	17%	20%	2%	2%	895	708
Seems to understand how to treat HIV/AIDS	93%	93%	6%	7%	<1%	1%	934	747
Is able to help me deal with other health issues besides HIV/AIDS	81%	80%	17%	18%	2%	2%	929	740
Offers me testing for other diseases like Hepatitis B or C, TB, STIs, or other health conditions	87%	85%	10%	11%	3%	4%	931	743
Treats me with respect	94%	93%	6%	6%	<1%	1%	936	748
Works with me to help me keep my appointments	81%	79%	11%	12%	8%	9%	865	693
Meets with my sexual and drug-using partners upon my request	57%	55%	10%	11%	33%	34%	599	477
Refers me to mental health or substance abuse services if I need them	74%	74%	13%	13%	13%	14%	755	593

Percentages calculated after N/A responses were removed.

viral load was not asked. Based on these parameters, very few respondents were "not in care"—98% of MA respondents and 99% of EMA respondents said they had seen their medical provider in the 12 months prior to the survey, and 95% and 94% respectively had done so within the prior six months. In addition, 91% of respondents indicated they were taking HIV medications. (More information on HIV medications is provided in the next section.)

For the very small number of individuals who said they had not seen their medical provider in the year prior to the survey, their responses to the HIV medications questions were analyzed to determine whether these PLWH respondents were truly "not in care." Of the small number who said they had not seen their medical provider in the prior 12 months, only three individuals also reported that they were not taking ARVs.

EXPERIENCES WITH MEDICAL PROVIDER

Respondents were asked a series of questions about their medical provider to assess the components of care that they received. Respondents were asked to indicate how often the factor was a part of their experience with their provider (e.g., always, sometimes, or never). The purpose of these questions was not to evaluate the medical provider, but rather assess respondents' experiences with their provider and whether they were receiving comprehensive primary care services.

As shown in Table 24, a high proportion of respondents reported "always" for the vast majority of the characteristics explored. The highest proportion of respondents reported that their medical provider "always" (1) treats me with respect (94% MA, 93% EMA) and (2) seems to understand how to treat HIV/AIDS (93%). The lowest proportion of respondents reported that their medical provider always (1) meets with my sexual and drug using partners upon my request (57% MA, 55% EMA), and (2) is easy to reach when I need to (65% MA, 66% EMA). For most characteristics, the proportion who reported "never" was below 5%, except for meeting with sexual and drug using partners upon request (33% MA, 34% EMA), referrals to mental health or substance abuse services if needed (13% MA, 14% EMA), and working with the client to keep medical appointments (8% MA, 9% EMA).

IMPORTANT SERVICE CHARACTERISTICS

Respondents were asked to select from a list of characteristics, those that were most important when they needed to use HIV primary care. Table 25 highlights the responses to this question among all respondents. As illustrated, the most important characteristics of primary care (reported by 60% or more of respondents) were (1) the ability to get there easily, (2) the presence of staff who understands the needs of PLWH, and (3) the provider accepting their insurance.

TABLE 25: MOST IMPORTANT CHARACTERISTICS OF HIV PRIMARY CARE

SERVICE CHARACTERISTICS	OVERALL (N=1,029)	MA (N=958)	EMA (N=763)
I can get there easily	63%	63%	64%
Staff understand needs of PLWH	61%	61%	61%
They take my insurance	60%	60%	59%
It is easy to make an appointment	58%	58%	58%
It is easy to reach someone	53%	53%	53%
The staff speak my language	48%	48%	47%
Located in my community and I know the people there	42%	42%	41%
The staff understand my culture and community	41%	41%	39%
I can get other services while I'm there	41%	41%	41%
Services are free or low cost	35%	35%	35%
There are no waiting lists	33%	32%	33%
Located outside my community and I won't see anyone I know	7%	6%	7%
None of these	7%	7%	7%

Respondents could select more than one option.
All response options on the survey are included in the table.

HIV MEDICATIONS

Among all MA and EMA respondents, 91% were taking HIV medications (anti-retrovirals or ARVs) as prescribed by their medical provider at the time of the survey. Among respondents who had an AIDS diagnosis, 96% to 97% were taking HIV medications. As shown in Table 26, among those taking HIV medications, a large majority (79%) had been taking them for five years or more.

TABLE 26: LENGTH OF TIME TAKING HIV MEDICATIONS

	OVERALL (N=995)	MA (N=926)	EMA (N=735)
1 year or less	6%	5%	5%
>1 year to 3 years	8%	8%	8%
>3 years to 5 years	8%	8%	9%
>5 years to 10 years	22%	22%	21%
>10 years	57%	57%	56%

A small number of respondents (<10%) indicated that they were not taking ARVs. Among this group, the majority said it was because they and their medical provider had decided to wait (53%) or their medical provider had not prescribed them (32%). None said it was because they could not afford them or because they did not have a medical provider.

TABLE 27: REASONS FOR NOT TAKING HIV MEDICATIONS

TOP REASONS	OVERALL (N=85)	MA (N=80)	EMA (N=60)
My medical provider and I decided to wait	53%	52%	53%
My medical provider has not prescribed them	32%	32%	37%
I do not feel sick	21%	20%	20%
I chose not to take them	19%	20%	18%

Respondents could select more than one option; table includes those options with ≥10% of responses.

HIV DRUG RESISTANCE TESTING

HIV drug resistance testing can help inform the selection of treatment options for PLWH, indicating whether an individual's HIV virus is resistant to particular types of HIV medications. Specifically, genotypic assays detect drug resistant mutations in specific viral genes and phenotypic assays assess the ability of the virus to grow in different concentrations of antiretroviral drugs. US treatment guidelines recommend HIV drug resistance testing when a PLWH enters care, before initiation of drug therapy, when changing drug regimens, and/or in cases of

virologic failure or suboptimal viral suppression[4]. Drug resistance testing is also recommended for all pregnant women with HIV, prior to initiation of drug therapy.

Forty-four percent of respondents said that they had ever had a baseline HIV drug resistance test. Over one-quarter (28%) said they had not; and another 29% said they weren't sure or didn't know if they had ever had such a test. The proportion who reported ever having a baseline drug resistance test was significantly higher among those who: (1) had lower self-reported CD4 cell counts, (2) had a recent mental health diagnosis, (3) had been told by a medical provider that they had AIDS, (4) had a disability, (5) reported that their health status had stayed the same in the past year, and (6) were living above poverty level.

DRUG COSTS

The Massachusetts HIV Drug Assistance Program (HDAP) and the New Hampshire AIDS Drug Assistance Program (ADAP) provide access to HIV-related medications for residents of each state who are otherwise unable to obtain these life-saving drugs. These programs are funded by the federal Ryan White Program and are administered by each state for their residents. PLWH who reside in Massachusetts are eligible if their income is below 500% of the federal poverty level; PLWH who reside in New Hampshire are eligible if their income is below 300% of the federal poverty level.

As shown in Table 28, the largest proportion of respondents indicated that their medication costs were covered by HDAP (65%) or Medicaid (60%).

TABLE 28: HIV MEDICATION COST COVERAGE

PAYOR	OVERALL (N=838)	MA (N=778)	EMA (N=634)
HDAP/ADAP or NH Care Program	65%	65%	67%
Medicaid	60%	62%	59%
Medicare	28%	28%	29%
Private Insurance	20%	20%	21%
Commonwealth Care/Choice	3%	3%	3%

Respondents could select more than one option; options with >1% of responses included.

Responses were analyzed to assess whether there were any significant differences in how NH respondents and all others covered the cost of HIV medications. In addition to the expected result that those from NH were significantly more likely than all other respondents to report that they used the NH Health Plan (7% vs. 0.3% overall; 7% vs. 0.2% EMA), NH respondents were also significantly less likely than others to report that they used Medicaid to cover drug costs (33% vs. 62% overall; 33% vs. 61% EMA).

4. DHHS. 2009. *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents.*

ADHERENCE

Among respondents who had been taking HIV medications for at least six months, 62% (EMA) to 64% (MA) said they had never missed a dose of their medications in the two weeks prior to the survey; 29% (MA) to 31% (EMA) said they had missed a dose once or twice. Those who reported missing a dose in the past two weeks were significantly more likely to have been living with HIV over 10 years, have experienced mental health-related symptoms in the prior 30 days, to have been diagnosed with a mental health condition in the prior three months, to have been under age 50, and have had a most recent CD4 count below 200.

Respondents were asked about who, if anyone, had talked with them in the three months prior to the survey about taking their HIV medications as prescribed. Among respondents who had been taking HIV medications for at least six months, nearly two-thirds (64%) said their medical provider had spoken with them about this topic. Nearly 30% said that "no one" had talked to them about this topic (see Table 29).

TABLE 29: DISCUSSIONS ABOUT MEDICATION ADHERENCE IN PRIOR THREE MONTHS (AMONG THOSE TAKING HIV MEDICATIONS)

WHO HAS TALKED WITH YOU ABOUT MEDICATION ADHERENCE	OVERALL (N=835)	MA (N=775)	EMA (N=630)
Medical provider	65%	64%	64%
No one+	28%	29%	28%
Case manager	24%	22%	25%
Family/friends	16%	16%	17%
Mental health counselor (therapist or psychiatrist)	13%	12%	14%
Other HIV services provider or outreach/community health worker	12%	11%	13%
Other people living with HIV that I know	9%	9%	10%

+Includes only respondents who selected "no one" and did not select any other option.
Respondents could select more than one option; table includes only those options with >10% of respondents.

MEDICATION STOPPAGE

In addition to adhering to their daily medication regimen, the survey also asked respondents if they had stopped taking their medications for more than a week in the six months prior to the survey. Thirteen percent of respondents said they had stopped taking their HIV medications for more than a week during that period. As shown in Table 30, the largest proportion (35%) said they stopped because they felt depressed or overwhelmed, followed by 30% who said they forgot to take them. It should be noted that of the top reasons for medication stoppage, nearly all appear to be "individual decisions" that may not have been discussed with their medical provider. Only 12% indicated that they had stopped because their medical provider told them to do so.

These responses were examined in more detail to determine whether any respondents indicated that their

medical provider had told them to stop, in addition to any other reason (thus suggesting some medical provider involvement). Of those who said they had stopped taking their medication, 85% did not indicate their medical provider had told them to do so.

Among those who said they had stopped taking their medications for more than a week, a small number (n=9) said they had stopped because they could not afford a prescription refill. The source of payment for medications was explored for this group of nine. Three (33%) said their medications were paid for by Medicaid, two (22%) said HDAP and private insurance, two (22%) said HDAP, Medicaid, and Medicare, one (11%) said Medicaid, Medicare, and Commonwealth Care/Choice, and one (11%) said HDAP, Medicaid, and private insurance. All nine resided in Massachusetts, and four were age 50 or older.

Twenty-four MA respondents (24%) and 16 EMA respondents (19%) selected "other" as a reason for having stopped taking their medications. Of these groups, the most frequently cited reasons were alcohol/drug use (MA = 3, EMA = 3), a medical insurance issue (MA = 3; EMA = 3), and a medication "holiday" (MA = 3; EMA = 0).

TABLE 30: REASONS FOR STOPPING MEDICATIONS FOR MORE THAN ONE WEEK IN PRIOR SIX MONTHS

REASONS FOR MEDICATION STOPPAGE	OVERALL (N=111)	MA (N=102)	EMA (N=83)
Felt depressed or overwhelmed	35%	33%	39%
Forgot to take them	30%	29%	30%
Wanted to avoid side effects	24%	26%	24%
Chose not to take them	20%	22%	22%
Felt too sick	19%	21%	20%
Was busy with other things	14%	14%	16%
Had a change in daily routine	11%	12%	15%
Had too many pills to take	14%	15%	15%
Medical provider told me to stop	12%	13%	13%
Had problems taking them at a specific time	10%	11%	12%

*Respondents could select more than one option; options with >10% of respondents included in table.

HIV CASE MANAGEMENT

As defined by MDPH and BPHC, HIV case management is a service that links clients with primary medical care and health-related support services in a manner that ensures timely, coordinated access to appropriate levels of care. Client-centered services support a client's ability to maximize his/her self-sufficiency and independence. Key activities include: information and referral; assessment of the client's needs and personal support systems; development of a comprehensive individualized service care plan; coordination of the services required to implement the plan; client monitoring to assess the efficacy of the plan; periodic reassessment; and implementation and periodic adaptation of the plan.

HIV case management services are an important component of the local HIV service delivery system and these services are jointly procured by MPDH and BPHC through a single competitive grant application process for service providers in Massachusetts. In FY10, HIV medical[5] case management was ranked 4th in priority by the Boston Ryan White Part A Planning Council, and with an FY10 allocation of over $2 million, represented the largest resource allocation of the 11 HIV services funded by the Part A Program.

More than three-quarters of survey respondents (79%) reported that they needed and used case management services in the six months prior to the survey. This high proportion was expected since nearly two-thirds of the initial surveys were distributed to clients of HIV case management programs.

Responses related to need and use of case management services (e.g., "needed and used" or "didn't need and didn't use") were linked to other responses on the survey to assess any significant differences between those who used and did not use case management services. Table 31 highlights these significant differences for a number of variables. For example, among the overall sample, 89% of those who needed and used case management services had a chronic condition compared to 79% of those who didn't need or use case management services. As illustrated in Table 31, a significantly higher proportion of those who needed and used HIV case management services had a chronic condition, were disabled, had been diagnosed with a drug or alcohol problem, had a recent mental health diagnosis or mental health symptoms, were not MSM, had a recent change in their living situation, were in school or a vocational training program, and had less formal education.

5. HIV case management services were recently renamed "HIV medical case management" services to reflect recent changes in the Ryan White Program legislation and the role of these services in linking PLWH with primary care.

TABLE 31: SIGNIFICANT VARIATIONS BETWEEN RESPONDENTS WHO USED AND DID NOT USE HIV CASE MANAGEMENT SERVICES

	OVERALL		MA		EMA	
	Needed & used	Didn't need or use	Needed & used	Didn't need or use	Needed & used	Didn't need or use
Had chronic condition	89%	79%	89%	79%	89%	80%
Was disabled	39%*	32%*	39%*	31%*	42%	28%
Ever dx with alcohol or drug problem	42%	27%	42%	26%	43%	26%
MH symptoms prior 30 days	81%	73%	80%	72%	81%	71%
Dx MH condition prior 90 days	49%	34%	49%	34%	49%	32%
MSM	40%	50%	40%	51%	38%	53%
Living situation changed in prior 6 months	12%	4%	11%	4%	12%	2%
Lived in own home or apartment	81%*	87%*	81%	88%	80%	88%
Less than high school or high school graduation	50%	39%	50%	38%	52%	38%
In school or vocational program	7%	1%	7%	1%	7%	2%
Viral load ≥400	18%*	12%*	18%*	12%*	19%	11%

*These differences were not statistically significant at the p=0.05 level

IMPORTANT SERVICE CHARACTERISTICS

From a list of characteristics, respondents were asked to select those that were most important when they needed to use HIV case management services. Table 32 highlights the responses to this question among those who said they used case management services in the six months prior to the survey. As illustrated, the largest proportion (43%) said none of the characteristics provided on the survey were important. Of those who selected a characteristic, the most important were the presence of staff that understands the needs of PLWH, being able to get to the provider, and ease in making an appointment and reaching a member of the staff.

TABLE 32: MOST IMPORTANT CHARACTERISTICS OF HIV CASE MANAGEMENT SERVICES (AMONG RESPONDENTS WHO USED THESE SERVICES)

SERVICE CHARACTERISTICS	OVERALL (N=940)	MA (N=871)	EMA (N=688)
None of these	43%	43%	42%
Staff understand needs of PLWH	30%	29%	30%
I can get there easily	29%	29%	31%
It is easy to make an appointment	27%	26%	26%
It is easy to reach someone	26%	26%	26%
Located in my community and I know the people there	24%	24%	24%
The staff speak my language	23%	23%	23%
Services are free or low cost	21%	20%	21%
I can get other services while I'm there	20%	19%	20%
The staff understand my culture and community	19%	19%	19%
They take my insurance	14%	14%	15%
There are no waiting lists	13%	12%	14%
Located outside my community and I won't see anyone I know	7%	7%	7%

Respondents could select more than one option.
All response options in the survey are included in the table.

» PEER SUPPORT SERVICES

Peer support is defined by MDPH and BPHC as a set of services provided by and for PLWH that enable them to empower themselves and develop effective strategies for living healthy lives. Through one-on-one interactions and in groups, peer support promotes clients' engagement in health care and provides opportunities for education, skill-building, and emotional support in a respectful setting. With harm reduction as a foundation, peer support helps clients access health information, develop coping skills, reduce feelings of social isolation, and increase self-determination and self-advocacy, helping improve quality of life for both participants and peer leaders.

Less than one-half (45%) of respondents reported that they needed and used peer support services in the six months prior to the survey. Responses related to need and use of peer support (e.g., "needed and used" or "didn't need and didn't use") were linked to other responses on the survey to assess any significant differences between those who used and did not use these services. Table 33 highlights these significant differences for a number of variables. For example, among the overall sample, 91% of those who needed and used peer support had a chronic condition compared to 82% of those who didn't need or use the service.

As illustrated in Table 33, a significantly higher proportion of those who needed and used peer support services had a chronic condition, were disabled, had been diagnosed with a drug or alcohol problem, had a recent mental health diagnosis or mental health symptoms, were in fair or poor health, were living in poverty, were not MSM, were female, were US born, had a recent change in their living situation, did not live in their own home or apartment, were people of color, were employed, were in school or a vocational training program, had less formal education, and had higher viral loads.

As reported previously in this report (see Table 12), peer support services was among the top 10 services that respondents said they needed but could not get. The top barriers experienced, as reported by respondents, were "didn't know it existed or how to get" and "service is not available near my area."

TABLE 33: SIGNIFICANT VARIATIONS BETWEEN RESPONDENTS WHO USED AND DID NOT USE PEER SUPPORT SERVICES

	OVERALL		MA		EMA	
	Needed & used	Didn't need or use	Needed & used	Didn't need or use	Needed & used	Didn't need or use
Had chronic condition	91%	82%	91%	83%	91%	83%
Was disabled	41%	34%	41%	33%	41%*	34%*
Ever dx with alcohol or drug problem	49%	29%	48%	28%	48%	30%
MH symptoms prior 30 days	81%	75%	81%	74%	81%*	75%*
Dx MH condition prior 90 days	51%	40%	51%	39%	51%	59%
Fair or poor health	32%	23%	31%	22%	32%	24%
Living in poverty	46%	35%	46%	35%	44%	35%
MSM	32%	51%	32%	51%	32%	49%
Female	37%	29%	37%	28%	37%	29%
US born	94%	89%	93%*	90%*	93%	87%
Living situation changed recently	16%	9%	15%	7%	14%	9%
Lived in own home or apartment	78%	85%	78%	86%	76%	86%
White, non-Hispanic	45%	65%	44%	66%	48%	65%
Non-white, non-Hispanic	30%	17%	31%	18%	32%	21%
Hispanic	25%	17%	26%	17%	20%	14%
Employed	22%	35%	22%	34%	22%	34%
Less than high school or high school graduation	58%	39%	58%	38%	59%	41%
In school or vocational program	8%	4%	9%	4%	21%*	12%*
Viral load ≥400	20%*	15%*	20%	14%	21%	15%

*These differences were not statistically significant at the p=0.05 level

HOUSING STATUS

The long form survey included several questions to assess respondents' housing status and the stability of their living situation (e.g., whether there had been any recent changes, and if they experienced any problems getting or keeping their housing). As shown in Table 34, more than three-quarters of respondents were living in their own home or apartment at the time of the survey. Because the initial survey was mail-based (meaning it was sent to clients who had an address), these results were expected. Nonetheless, field methods were used to ensure that homeless individuals were included in the sample, but they represent a small proportion of the overall respondents. Less than half of respondents (42%) said that they were living in subsidized housing.

TABLE 34: HOUSING STATUS (PRIOR 30 DAYS)

WHERE ARE YOU LIVING CURRENTLY (PAST 30 DAYS)?	OVERALL (N=1,012)	MA (N=941)	EMA (N=752)
Home or apartment of my own	80%	81%	80%
Someone else's house or apartment for a short time because I have no place else to go	9%	9%	9%
Residential program	6%	6%	6%
Street, shelter, car or other temporary place	2%	1%	2%
Other	3%	3%	3%
Jail or prison	<1%	<1%	<1%

The proportion who reported that they lived in their own home or apartment was significantly lower among numerous groups of respondents. These variations are highlighted in Table 35. In general, those who were sicker, had either a mental health or substance use diagnosis or concern, lived below the poverty level, and/or were non-White were significantly less likely to be living in their own home or apartment.

To assess potential challenges with housing, all respondents were asked to indicate whether they had experienced any problems obtaining housing or any problems keeping housing in the prior six months. Just over one-quarter of respondents reported any problem getting housing (29% overall and MA; 28% EMA) or keeping housing (27% overall; 26% MA; 26% EMA). Of those who reported a problem, the top reasons are listed in Table 36.

TABLE 35: SIGNIFICANT VARIATIONS BETWEEN RESPONDENTS WITH AND WITHOUT THEIR OWN HOME OR APARTMENT

	MA RESPONDENTS		EMA RESPONDENTS	
	Had own home/ apt	Did not have own home/apt	Had own home/ apt	Did not have own home/apt
Viral load over 400	17%	26%	NS	NS
On ARVs at time of survey	92%	87%	92%	87%
Ever dx with alcohol/drug problem	36%	49%	37%	50%
Possible alcohol/drug problem (CAGE)	17%	24%	NS	NS
Mental health symptoms prior 30 days	78%	86%	NS	NS
Dx mental health condition prior 3 mths.	44%	61%	45%	56%
Excellent/very good health	40%	26%	38%	26%
Living with chronic condition or disability	37%	49%	NS	NS
Poor	37%	56%	36%	54%
MSM transmission risk	NS	NS	42%	32%
Employed at time of survey	29%	15%	29%	15%
Non-Hispanic white	55%	43%	59%	42%
Non-Hispanic “other” race	23%	29%	25%	32%
Hispanic	22%	29%	16%	26%

All results in table are significant at .05 level, except where indicated by NS (not statistically significant)

HOUSING STABILITY

A small proportion of respondents (12%) said that their living situation had changed in the six months prior to the survey. Because a change in living situation does not necessarily suggest an unstable housing situation, this group of respondents was then asked to indicate where they had lived most of the time during the prior six months. These results are presented in Table 37.

The largest proportion indicated that they had lived in their own home or apartment, suggesting that they had simply moved or changed residences. However, about one-third had been living with someone else temporarily because they had nowhere else to go, 15% had lived in a residential program, and 10% had been homeless. The higher proportion in the overall sample that reported living on the street or in a shelter, car, or other temporary place is expected, since homeless individuals are included only in the overall sample. A greater proportion of EMA respondents than others said they had lived in a home or apartment of their own, and a small proportion said they had lived in someone else’s home temporarily.

TABLE 36: CHALLENGES OBTAINING OR KEEPING HOUSING AMONG THOSE THAT REPORTED A PROBLEM

TOP PROBLEMS OBTAINING HOUSING	OVERALL (N=260)	MA (N=239)	EMA (N=183)
Waiting lists	61%	62%	60%
Credit problems	33%	31%	30%
CORI	27%	28%	28%
Eligibility requirements for subsidies or programs	28%	28%	26%
TOP PROBLEMS KEEPING HOUSING	**OVERALL (N=238)**	**MA (N=213)**	**EMA (N=169)**
Difficulty paying rent, mortgage, or utilities	76%	76%	79%
Credit problems	19%	18%	15%
Drug or alcohol use	10%	10%	11%
Legal problems	9%	9%	8%

TABLE 37: WHERE RESPONDENTS LIVED MOST OF THE TIME FOR THOSE WHO REPORTED A CHANGE IN LIVING SITUATION IN PRIOR SIX MONTHS

	RESPONDENTS WITH CHANGE IN LIVING SITUATION IN PRIOR SIX MONTHS		
WHERE DID YOU LIVE MOST OF THE TIME IN THE PAST 6 MONTHS?	OVERALL (N=114)	MA (N=94)	EMA (N=78)
Home or apartment of my own	38%	38%	44%
Someone else's house or apartment for a short time because I have no place else to go	28%	26%	21%
Residential program	15%	18%	18%
Street, shelter, car or other temporary place	10%	7%	9%
Other	5%	6%	5%
Jail or prison	4%	4%	4%

Recent research suggests that moving can affect PLWH access to and engagement in care.[6] To assess the potential impact of a change in living situation on PLWH health and quality of life, those who reported a change in the prior six months were further analyzed. Among 114 respondents who changed living situations, 83 (73%) were considered "unstably housed" (meaning they had not moved from a home/apartment of their own to another home/apartment of their own). These 83 unstably housed respondents were compared to the vast majority (n=910) who had not changed living situations or had moved, but from a home/apartment of their own to another home/apartment of their own. The results of this comparison indicate that those who were unstably housed were significantly more likely to have reported: lower CD4 and higher viral loads; fair/poor health status; having a disability; being diagnosed with an alcohol/drug problem; recent mental health symptoms and a recent mental health diagnosis; living in poverty; being under age 50; having less than a high school education; and being a person of color. Those who were unstably housed were also significantly less likely to report that they were taking ARVs.

6. Hartmut, Worthington, and Gill. 2011. Adverse health effects for individuals who move between HIV care centers. *Journal of Acquired Immune Deficiency Syndromes*. May (57,1): 51-54.

SUBSTANCE USE AMONG RESPONDENTS

Overall 37% of respondents indicated that they drank alcohol, and 68% said that they had ever experimented with drugs; 76% reported at least one of these behaviors.

Nearly 40% of respondents said they had ever been diagnosed with an alcohol or drug problem. This is consistent with other data on substance use disorders among PWLH.[7]

To assess potential current substance use problems, the survey tool included questions based on the standard CAGE assessment, which is often used to quickly assess possible problems with alcohol. The survey tool used the four basic "yes/no" CAGE questions (**C**utting down on alcohol, experiencing **A**nnoyance from others about alcohol use, feeling **G**uilty, and using alcohol as an **E**ye opener). For the survey, these questions were adapted to reference alcohol and/or drug use and were time-limited to the three months prior to the survey to assess potential current problems. A positive (YES) response to at least two of the four questions may indicate a problem with alcohol or drugs.

Of the 76% of respondents who said they drank alcohol or had ever experimented with drugs, nearly one-quarter (24% MA, 23% EMA) answered "yes" to two or more of the CAGE questions, indicating they may have a current issue with alcohol or drug use.

About one-third of respondents (34% MA, 33% EMA) said they had ever used a needle/syringe to inject drugs or hormones into their body; 6% (EMA) to 8% (MA) said they had done so in the 30 days prior to the survey.

Of this group of recent users of injection drugs or hormones, 47% (MA) to 48% (EMA) said the drugs/hormones **had not** been prescribed by their medical provider, 9% said they had shared needles/works with someone else, and 96% (MA) to 100% (EMA) said they were able to get clean needs/works when they needed them, either from a pharmacy, needle exchange, or syringe access.

ALCOHOL OR DRUG TREATMENT SERVICES

Of the respondents who said they had ever been diagnosed with an alcohol or drug problem (39% MA, 40% EMA), 96% said they had used some form of drug or alcohol services. The use of drug or alcohol treatment services was significantly higher among (1) those who had ever been diagnosed with an alcohol or drug treatment problem than those who had not ($p=<.0001$), and (2) among those who answered "yes" to two more of the CAGE questions, suggesting a potential substance abuse issue at the time of the survey ($p=<.0001$).

Table 38 illustrates the types of services used by respondents who had ever been diagnosed with a problem and who said they had ever used alcohol or drug treatment services. Over three-quarters of respondents reported either using 12-step meetings or detoxification /rehab programs.

To explore more about the need, use, and access to substance abuse treatment services among those who could possibly benefit from them, data were analyzed across the short and long form surveys. Specifically, the long form responses of individuals with potential substance abuse issues within three months prior to the survey (i.e., positive response to two or more of the CAGE screening questions) were linked to their responses

7. Bing et al. 2001. Psychiatric disorders and drug use among HIV-Infected adults in the US. Arch Gen Psychiatry. 2001;58:721-728. http://archpsyc.ama-assn.org/cgi/content/abstract/58/8/721

on the short from about the role of, need for/use of (in prior six months), and barriers to "services that help deal with alcohol and/or drug use."

Respondents with potential substance abuse issues at the time of the survey were significantly more likely than those without to report that:

- substance abuse services were essential (66% vs. 43% MA, 68% vs. 42% EMA),
- they needed but could not get substance abuse services (12% vs. 3% MA, 15% vs. 3% EMA), and
- they experienced a barrier to accessing substance abuse services (26% vs. 16% MA, 29% vs. 16% EMA).

TABLE 38: MOST COMMONLY USED ALCOHOL AND DRUG TREATMENT SERVICES (AMONG RESPONDENTS EVER DIAGNOSED WITH A PROBLEM AND EVER USING SUCH SERVICES)

SERVICE TYPE	OVERALL (N=362)	MA (N=341)	EMA (N=276)
12-step meetings	81%	81%	83%
Detox programs or rehab	76%	75%	76%
Inpatient services	48%	48%	50%
Outpatient services	47%	47%	48%
Residential or halfway house	41%	41%	42%
Methadone	37%	38%	36%
Services or treatment in a shelter	17%	16%	18%
Needle exchange	16%	17%	17%
Suboxone or Subutex	12%	12%	12%
Other meds to treat addiction	10%	11%	10%

Respondents could select more than one option; options with >10% of respondents included in table.

IMPORTANT SERVICE CHARACTERISTICS

From a list of characteristics, respondents were asked to select those that were most important when they needed to use substance abuse services. Table 39 highlights the responses to this question among those who said they used substance abuse services in the six months prior to the survey. As illustrated, the largest proportion (53%) said none of the characteristics provided on the survey were important. Of those who selected a characteristic, the most important were being able to get to the provider, location of the service in their community where they know people, and the presence of staff who understands the needs of PLWH.

TABLE 39: MOST IMPORTANT CHARACTERISTICS OF SUBSTANCE ABUSE SERVICES (AMONG RESPONDENTS WHO USED THESE SERVICES)

SERVICE CHARACTERISTICS	OVERALL (N=493)	MA (N=461)	EMA (N=369)
None of these	53%	52%	51%
I can get there easily	26%	26%	27%
Located in my community and I know the people there	23%	24%	25%
Staff understand needs of PLWH	23%	23%	26%
It is easy to reach someone	22%	22%	22%
They take my insurance	21%	21%	21%
The staff speak my language	19%	19%	18%
It is easy to make an appointment	18%	19%	19%
The staff understands my culture and community	18%	18%	18%
Services are free or low cost	17%	17%	17%
I can get other services while I'm there	14%	14%	14%
There are no waiting lists	11%	12%	12%
Located outside my community and I won't see anyone I know	5%	5%	5%

Respondents could select more than one option. All response options on the survey are included in the table.

RISK REDUCTION

All respondents were asked who (if anyone) had talked with them about alcohol or drug use in the six months prior to the survey. Table 40 illustrates the responses for all respondents whether or not they had a drug or alcohol problem. Among respondents who said someone had spoken with them about these issues, the most common responses were a medical provider (39%) and a case manager (26%).

As shown in Table 40, 46% of all respondents said that no one had talked with them about alcohol or recreational drug use in the six months prior to the survey. However, it is likely that for some respondents, such conversations were not appropriate or warranted based on their history, the length of their relationship with medical or support services providers, and/or recent behavior. When the data were stratified to include only those who may have had a recent substance abuse issue (i.e., those with a positive response to two or more of the CAGE screening questions), a large majority reported that someone had spoken with them about these issues in the prior six months (82% MA, 85% EMA), and was significantly higher than among those who did not appear to have a recent substance abuse issue (p=<.0001).

TABLE 40: DISCUSSIONS ABOUT ALCOHOL OR DRUG USE IN PRIOR SIX MONTHS (AMONG ALL RESPONDENTS)

INDIVIDUALS WHO TALKED WITH RESPONDENTS	OVERALL (N=977)	MA (N=911)	EMA (N=726)
No one	46%	46%	46%
Medical provider	39%	39%	39%
Case manager	26%	25%	25%
Mental health counselor (therapist or psychiatrist)	21%	21%	21%
Family/friends	17%	17%	17%
Support group members	12%	12%	12%
Other HIV services provider or outreach/community health worker	12%	12%	12%
Other PLWH I know	10%	10%	11%
Substance abuse counselor	10%	11%	10%

Respondents could select more than one option; includes only those options with >10%

The data were also analyzed to assess whether any groups of respondents were more likely to report that someone had not spoken with them about alcohol or substance abuse issues in the prior six months. Among respondents who may have had a recent substance abuse issue (i.e., those with a positive response to two or more of the CAGE screening questions), the proportion who said no one had talked to them about substance abuse issues was significantly higher among MSM respondents than non-MSM respondents (59% vs. 41% MA; 60% vs. 40% EMA).

Among respondents who had *ever been diagnosed* with an alcohol or drug problem, the proportion who said no one had talked to them about substance abuse issues was significantly higher among those over 50, women, and those who reported either Black (non-Hispanic) or "other" racial backgrounds.

SUBSTANCE USE AND POSITIVE PREVENTION

Eight percent (MA = 70, EMA = 56) of respondents said that in the six months prior to the survey, they needed "help figuring out ways to stay healthy if using drugs and how to use drugs more safely." Of this group, 31% (MA) to 35% (EMA) said they had not gotten this help.

Respondents were asked about their own, as well as their medical provider and case manager's comfort with discussing alcohol and drug use. Excluding those who said they did not have a medical provider or a case manager, the vast majority of respondents said they were comfortable talking about alcohol and drug use with their medical provider and case manager, and conversely, that their medical provider or case manager was comfortable talking about it with them (see Table 41).

TABLE 41: COMFORT DISCUSSING ALCOHOL OR DRUG USE WITH MEDICAL PROVIDER AND CASE MANAGER

	OVERALL		MA		EMA	
	Agree	n	Agree	n	Agree	n
My medical provider seems comfortable discussing alcohol or drug use with me	92%	976	92%	909	92%	721
I am comfortable discussing alcohol or drug use with my medical provider	91%	967	91%	900	90%	717
My case manager seems comfortable discussing alcohol or drug use with me	90%	819	89%	754	90%	588
I am comfortable discussing alcohol or drug use with my case manager	88%	806	88%	741	89%	579

"n" and % exclude respondents who said they did not have a medical provider or case manager.

SUBSTANCE USE AS BARRIER TO ACCESSING SERVICES

Beyond the impacts to a person's health, drug and alcohol use can affect PLWH self-sufficiency and access to or engagement in medical care and support services. The findings below illustrate some of these additional effects of alcohol or drug use:

- In the six months prior to the survey, 3% (MA) to 4% (EMA) of respondents said they had problems getting housing and 2% (MA) to 3% (EMA) said they had trouble keeping housing because of their history of drug or alcohol use.
- 3% (EMA) to 4% (MA) of respondents said that "help dealing with drug or alcohol issues/addiction" would have helped them get HIV medical care sooner (after learning they were HIV positive).
- 9% (MA) to 10% (EMA) of respondents said "help dealing with drug or alcohol issues/addiction" would have helped them get HIV services other than medical care sooner (after learning they were HIV positive).
- 6% (MA and EMA) of respondents said they were not employed at the time of the survey because of their own issues with drugs or alcohol.

MENTAL HEALTH CONDITIONS

About one-half (47% MA and EMA) of respondents said they had been diagnosed with a mental health condition in the three months prior to the survey. While this proportion is consistent with prior studies of PLWH in Massachusetts and southern New Hampshire,[8] it is higher than among the general population.[9] Among this group, the most common mental health diagnoses were **depression** (83% MA, 84% EMA), **anxiety disorder** (61% MA, 62% EMA), **bipolar disorder** (21% MA, 25% EMA), **post-traumatic stress disorder** (24% MA, 25% EMA), **panic disorder** (24% MA, 25% EMA), and **ADHD** (10% MA, 11% EMA). The proportion reporting a mental health diagnosis was significantly higher among those who were born in the US, reported a change in their living situation in the prior six months, were unemployed, were White, and were living in poverty (MA only).

Respondents were also asked a series of "yes/no" questions about symptoms they experienced in the 30 days prior to the survey that could suggest potential mental health-related issues. These questions were adapted from the mental health portion of the MDPH and BPHC *HIV Case Management Assessment Form* and are based on widely-used screening tools for depression, post-traumatic stress disorder, and other mental health conditions. The purpose of these survey questions was not to screen definitively for mental health conditions among respondents, but rather to highlight potential mental health issues (e.g., depression) among respondents whether or not they reported that they had received a mental health diagnosis.

TABLE 42: RESPONDENTS WHO EXPERIENCED POTENTIAL MENTAL HEALTH-RELATED SYMPTOMS IN PRIOR MONTH

IN THE PAST 30 DAYS, HAVE YOU . . .	OVERALL "YES"	N	MA "YES"	N	EMA "YES"	N
Felt anxious, depressed, or confused?	70%	1,002	69%	934	69%	745
Felt sad or hopeless?	58%	997	57%	928	57%	738
Worried so much that it has kept you from doing activities you would have liked to do?	46%	997	46%	930	46%	737
Found it difficult to enjoy yourself when engaging in activities you have enjoyed in the past?	53%	999	52%	931	53%	743
Had any significant difficulties sleeping?	60%	1,002	59%	933	60%	744
Found yourself reliving bad experiences from the past (flashbacks, feeling as if you're re-experiencing the event)?	40%	999	40%	930	40%	739

Presented in the order posed on survey.

8. Suffolk University. 2004. *Voices of Experience*.

9. According to the National Institute of Mental Health, over 26% of adults in the US are diagnosable with one or more mental health disorders in a year (http://www.nimh.nih.gov/statistics/1ANYDIS_ADULT.shtml).

As illustrated in Table 42, between 40% and 70% of respondents indicated that had experienced each of the symptoms. When looking at all six symptoms, 79% of both MA and EMA respondents reported that they experienced at least one of them. The proportion who reported at least one of the symptoms was significantly higher among those who reported that they had an AIDS diagnosis, experienced a change in their living situation in the prior six months, were unemployed, and were White (non-Hispanic).

MENTAL HEALTH IMPACTS ON HIV TREATMENT

Data from the survey suggest that mental health issues may affect the ability of PLWH to adhere to the day-to-day requirements of their HIV medication regimen (e.g., missing a dose periodically) as well as their ability to maintain that regimen over time (e.g., deciding to stop taking medications). As noted above in the section on HIV Medications, 14% of respondents who were taking HIV medications said they had stopped for more than a week in the six months prior to the survey. The largest proportion (39%) said they stopped because they felt depressed or overwhelmed. Among those taking HIV medications, a significantly higher proportion of those with a mental health diagnosis (in the three months prior to the survey) than those without a diagnosis said they had stopped taking their meds for more than a week in the prior six months (17% vs. 11% MA, 17% vs. 10% EMA) and had missed a dose in the prior two weeks (39% vs. 32% MA, 43% vs. 33% EMA). Similarly, a significantly higher proportion of those who reported a recent mental health-related issue (e.g., responded "yes" to one of the questions in Table 42) said they missed a dose in the past two weeks (39% vs. 24% MA, 42% vs. 22% EMA).

MENTAL HEALTH SERVICES

As highlighted in the services needs and barriers section, 52% of the short form respondents said they needed and used professional counseling or treatment for a diagnosed mental health issue in the six months prior to the survey. Among those who also completed a long form survey, 47% (MA) to 48% (EMA) said they had gotten professional mental health treatment or counseling in the three months prior to the survey. Both proportions roughly correspond to the 47% of respondents who reported a mental health diagnosis during the same period. Access to mental health services among respondents may be the result of the high proportion of respondents who were in care and linked to services.

Of those who reported a mental health diagnosis in the three months prior to the survey, 77% (MA) to 78% (EMA) said they had received professional mental health treatment or counseling during the same period. Of those who reported at least one mental health-related symptom (see Table 42) in the prior 30 days, 55% said they had received professional mental health treatment or counseling in the prior three months.

To explore more about the need, use, and access to mental health services among those who could possibly benefit from them, data were analyzed across the short and long form surveys. Specifically, the long form responses of (1) individuals who either reported a diagnosed mental health condition within three months prior to the survey and (2) those who reported experiencing mental health symptoms in the three months prior to the survey were linked to their responses on the short from about the role of, need for/use of (in prior six months), and barriers to "professional counseling or treatment for a diagnosed mental health issue."

Role of Service. Among respondents with a **diagnosed mental health condition**, 79% (EMA) to 80% (MA) said that mental health services were essential to their overall health. These proportions were significantly higher than those who did not report a mental health diagnosis (57% MA and EMA). Similarly, 71% (EMA) to 72% (MA)

of those who **reported mental health symptoms** said that mental health services were essential. These proportions were also significantly higher than among those who did not report such symptoms (49% EMA, 51% MA).

Need for/Use of Service. Among respondents with a **diagnosed mental health condition**, 76% (MA and EMA) said they needed and used mental health services in the six months prior to the survey. This was significantly higher than among those without a diagnosis (76% vs. 57% EMA, 76% vs. 58% MA). Among those who **reported mental health symptoms**, 59% (MA) to 60% (EMA) said they needed and used mental health services. These proportions were also significantly higher than among those who did not report such symptoms (31% MA and EMA). About 6% of respondents (MA and EMA) with a mental health diagnosis and 8% of those with mental health symptoms said they needed but couldn't get mental health services in the six months prior to the survey. These proportions were not significantly different than those without a diagnosis or report of symptoms.

Among all respondents, 67% (MA) to 68% (EMA) said that someone had talked with them about mental health issues in the prior six months. As shown in Table 43, the highest proportion (46%) said their medical provider, followed by mental health counselor (39%) and "no one" (32%). Of those who reported a mental health diagnosis in the prior three months, 88% said that someone had talked to them about mental health issues in the prior six months. Of those who reported at least one mental health-related symptom (see Table 42) in the prior 30 days, 75% said someone had talked to them about mental health issues in the prior six months.

In addition to their medical and support services providers, respondents were asked about other individuals upon whom they depend for support. The largest proportions indicated friends (49%) and other family members (45%); 20% indicated that they relied on no one else, suggesting either a level of self-sufficiency or a degree of isolation among these respondents (see Table 44).

TABLE 43: DISCUSSIONS ABOUT MENTAL HEALTH TOPICS IN PRIOR SIX MONTHS (AMONG ALL RESPONDENTS)

INDIVIDUALS WHO TALKED WITH RESPONDENTS*	OVERALL (N=993)	MA (N=924)	EMA (N=737)
Medical provider	46%	46%	47%
Mental health counselor	39%	38%	38%
No one	32%	33%	32%
Case manager	30%	29%	29%
Family/friends	17%	17%	18%
Other HIV services provider	12%	12%	13%
Support group member	9%	9%	10%

*Respondents could select more than one option; includes options with >10% of respondents

TABLE 44: OTHER SOURCES OF SUPPORT FOR PLWH

SOURCES OF SUPPORT	OVERALL (N=1,002)	MA (N=933)	EMA (N=742)
Friends	49%	49%	49%
Other family	45%	46%	45%
Husband/wife/partner/significant other	35%	35%	36%
Another HIV-positive person	26%	26%	26%
Support group members	23%	24%	23%
No one*	17%	16%	17%
Religious/spiritual leaders	15%	15%	16%

Respondents could select more than one option; includes only those options with >10% of respondents
* Includes only respondents who selected "no one" and no other option.

Further analysis was conducted on those respondents who said they relied on "no one" to assess potential isolation and/or poor health status. Overall, this group appeared to be doing well in terms of their HIV status (e.g., 86% had a CD4 count above 200, 89% were taking ARVs, 68% reported good to excellent health), but also were dealing with other issues (e.g., 80% reported experiencing mental health symptoms in the prior 30 days, and 87% reported a chronic disease other than HIV). The majority of this group was male (70%) and living above poverty (63%), and nearly half were MSM (47%) and over age 50 (47%).

The long form survey included several questions to assess the overall health status of respondents, including clinical markers of HIV disease (e.g., results of most recent viral load and CD4 tests, and/or AIDS diagnosis), other disabilities or conditions they had at the time of the survey, and a self-assessment of their own health status.

HIV VIRAL LOAD AND CD4 TEST RESULTS

Together, HIV viral load and CD4 cell test (also known as a CD4 count) results provide important information to help monitor the status of a person's HIV disease and guide treatment options.

The *HIV viral load test* is a measurement of HIV nucleic acid in the blood of a person living with HIV. A low viral load (e.g., less than 400 copies/mL) indicates that HIV is reproducing at a very low rate and the risk of disease progression is correspondingly low. Higher viral load indicates a moderate to high rate of viral reproduction, and can indicate very recent or acute HIV infection, untreated HIV disease, and/or failure of an existing treatment regimen. Sustained viral suppression is essential to decrease the complications of HIV disease, slow the progression from HIV infection to AIDS, and prolong life.

A *CD4 or T-cell test* is a measure of the CD4 lymphocyte or "T-helper" cells present in the blood of a person living with HIV, and provides information about the health of a person's immune response. A low CD4 count suggests impaired immune response, and indicates potential risk for opportunistic infections. Based on US HIV treatment guidelines, when a person's CD4 cell count falls to 350/mm^3 or less, antiretroviral drug therapy should be initiated.[10] Between 350 and 500/mm^3, antiretroviral drug therapy is recommended. When a person's CD4 cell count falls to 200/ mm^3, he/she has a diagnosis of AIDS.

According to the US treatment guidelines, CD4 counts should be monitored every three to four months to (1) determine when to start antiretroviral therapy in patients not being treated; (2) assess immunologic response to antiretroviral therapy; and (3) assess the need for prophylaxis for opportunistic infection. For patients who are adherent to therapy with sustained viral suppression and stable clinical status for more than two to three years, the frequency of CD4 count monitoring may be extended to every six months.[11]

TABLE 45: SELF-REPORTED RESULTS OF MOST RECENT VIRAL LOAD TEST

VIRAL LOAD (COPIES/ML)	OVERALL (N=1,006)	MA (N=936)	EMA (N=748)
Undetectable or less than 400	72%	72%	72%
400 to 4,999	8%	8%	8%
5,000 to 10,000	3%	3%	3%
10,0001 to 100,000	4%	4%	4%
>100,000	1%	1%	1%
Can't remember results	11%	11%	10%

10. DHHS. 2009. *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents.*

11. Ibid.

TABLE 46: SELF-REPORTED RESULTS OF MOST RECENT CD4 (T-CELL) TEST

CD4 COUNT (CELLS/MM³)	OVERALL (N=1,008)	MA (N=938)	EMA (N=749)
>350	57%	58%	58%
200 to 350	20%	20%	21%
<200	12%	11%	11%
Can't remember results	10%	10%	10%

As illustrated in Tables 45 and 46, respondents' self-report of their HIV viral load and CD4 test results suggests that for the majority of respondents, their HIV disease is under control. Nearly three-quarters reported a viral load that is undetectable or under 400 copies, and more than half reported CD4 counts above 350.

Further analysis was conducted on those who said that they could not remember their most recent viral load and CD4 tests. Those who could not remember their results were significantly *more likely* to have been people of color, diagnosed more recently (≤5 years prior), female, living at or below poverty level, and to have had less than a high school education. They were also significantly *less likely* to have (1) been on ARVs, (2) reported a chronic disease other than HIV, (3) told someone other than their medical provider about their HIV status, and (4) reported excellent/very good health status.

AIDS DIAGNOSIS

The long form survey included two questions to determine if respondents' HIV disease had progressed to AIDS. First, respondents were asked if they had ever had a T-cell (CD4) count under 200, and if they had ever had an opportunistic infection (OI).[12] A positive response to either of the questions would indicate an AIDS diagnosis. Several questions later in the survey, respondents were also asked if their medical provider had ever told them that they had AIDS. Table 47 highlights the responses to these questions. The proportion who reported an OI (36%) was lower than the proportion who reported a T-cell count below 200 (53%). In addition, 60% had either one or more AIDS-defining conditions. There was, however, discrepancy between the proportion who had an AIDS diagnosis based on these clinical markers and the proportion who said that a medical provider had told them they had AIDS. This issue is discussed later in this report in the *HIV Knowledge and Literacy section*.

TABLE 47: AIDS DIAGNOSIS AMONG RESPONDENTS

	OVERALL (N=1,004)	MA (N=935)	EMA (N=744)
Ever had a T-cell count below 200	53%	53%	53%
Ever had an opportunistic infection	36%	36%	37%
(Yes to either of the above two options)	60%	61%	61%
Ever been told by a medical provider that you have AIDS	42%	43%	44%

12. The survey tool included a definition and list of common OIs.

RESPONDENTS' PERCEPTIONS OF HEALTH STATUS

The majority of respondents (70%) reported that their health status was good, very good, or excellent at the time of the survey. Figure 6 illustrates the responses for the overall sample. Proportions were nearly identical for MA and EMA respondents.

FIGURE 6: GENERAL HEALTH STATUS OF RESPONDENTS (SELF-REPORTED; N=1,010)

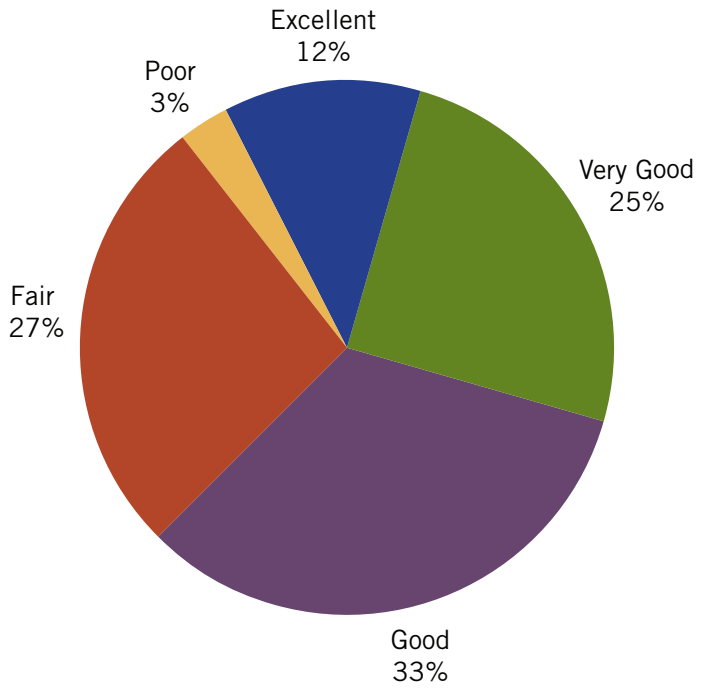
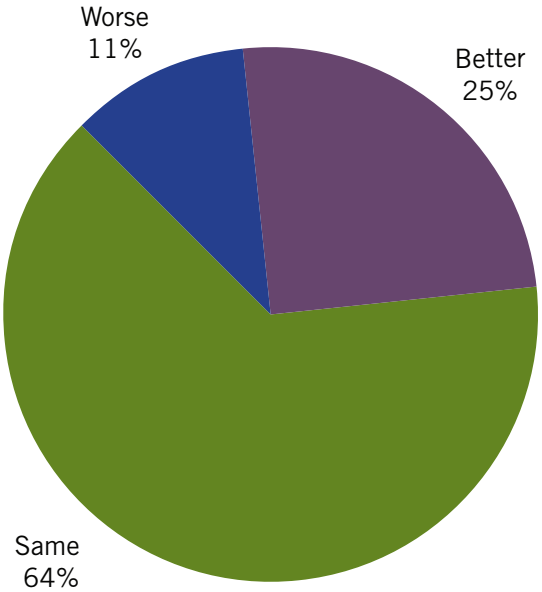


FIGURE 7: CHANGE IN GENERAL HEALTH STATUS IN PRIOR SIX MONTHS (SELF-REPORTED; N=1,001)



Respondents were also asked to assess their general health at the time of the survey compared to six months prior. As shown in Figure 7, the vast majority indicated that their health was either the same or better than six months prior to the survey. Proportions were nearly identical for MA and EMA respondents.

OTHER CONDITIONS AND DISABILITIES

Respondents were asked whether they had, at the time of the survey, any other health conditions in addition to HIV. A list of 18 conditions was provided, and respondents could select all that applied, or write in others. Health conditions reported by 10% or more of respondents are provided in Table 48. Hepatitis C and high cholesterol were the top conditions, representing nearly 30% of respondents. Thirteen percent of respondents said they had none of the listed conditions. Eighty-eight percent of respondents (MA and EMA) had at least one condition other than HIV; 68% had at least two conditions; and 44% had three or more.

Caution should be taken in the interpretation of data related to other health conditions. The proportion of respondents who indicated that they had a current STI or Hepatitis B appears to be relatively high based on recent HIV clinical chart review data. This may suggest that some survey respondents reported conditions that they had *ever* had, rather than those they had at the time of the survey.

TABLE 48: MOST COMMON OTHER HEALTH CONDITIONS REPORTED BY RESPONDENTS AT TIME OF SURVEY

IN ADDITION TO HIV, DO YOU CURRENTLY HAVE ANY OF THE FOLLOWING CONDITIONS?	OVERALL (N=1,003)	MA (N=934)	EMA (N=745)
Hepatitis C	28%	29%	29%
High cholesterol	28%	28%	28%
Memory problems	24%	24%	25%
Neuropathy	23%	23%	23%
Asthma	22%	23%	22%
Arthritis	22%	22%	23%
Sexually transmitted infection	12%	12%	12%
Liver disease	11%	11%	11%
Hepatitis B	11%	10%	11%
Diabetes	10%	10%	10%

Respondents could select more than one option; table includes only those options with ≥10% of respondents

The proportion who reported a health condition was significantly higher among MA and EMA respondents who:

- were diagnosed with an alcohol or drug problem compared to those who were not
- were diagnosed with a mental health condition in the prior three months compared to those who were not

- reported a mental health-related symptom in the prior 30 days compared to those who did not
- reported being in fair or poor health, compared to those who reported good, very good, or excellent
- were over 50 years of age compared to those under 50
- were born in the US compared to those born outside the US
- had been living with HIV for more than five years compared to those for five years or less
- had an AIDS diagnosis (either told by a medical provider or reported a CD4 below 200 or an OI) compared to those who did not
- were White, non-Hispanic compared to other racial/ethnic groups
- were unemployed at the time of the survey compared to those who were employed.

Respondents were also asked to select any disabilities that they had from a list, including blindness, deafness, and other physical and neurological conditions. The list did not include disabilities related to HIV/AIDS. As shown in Table 49, the most common response was neurological/psychiatric disabilities, representing nearly one-quarter of respondents. Other disabilities were reported by much lower proportions of respondents. Just under two-thirds of respondents (60%) reported that they had none of the listed disabilities.

TABLE 49: DISABILITIES REPORTED BY RESPONDENTS

DISABILITIES	OVERALL (N=1,003)	MA (N=934)	EMA (N=745)
Neurological/psychiatric disability	23%	22%	24%
Deafness or loss of hearing	7%	7%	7%
Pulmonary condition that affects mobility	7%	7%	7%
Blindness or visual impairment (not correctable with glasses)	6%	6%	6%
Physical disability that requires use of walker, crutches, brace	7%	6%	6%
Cardiac condition that affects mobility	4%	4%	3%
Physical disability that requires use of wheelchair	2%	2%	2%
None of the above	60%	61%	59%

The proportion reporting a disability was significantly higher among respondents who:

- had a CD4 <350 at the time of the survey compared to those over 350 (overall and EMA only)
- had been diagnosed with an alcohol or drug problem compared to those who were not
- had a potential alcohol or drug problem based on CAGE questions compared to those who did not (overall and MA only)

- had been diagnosed with a mental health condition in the prior three months compared to those who were not
- reported a mental health-related symptom in the prior 30 days compared to those who did not
- reported being in fair or poor health compared to those who reported good, very good, or excellent health
- were living in poverty compared to those who were not
- were born in the US compared to those who were born outside the US
- had an AIDS diagnosis (either told by a medical provider or reported a CD4 below 200 or an OI) compared to those who did not
- were White, non-Hispanic or Hispanic compared to other racial/ethnic groups (EMA only)
- were unemployed at the time of the survey compared to those who were working
- less than a high school education compared to those with more than a high school education (overall and MA only)
- were male rather than female (EMA only)

HIV AND AGING

There was strong interest among community stakeholders in using this survey to understand more about the impacts of HIV as PLWH live longer and grow older. MDPH, BPHC, and the JSI research team shared this interest. For this reason, age-related response options were included for a number of relevant questions on the Phase II survey.

For the analyses conducted for this report, age was a consistent independent variable and significant variations between older or younger PLWH have been identified throughout. It is important to remember that nearly one-half (46%) of all respondents were age 50 or older. As such, the needs, challenges, and issues affecting this population have been reflected throughout this report.

One survey question focused specifically on the challenges of growing older living with HIV/AIDS. Respondents were asked to select from a list those issues that they think or worry about as they grow older living with HIV/AIDS. All response options are provided in Table 50 for all respondents. The most common responses, shared by over one-half to two-thirds of respondents, are related to HIV, health, and quality of life. The least common responses, shared by less than 25% of respondents, are related to disclosure, retirement, education, and having a family. For about one-half of the options, the proportion of EMA respondents slightly exceeded the proportions in the overall sample.

Given the interest in understanding the needs and experiences of older PLWH, further analyses of data from this survey will be conducted and the results published after this report. Based on the analysis conducted for this report, the following findings are relevant to this age group:

- As noted previously, 84% of respondents indicated that their medical provider "always" seems to understand "the needs of people my age." This proportion did not vary significantly by age.
- Those over 50 were significantly more likely than younger groups to report that they needed and used HIV drugs, adherence, and legal support services.
- Where differences were identified, those over 50 were significantly less likely than younger groups to report an unmet need or service gap for HIV care and support services.
- Those over 50 were significantly less likely to report a need for help with disclosure or to report experiencing stigma related to disclosure concerns.
- Those over 50 were significantly less likely to report problems with adherence to HIV drug treatments.
- Those over 50 were significantly more likely to report that they were living with chronic conditions other than HIV.
- Those over 50 were significantly more likely to report higher educational attainment.

TABLE 50: WORRIES RELATED TO GROWING OLDER LIVING WITH HIV/AIDS

	OVERALL (N=1,010)	MA (N=939)	EMA (N=750)
Staying healthy	70%	70%	71%
Long term impacts of HIV medications	64%	63%	65%
Impact of HIV on my quality of life	59%	58%	60%
Managing HIV and other conditions that come with aging	56%	55%	57%
Finding or having someone to share my life with	54%	54%	53%
Being a burden on friends, family, or people who take care of me	51%	50%	51%
Planning for the end of my life (making a will, long term care, etc.)	41%	41%	41%
Dating	41%	41%	40%
Maintaining access to or getting the HIV services I need	39%	37%	39%
Finding or having a place to live	35%	35%	36%
Going to work or having a job	29%	29%	31%
Maintaining healthy behaviors or practices (such as safe sex) over time	27%	27%	27%
Taking care of my husband, wife, partner, S.O., or other family member	27%	26%	27%
Finding retirement or nursing home providers who understand HIV	26%	26%	27%
Finding medical providers who understand HIV and aging	23%	23%	24%
Telling people about my HIV status	22%	23%	23%
Getting more education	14%	14%	14%
Retiring	13%	13%	13%
Having a family	13%	12%	13%

All responses options included in table
Respondents could select more than one option

Respondents were asked to assess their medical provider and case manager's comfort in discussing alcohol or drugs and sex with them, as well as their own comfort having such conversations with each of these providers. The results are presented in Table 51. (Note that the alcohol/drug use discussion data were presented in Table 41 in the substance abuse section above and are included again here for comparison and relevance to positive prevention.)

TABLE 51: COMFORT HAVING DISCUSSIONS WITH MEDICAL PROVIDERS AND CASE MANAGERS ABOUT ALCOHOL/DRUG USE AND SEXUAL HEALTH

	OVERALL		MA		EMA	
	Agree	n	Agree	n	Agree	n
Medical Provider						
My medical provider seems comfortable discussing **sex** with me, including ways to keep my partner(s) and me healthy.	90%	992	90%	924	91%	736
I am comfortable discussing **sex** with my medical provider, including ways to keep me and my partner(s) healthy.	87%	984	87%	915	88%	734
My medical provider seems comfortable discussing **alcohol or drug use** with me	92%	976	92%	909	92%	721
I am comfortable discussing alcohol or drug use with my medical provider	91%	967	91%	900	90%	717
Case Manager						
My case manager seems comfortable discussing **sex** with me, including ways to keep my partner(s) and me healthy.	86%	830	86%	763	87%	600
I am comfortable discussing **sex** with my case manager, including ways to keep me and my partner(s) healthy.	84%	828	83%	762	84%	595
My case manager seems comfortable discussing **alcohol or drug use** with me	90%	819	89%	754	90%	588
I am comfortable discussing **alcohol or drug use** with my case manager	88%	806	88%	741	89%	579

"n" and % exclude respondents who said they did not have a medical provider or case manager.

The results indicate that a relatively high proportion of respondents are comfortable having these discussions with both their medical provider and case manager, and that both types of providers are perceived to be comfortable with those discussions too. Across both sets of questions, slightly more respondents were comfortable having both types of discussion with their medical providers than they were with their case managers. Similarly, overall, slightly more respondents indicated comfort with discussions about drugs or alcohol than discussions about sex, regardless of provider type.

In addition to assessing "comfort" with such discussions, the survey also sought to understand whether anyone was talking with respondents about these issues. The survey asked respondents to select from a list any individuals who had spoken with them in the prior six months about drug/alcohol use and about their sexual health, including reducing their own or their partners' risk of sexually transmitted infections and viral hepatitis. The results for alcohol/drug use were provided in Table 41 and discussed in the substance abuse section above. For sexual health, as shown in Table 52, over one-half of respondents said that a medical provider had spoken with them about such topics, followed by over one-quarter who said a case manager. In spite of the large proportion who reported that they think their providers are comfortable discussing sex with them, over one-third of respondents said that no one had talked with them about their sexual health in the six months prior to the survey (see Table 52).

TABLE 52: DISCUSSIONS ABOUT SEXUAL HEALTH IN PRIOR SIX MONTHS

INDIVIDUALS WHO TALKED WITH RESPONDENTS	OVERALL (N=990)	MA (N=924)	EMA (N=732
Medical provider	54%	54%	54%
No one	37%	38%	38%
Case manager	28%	27%	26%
Other HIV services provider or outreach/community health worker	16%	16%	17%
Mental health counselor (therapist or psychiatrist)	14%	14%	14%
Family/friends	12%	12%	11%
Support group members	10%	11%	10%
Other PLWH I know	10%	10%	11%

Respondents could select more than one option; includes only those options with >10%

POSITIVE PREVENTION SERVICES

To help assess the need for prevention services among PLWH, the survey included a few questions about the need for and access to such services. Specifically, respondents were asked if they had needed help with three general positive-prevention related issues in the prior six months (sex, drugs, and disclosure). Those who said they needed help were asked whether they were able to get it. Relatively low proportions (8% to 23%) of respondents indicated that they needed help with these topics, and of those who said they did, more than half (50% to 69%) said they had gotten it (see Table 53).

There were significant variations in reported need for positive prevention services among some groups described below for each type of service.

A significantly higher proportion of the following groups said they needed help figuring out ways to be sexually active and stay healthy:

- Those with a recent **mental health diagnosis** or recent **mental health symptoms** compared to those without;
- Those **born outside the US** compared to those born in the US;
- Those who were **Hispanic** compared to other racial/ethnic groups;
- Those who were **male** rather than female (MA respondents only).

TABLE 53: POSITIVE PREVENTION SERVICES

POSITIVE PREVENTION SERVICES (PRIOR SIX MONTHS)	% "YES" OVERALL	% "YES" MA	% "YES" EMA
Have you needed help figuring out ways to be sexually active and stay healthy?	(n=948)	(n=886)	(n=707)
	23%	**23%**	**22%**
If yes, have you gotten this help in the past 6 months?	(n=212)	(n=196)	(n=150)
	55%	54%	53%
Have you needed help figuring out ways to stay healthy if using drugs and how to use drugs more safely?	(n=949)	(n=887)	(n=707)
	8%	**8%**	**8%**
If yes, have you gotten this help in the past 6 months?	(n=72)	(n=64)	(n=49)
	68%	69%	65%
Have you needed help figuring out if, when, and how to tell people about your HIV status?	(n=955)	(n=893)	(n=710)
	19%	**19%**	**18%**
If yes, have you gotten this help in the past 6 months?	(n=160)	(n=147)	(n=111)
	51%	50%	51%

A significantly higher proportion of the following groups said they needed help figuring out ways to stay healthy if using drugs and how to use drugs more safely:

- Those with a recent **mental health diagnosis** or recent **mental health symptoms** (than those without);
- Those with a potential substance abuse issue identified by the CAGE assessment (than those without); and
- Those who had been **living with HIV for five years or less**, compared to those for more than five years (EMA only).

A significantly higher proportion of the following groups said they needed help figuring out if, when, and how to tell people about their HIV status:

- Those with a recent **mental health diagnosis** or recent **mental health symptoms** compared to those without;
- Those with a **potential substance abuse** issue identified by the CAGE assessment compared to those without;
- Those who were **under age 50** compared to those above 50 (MA only);

- Those who were **disabled** compared to those who were not; and
- Those who had been **living with HIV for five years or less**, compared to those for more than five years (MA only).

There were few significant variations in those who said they needed the service and also said they got the service. Specifically,

- Among MA respondents who said they needed help figuring out ways to be sexually active and stay healthy, a significantly higher proportion of people of color than whites reported that they got the service.
- Among EMA respondents who said they needed help figuring out ways to stay healthy if using drugs and how to use drugs more safely, a significantly higher proportion of those without a potential substance abuse issue compared to those with a potential issue (CAGE assessment) said they got the service. Also, a significantly higher proportion of women than men said they got this service.

EMPLOYMENT, EDUCATION, AND VOLUNTEERISM

As part of this survey, community stakeholders and members of the Advisory Group wanted to explore and understand dimensions of self-sufficiency and potential barriers to PLWH becoming more independent. This interest was driven, in part, by improvements in some PLWH's health status, quality of life, and potential life expectancy after diagnosis, as well as the trend toward responding to HIV/AIDS as a chronic disease. As such, a number of questions were included in the survey to explore specific dimensions of self-sufficiency, including having a job, pursuing educational opportunities, and/or participating in volunteer activities. While it was not assumed that all PLWH should or can be working, going to school, or volunteering, these questions were an attempt to learn more about who is and is not participating in these activities and any potential barriers that prevent those who want to participate from doing so.

It should be noted that during the data collection period, the unemployment rate in Massachusetts was near historic highs, ranging from 8.5% (June 2009) to 9.0% (September 2009)[13] during the worst recession in the US since the Great Depression. This job environment undoubtedly affected responses to questions related to employment, education, and volunteerism.

EMPLOYMENT

Twenty-six percent of MA and EMA respondents reported that they were working at the time of the survey. Of the 74% who said they were not working, the largest proportion said they were unemployed because of a disability (either related to HIV or another condition), followed closely by lack of energy, and a fear of earning too much and losing government benefits (e.g., social security, Section 8, food stamps). The most common responses are provided in Table 54.

TABLE 54: BARRIERS TO EMPLOYMENT

REASONS	OVERALL (N=697)	MA (N=654)	EMA (N=522)
Disabled as a result of HIV/AIDS	38%	38%	36%
Disabled as the result of some other condition (besides HIV/AIDS)	37%	37%	38%
Do not have the energy	37%	37%	35%
Afraid of earning too much and losing government benefits	33%	33%	33%
Worried about getting sick on the job	24%	25%	23%
Worried about medication side effects in the workplace	20%	20%	20%
Unable to find a job	17%	17%	18%
Afraid of losing access to HIV services	15%	15%	16%
Do not have enough training or skills	14%	15%	14%
Worried people will find out I have HIV	13%	13%	13%

Respondents could select more than one option; includes only those options with >10% of respondents

13. Bureau of Labor Statistics, US Department of Labor. *Local Area Unemployment Statistics.* http://data.bls.gov

The survey asked those who were employed at the time of the survey about any challenges experienced as a PLWH who worked. About one-quarter (23%) of respondents reported that they experienced no challenges. For those who did report challenges, the most common responses are provided in Table 55.

TABLE 55: CHALLENGES EXPERIENCED BY EMPLOYED PLWH

CHALLENGES	OVERALL (N=264)	MA (N=241)	EMA (N=192)
Energy level sometimes makes it hard to get through the day	57%	57%	58%
Do not feel I can be open about my HIV status in the workplace	38%	37%	41%
Worry about getting sick on the job	37%	36%	38%
Worry about medication side effects on the job	31%	30%	32%
None (experience no challenges)	23%	23%	23%
Difficult during workday to go for HIV medical/service appointments	18%	17%	19%

Respondents could select more than one option; table includes only those options with >10% of respondents

EDUCATION

As noted previously, 76% of survey respondents said they had at least a high school diploma (or equivalency), 43% had at least some college education or more, and 21% (EMA) to 22% (MA) had a college or graduate degree. Based on the US Census, 88% of the Massachusetts population and 91% of the New Hampshire over age 25 had graduated high school, and 38% and 32% respectively had a bachelor's degree or higher. Higher educational attainment was significantly associated with having better health indicators (CD4 and viral loads), being on antiretroviral treatment, not having a substance use or mental health diagnosis/potential issue, self-reporting excellent or good health, not having a disability, living above poverty level, being an MSM, being older than 50 years of age, having a stable housing situation (no recent changes and living in own home or apartment), having a job, being White or non-Hispanic, and being male.

As with employment (discussed above), improvements in HIV treatments, quality of life, and potential life expectancy, some PLWH may be interested in educational opportunities, either completing a high school degree, or pursuing college or vocational training. The survey asked several questions to assess respondents' interests in further education. Of all respondents, 94% of MA and EMA respondents said they were not in an educational program (school, college, or vocational training) at the time of the survey. Of this group, 31% (EMA) to 32% (MA) said they were interested in enrolling in an educational program. Among this group, the most common reasons for not going to school, college, or vocational training are provided in Table 56.

Of the top five most common barriers to pursuing additional education, only one (not having enough energy) was related to the person's HIV status and was reported by about one-third of respondents. The remaining top four barriers (cost, workload, not getting around to doing it, and not knowing where to go) are not necessarily specific to PLWH and may be experienced by anyone considering higher education. Other barriers more directly related to HIV status (medication side effects, fear of losing disability status, getting sick at school, or worry about disclosure of HIV status) were reported by smaller proportions of respondents.

TABLE 56: REASONS FOR NOT ENROLLING IN AN EDUCATIONAL PROGRAM (AMONG THOSE WHO EXPRESSED AN INTEREST)

REASON	OVERALL (N=300)	MA (N=278)	EMA (N=216)
Costs too much or worried about getting/repaying loans	54%	53%	55%
Don't think I have the energy	32%	32%	30%
Don't know if I can handle the workload	28%	28%	26%
Nothing, just have not done it	23%	22%	24%
Don't know where to go or how to apply	24%	25%	23%
Worried about medication side effects	18%	19%	18%
Heard I could lose my disability status	18%	17%	18%
Worried about getting sick at school	17%	17%	17%
Worried about people knowing I have HIV	11%	11%	11%

Respondents could select more than one option; table includes only those options with >10% of respondents

VOLUNTEERISM

About one-third of respondents (34%) reported that they had done some volunteer work in the six months prior to the survey. Of this group of volunteers, about one-third was also currently employed.

The survey also asked respondents whether they had ever participated in several HIV-specific groups or planning bodies, either as a member or a guest. As illustrated in Table 57, the majority (58%) of respondents indicated that they had never participated in any of these groups.

TABLE 57: PARTICIPATION IN HIV-RELATED CONSUMER OR PLANNING GROUPS

GROUP	OVERALL (N=940)	MA (N=876)	EMA (N=698)
Consumer advisory board (CAB) of organization providing HIV services	24%	25%	23%
Massachusetts Statewide Consumer Advisory Board	16%	17%	14%
Boston HIV Health Services Planning Council	12%	11%	14%
Massachusetts Service Coordination Collaborative (SCC)	8%	8%	7%
Massachusetts Prevention Planning Group (MPPG)	3%	3%	2%
New Hampshire HIV Community Planning Group (NHCPG)	1%	<1%	2%
Participated in none of the above	58%	58%	59%
Participated in at least one of the above, but prefer not to say which	5%	6%	5%

HIV-RELATED STIGMA

The prevalence of HIV-related stigma was a common theme expressed by various stakeholders during the planning phase of this study, and was repeatedly identified as an issue that would be important to explore as part of the survey. For that reason, one section of the Phase II survey focused specifically on HIV-related stigma, while stigma-related response options to other questions were integrated throughout the survey where appropriate.

For the stigma-specific section of the survey, a series of questions was drawn from the work of Berger, Ferrans, and Lashley[14] who developed and pilot-tested a 40-question stigma scale. Berger et al. used factor analysis to identify the underlying relationships between variables. Eleven of the HIV stigma scale items with the highest factor correlations in the Berger et al. article—indicating that they best assessed the different stigma-related factors—were included in the Consumer Study. A 12th item (long-term relationships) was added based on interest among members of the Advisory Group.

Respondents were asked whether they agreed or disagreed with each of the 12 statements. Agreement with the statement would suggest that the respondent has experienced HIV-related stigma. Cluster analysis was performed to describe the underlying relationships between the 12 items that comprised the scale and the following factors were identified:

1. Negative self-image
2. Disclosure concerns
3. Negative perceptions of how others see PLWH
4. Experiences of discrimination/rejection

Table 58 lists the 12 stigma scale items included on the survey, grouped according to the four factors above. For each stigma scale item, the proportion of overall respondents who agreed with each statement is also provided. The proportions of MA and EMA respondents who agreed with each statement was very similar, but is not provided here for ease of presentation.

As illustrated in Table 58 and Figure 8, prevalence was highest for Factor 2 items (disclosure concerns) and Factor 4 (experiences with discrimination/rejection). Prevalence was lowest for Factor 1 (negative self image) and Factor 3 (negative perceptions of how others see PLWH) items. Experiences with stigma varied by age: Respondents less than 50 years of age were more likely to report stigma related to disclosure (Factor 2: items D, E and F) and negative self-image (Factor 1: items B and C) than respondents 50 years or older.

Overall, the results from the stigma scale questions suggest that local experiences with HIV-related stigma are more external, related to factors outside the individual and related to PLWH perceptions and interactions with other members of the broader community. Efforts to address stigma in Massachusetts and Boston EMA can be informed by these results and tailored to address the specific forms of stigma experienced locally.

Throughout the survey, stigma-related response options were included for a number of questions, where appropriate. For example, respondents were asked what was most difficult about using HIV services. Among a series of possible options, 13% of MA and EMA respondents selected *"I do not want people to see me getting HIV*

14. Berger, B. E., C.E. Ferrans, and F.R. Lashley. 2001. Measuring Stigma in People with HIV: Psychometric Assessment of the HIV Stigma Scale. *Research in Nursing & Health, 2001, 24, 518-529.*

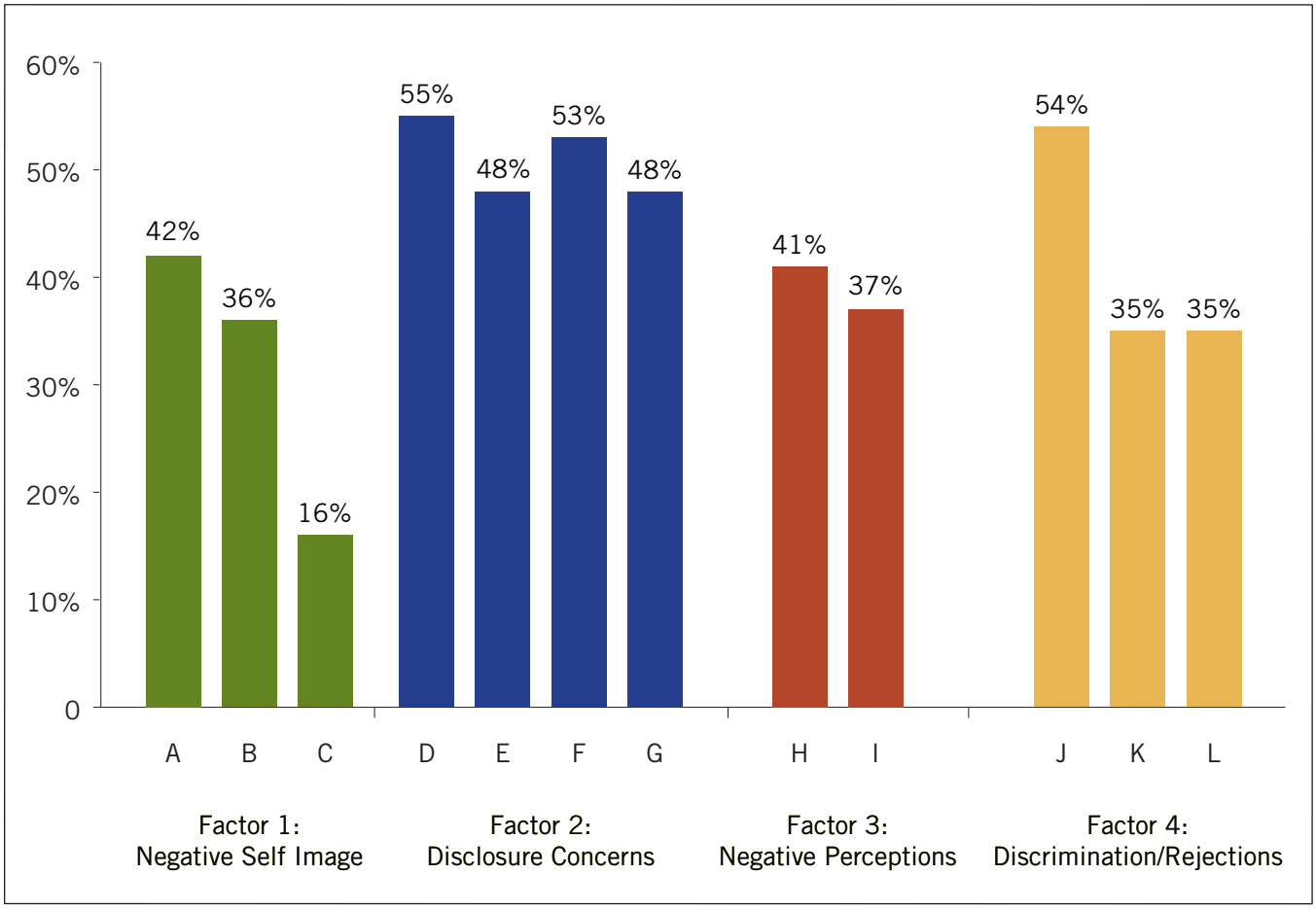
services." Similarly, among MA and EMA respondents who were not working, 13% said that they were not working because they were worried people would find out they had HIV.

Respondents were also asked whether they were in school, and if not, if they were interested in attending school, college, or a vocational training program. Of those who said they were not currently in school and responded to the follow-up questions (MA, n= 638; EMA, n=505), 42% (EMA) to 43% (MA) said they would like to go to school, college, or a vocational training program. When asked what was keeping them from attending, 11% of MA and EMA respondents said they were worried about people knowing they had HIV.

TABLE 58: AGREEMENT WITH STIGMA SCALE FACTORS (ALL RESPONDENTS)

FACTOR	STIGMA SCALE ITEM	% AGREED/ STRONGLY AGREED	N
(1) Negative self-image	A. I feel set apart or isolated from the rest of the world.	42%	996
	B. I feel guilty because I have HIV.	36%	1,000
	C. Having HIV makes me feel like a bad person.	16%	1,007
Respondents who agreed/strongly agreed with at least one Factor 1 Item		**54%**	**1,011**
(2) Disclosure concerns	D. I worry that people who know I have HIV will tell others.	55%	1,001
	E. I work hard to keep my HIV a secret from others.	48%	1,002
	F. Most people are uncomfortable around someone who has HIV.	53%	1,005
	G. It is hard for PLWH to have long-term relationships.	48%	1,005
Respondents who agreed/strongly agreed with at least one Factor 2 Item		**79%**	**1,012**
(3) Negative perceptions	H. Most people believe a PLWH deserves it for how he/she lived.	41%	1,006
	I. People's attitudes make me feel worse about myself.	37%	1,003
Respondents who agreed/strongly agreed with at least one Factor 3 Item		**55%**	**1,010**
(4) Experiences of discrimination or rejection	J. People with HIV can lose their jobs when employers find out.	54%	1,001
	K. I have stopped hanging out with some people because of their reaction to my having HIV.	35%	1,002
	L. I have lost friends or family by telling them I have HIV.	35%	1,006
Respondents who agreed/strongly agreed with at least one Factor 4 Item		**68%**	**1,014**

FIGURE 8: AGREEMENT WITH STIGMA SCALE FACTORS (ALL RESPONDENTS)



HIV STATUS DISCLOSURE

The long form survey included several questions focused on disclosure of HIV status, including who in respondents lives knew their HIV status, reasons for not disclosing to others (if they indicated they had not), as well as an open-ended question to assess what would help respondents share their status with more people.

Nearly all (96%) of respondents indicated that someone other than their HIV medical provider knew that they were living with HIV/AIDS. Table 59 lists the other individuals who were aware of respondents' HIV status. In reviewing the table, it is important to note that the survey neither assessed respondents' relationship/marital status nor whether they had any children. For this reason, care should be taken in interpreting the proportion who indicated that their husband/wife/significant other and/or children knew their status.

TABLE 59: INDIVIDUALS AWARE OF RESPONDENTS' HIV STATUS (OTHER THAN MEDICAL PROVIDER)

INDIVIDUALS	OVERALL (N=925)	MA (N=241)	EMA (N=192)
Other family members	79%	80%	80%
Friends	76%	77%	77%
Case manager	77%	76%	75%
Other medical provider	65%	64%	65%
Dentist	65%	65%	61%
Husband/wife/significant other	49%	48%	50%
Other providers	44%	44%	44%
My children	30%	28%	28%
Spiritual leaders	16%	15%	15%

Respondents could select more than one option; survey did not assess relationship status or number of children of respondents.

Among women respondents, nearly two-thirds (64%) said their OB/GYN knew their HIV status. Among those who were working at the time of the survey and answered this question (MA n= 240, EMA n=182), 37% (EMA) to 40% (MA) said their co-workers were aware of their HIV status, and 32% (EMA) to 34% (MA) said their manager, supervisor, or human resource person knew.

Among the small group who said they have not told anyone else about their HIV status and indicated why (n=34), 71% said it was because they were afraid people would judge them, 59% said they were afraid of how others would react, 41% said it was their own business and no one else needed to know, and 24% said they felt like they can handle it on their own.

DISCLOSURE FACILITATORS

The long form survey included an open-ended question that asked respondents *"What would help you share your HIV status with others?"* Over 80% of respondents answered this question. Responses were coded and

analyzed for themes and patterns. Table 60 highlights the results of the qualitative analysis of the responses to this question, focused on the most commonly-identified themes. It should be noted that these themes are based on a qualitative interpretation of the primary point of each response; they are used to facilitate the interpretation of these data and may be inter-related with other themes identified. The data presented and discussed below are for the overall group of respondents to this question and have not been stratified by MA or EMA. Each of the themes is described in more detail below.

TABLE 60: WHAT WOULD HELP PLWH SHARE THEIR HIV STATUS

THEMES	OVERALL (N=762)
Nothing (no problems or challenges with disclosure)	16%
Stigma reduction	14%
Education	11%
Support	11%

No Problems with Disclosure

As shown in Table 60, the largest group (16%, n=123) of respondents to the question about sharing their HIV status indicated that this was not a problem for them. Given the demographics of the survey sample, including the high proportion of people who have been living with HIV for 10 years or more, this result is not unexpected. It may also be assumed that a large proportion of the 20% who chose not to answer this question fell within this category too, and have few problems with disclosure. These responses are characterized by the following quote:

» ***"I am completely comfortable with my HIV status and have no problem if anyone knows about it. I have been living with HIV for 20 years and have resolved any issues with it a long time ago."***

Stigma Reduction

The second largest theme (14%, n=109) of the responses focused on stigma and its role in preventing respondents from disclosing their HIV status to more people. Similar to the analysis of the HIV-related stigma questions above, these responses were further stratified into four groups (1) concerns with public attitudes, (2) fear of rejection, (3) concerns about disclosure, and (4) negative self image.

Concerns with Public Attitudes. Nearly one-half (48%, n=53) of this group of responses was focused on public attitudes toward PLWH. For these responses, individuals indicated some concern about what "most people" think about PLWH and the impact this has on disclosure of their HIV status. These responses are characterized by the following quote:

» ***"If people would not look at me differently, wondering what I did to get [infected]."***

Fear of Rejection. About one-quarter (24%, n=26) of respondents indicated that they were worried about the perceived consequences of disclosing their HIV status to other people, especially fearing rejection or a loss of friends or family relationships. Of this group (n=26), about one-third (n=9) also expressed concern

about the potential negative consequences of disclosure on romantic or intimate relationships. Responses related to a fear of rejection are characterized by the following quotes:

- ***"Being honest with others, but afraid to because I don't want to lose their friendship."***
- ***"Nothing will help me. I'm too scared about rejection."***
- ***"Disclosure when dating in community often results in rejection – even if your date may be positive."***

Disclosure Concerns. While somewhat related to the issue of concerns with public attitudes, this subcategory includes the 15% (n=16) of responses within this theme related to general concerns about disclosure and/or a desire to keep their HIV status secret or closely controlled. These responses are characterized by the following quotes:

- ***"I'm not sure. Most of the time, I just keep it to myself. I guess that I don't want people to 'broadcast' it . . ."***
- ***"I don't know. I'm afraid that others make fun of me. I prefer to be anonymous."***

Negative Self Image. Similar to the stigma analysis above, the theme of "negative self image" was a small proportion (6%, n=6) of stigma-related disclosure responses. This theme includes responses that indicated a feeling of being unclean, ashamed, or a bad person, and therefore, presenting a barrier to disclosure. These responses are characterized by the following quotes:

- ***"I don't know. I'm too ashamed to tell people about it."***
- ***"If I liked myself . . ."***

Education

The third largest (11%, n=87) theme of the disclosure responses is education. This theme is based on respondents' use of the word "education" or a description of the need for people to become more informed or aware. This theme was stratified into three groups: (1) community/public education, (2) general education, and (3) self-education, each described below.

Community/Public Education. The vast majority (85%, n=74) of responses within this theme suggested that increased awareness or education of the public or members of their communities would help them disclose their status. The implication of these responses was that increased public awareness of HIV would make it easier for more people to be open about their HIV status, by enabling the general public to better understand the disease and/or help correct misperceptions or misunderstandings. A small group of these responses (6%, n=5) focused on the use of media and technology to educate the public. Community/public education responses are characterized by the following quotes:

- ***"For there to be more information and education for the community. This way, there is an education piece for them to learn how to live with people that are HIV positive."***
- ***"Too many people do not have the correct facts and assume that 'certain' people get infected. I would feel comfortable if I knew they would feel safe and that I could not infect them by touching, talking, coughing, etc."***

General Education. About 10% (n=9) of responses within this theme simply said "education."

Self Education. A small proportion (6%, n=5) of responses within this theme focused on self-education as a way of increasing their ability to disclose their HIV status. These responses are characterized by the following quote:

» ***"Educate myself, learn as much as I can about HIV+ and educate them as well."***

Support

The final theme of the disclosure responses was support, identified by 11% (n=87) of respondents. This theme includes individuals who reported a need for with coming to terms with their diagnosis, making changes in their lifestyle, and learning how to share information with others. This theme was stratified into three groups: (1) peer support, (2) support from others, (3) professional counseling, and (4) general support. Each of these is described in more detail below.

Peer Support. Of the responses within the "support" theme, 59% (n=51) suggested some form of peer support, including being able to talk with another PLWH, formal peer support groups or programs, and other less-formal activities where PLWH could interact and find support (e.g., social events, community activities, etc.). A number of respondents suggested support groups that were focused on specific races/ethnicities, gender, or geographic location. The peer support responses are characterized by the following quotes:

» ***"Knowing that the other person is also infected with the HIV virus!"***

» ***"Support groups with HIV-positive colleagues who might be more understanding, open mind[ed] the better to support."***

» ***"Sharing in support groups so we can help other people with the condition."***

» ***"Social events with other HIV people."***

Support From Others. About one-quarter (23%, n=20) of support-related responses suggested the role of other people (not necessarily peers) in helping them be more comfortable to share their HIV status. This included those who simply needed someone to talk to, as well as those who got emotional support from their families or friends. These responses are characterized by the following quotes:

» ***"Talk with other people."***

» ***"To talk a lot about how they are feeling emotionally."***

» ***"Having my family around to give me the encouragement and be true to myself."***

Professional Counseling or Advice. A smaller group (17%, n=15) of support-related responses suggested the need for counseling services or other professional advice to deal with their status and/or disclose their status to other people. These responses are characterized by the following quotes:

» ***"After counseling, I may feel better about myself."***

» ***"Advice on how to [disclose]."***

General Support. A small proportion (5%, n=4) of these responses simply indicated "support" and could not be characterized further.

The long form survey included five "true/false" questions intended to help assess what respondents know about HIV and provide insight on their HIV literacy. These questions were adapted from several validated scales or surveys developed to measure HIV treatment knowledge.[15,16] The questions and the correct answers are provided in Table 61, as well as the proportion of respondents who chose the correct answer. Respondents could also select "don't know/not sure" for each question.

For respondents who answered all five questions, the average number of correct responses was 4.2 (MA) to 4.3 (EMA).

TABLE 61: HIV KNOWLEDGE

KNOWLEDGE QUESTION (TRUE OR FALSE)	CORRECT RESPONSE	% CORRECT MA (N=932)	% CORRECT EMA (N=742)
1. A T-cell (CD4) test measures the amount of HIV virus in an HIV-positive person's blood.	FALSE	44%	44%
2. Using a condom is an effective way to prevent HIV transmission during sex.	TRUE	92%	92%
3. If an HIV-positive person's viral load is "undetectable," it means he/she is cured of HIV.	FALSE	94%	95%
4. The use of recreational drugs can impact the effectiveness of HIV medications.	TRUE	84%	85%
5. An HIV-positive woman can give birth to a child without giving HIV to the baby.	TRUE	70%	71%

VARIATIONS IN HIV KNOWLEDGE

HIV knowledge, as measured by correct responses to the above questions, varied significantly across several groups in the survey sample, depending on the question. For example, for three of the five questions (1, 3, and 4), MSM were significantly more likely than non-MSM to have answered correctly. In addition, for the same three questions, those that had disclosed their HIV status to someone other than their medical provider were significantly more likely than those who had not to have answered correctly. Lastly, for questions 1 thru 4, respondents who had not graduated from high school (or received GED) were significantly less likely to have answered correctly.

As noted previously in this report (see *Health Status* section), the long form survey included two questions to determine if respondents' HIV disease had progressed to AIDS. First, respondents were asked if they had ever had a T-cell (CD4) count under 200, and if they had ever had an opportunistic infection (OI).[17] A positive response

15. Balfour, L., J. Kowall, G.A. Taska, C.L. Cooper, J.B. Angel, P.A. McPherson, G. Garber, L. Beique, and D.W. Cameron. 2007. Development and psychometric validation of the HIV treatment knowledge scale. *AIDS Care, 19(9): 1141-1148.*

16. Carey, M. and K. Schroder. 2002. Development and psychometric evaluation of the brief HIV knowledge questionnaire. *AIDS Educ Prev, 14(2) 172-182.*

17. The survey tool included a definition and list of common OIs.

to either of the questions would indicate an AIDS diagnosis. Several questions later in the survey, respondents were also asked if their medical provider had ever told them that they had AIDS. The proportion who reported an OI (36% to 37%) was lower than the proportion who reported a T-cell count below 200 (53%). In addition, 60-61% had either one or the other AIDS-defining conditions. This is not an unexpected result, since immune suppression in the absence of an opportunistic infection is possible.

There was, however, discrepancy between the proportion who had an AIDS diagnosis based on these clinical markers and the proportion who said that a medical provider had told them they had AIDS. Of those who reported ever having a T-cell count under 200 or having had an OI (60 to 61% of respondents), approximately two-thirds (65%) also reported that they had been told by a medical provider that they had AIDS.

A statistical test to assess the level of agreement between these responses was conducted (Kappa statistic). The Kappa value ranges from zero to one. A Kappa value of one indicates perfect agreement between the two variables, and a zero indicates perfect disagreement. In this case, a Kappa value of one (1.0) means everyone with a clinical indicator of AIDS also had been told by their medical provider that they had AIDS, and conversely, everyone without a clinical indication of AIDS had not been told that they had AIDS. The Kappa statistic for the survey responses was 0.51, suggesting only moderate agreement between those who had AIDS (based on clinical indicators) and those who seemed to be aware they had AIDS (based on response to whether they had ever been told).

As noted above, these questions were analyzed to assess the level of health literacy and HIV knowledge among respondents. The moderate agreement between these variables is concerning because it suggests they have been diagnosed with AIDS, but aren't fully aware of that fact. However, given that a large proportion of the survey sample was older and diagnosed more than 10 years prior to the survey, it is possible that many who were historically diagnosed with AIDS now have viral loads and immune responses similar to those who were more recently diagnosed with HIV. As such, having been historically diagnosed with AIDS may have diminishing salience and may explain the discrepancy detected in this analysis.

The final question on the long form survey was an open-ended question that asked *"In your opinion, what can be done to help people in your community to stay HIV negative?"* The purpose of this question was to solicit ideas and opinions about some of the driving forces behind ongoing HIV risk in respondents' communities and approaches to preventing new infections among people like them. Despite being the final question of the survey and one that required a written response, 90% (n=832) of respondents answered this question. Responses ranged in length from a single word, to several sentences, to even a few paragraphs. Responses were coded and then analyzed to identify broad themes among the responses. The most common themes are highlighted in Table 62 and the top three are explained in more detail in the section that follows.

TABLE 62: WHAT CAN BE DONE TO KEEP PEOPLE IN COMMUNITY HIV NEGATIVE?

THEMES	OVERALL (N=832)
Education	48%
Sexual behaviors	25%
Outreach	21%
Harm reduction/needle exchange	8%
"Not sure" or "nothing"	5%
HIV testing	4%

Education

The largest proportion of respondents (48%, n=397) indicated that education was the most important factor in helping keep people HIV negative in their communities. These responses were further stratified into three groups: (1) general education (non-specific), (2) public/community education, and (3) youth education. Each of these is described more below. [Note: Percentages provided may not sum to 100% because responses may have included reference to more than one category of education.]

1. **General Education.** Nearly one-half (49%, n=194) of the education-themed responses referred to or used the word "education," but neither elaborated more or provided a specific focus or target.

2. **Public/Community Education.** Nearly one-half (45%, n=179) of the education-themed responses referred to educating members of the community or the public. Of this group, about 40% (n=71) referenced education about HIV specifically, including prevention, risks, consequences, medications, and the persistence of HIV as a public health issue. Another 35% (n=63) of this group described education for their community, but without additional information on the content of the education. Lastly, 25% (n=45) of this group specifically referenced "sex education," including the need to teach people about sex, the risks of unprotected sex, and methods of reducing the risk of HIV infection. Responses related to public/community education are characterized by the following quotes:

   » ***"Educating HIV negative people so as to decrease or eliminate stigma regarding HIV."***

- » ***"More available HIV education, real life example of what HIV can do to your life."***
- » ***"More education on safe sex"***
- » ***"Stop abstinence-only programs and promote sex education in schools."***

3. **Youth Education.** A smaller proportion (14%, n=54) of education-themed responses focused specifically on education for children and youth. Among these responses, a focus on teaching younger generations was prevalent. This group also includes sex education responses and overlaps somewhat with the category above; however, the responses included here were explicit in their focus on young people. Responses related to youth education are characterized by the following quotes:
   - » ***"Teaching from grades 2-3 and up. Start early."***
   - » ***"Sex education at an early age."***
   - » ***"Continue educating the youth about sex, HIV, etc."***

Sexual Behaviors

The second largest proportion (25%, n=209) of respondents indicated that decisions about sexual behaviors were critical to preventing the spread of HIV. These responses were further stratified into two categories: (1) safer sex practices, or (2) abstaining from sex. Each of these is described more below. [Note: Percentages provided do not sum to 100% because responses may have included reference to both categories.]

1. **Safer Sex Practices.** The vast majority (93%, n=193) of the sexual behavior-themed responses referred to safer sex practices, such as using a condom. These responses are characterized by the following quotes:
   - » ***"Safe sex practices such as always using a condom. It would be nice for people who know they have HIV to practice safe sex with people who don't have HIV. We need to stop the spread of this disease by being smart and exercising control over the decisions we make."***
   - » ***"Stop having unsafe sex. Period."***
2. **Abstinence.** A smaller proportion (15%, n=31) of sexual behavior-themed responses referred to abstinence as the only sure way to prevent the spread of HIV. These responses are characterized by the following quotes:
   - » ***"Increase HIV awareness in grade school; applaud the blessings of virginity to our young people; return to the idea of abstinence and install that in our young people."***
   - » ***"Don't have sex. Don't believe in men."***
   - » ***"To wear condoms all the time, or just don't have sex."***
   - » ***"No sex at all."***

Outreach

The third largest proportion (21%, n=174) of respondents said that "outreach" was important to preventing the spread of HIV. Because outreach is a broad category that may include a range of activities, responses were divided into groups using CDC's definition of health education and risk as a guide. CDC defines outreach as

activities outside a more traditional health care setting focused on providing health education and risk reduction services and may include street outreach, community outreach, or peer education. Responses were stratified into these three categories, plus three additional categories based on the responses (condom distribution, youth/school outreach, and general outreach). Percentages provided do not total 100% because responses may have included reference to more than one category.

1. **General Outreach.** The largest proportion (31%, n=54) of outreach-related responses was non-specific and simply noted "outreach" as an important strategy.

2. **Community Outreach.** CDC guidelines define community outreach as activities such as workshops or presentations to the community. While the CDC indicates that community outreach activities are generally time-limited events, more sustained community outreach responses were included in this category for analytical purposes. Twenty-eight percent (n=48) of the outreach-related responses focused on community efforts and are characterized by the following quotes:

   » ***"Education in church, community centers, free condoms . . ."***

   » ***"More demonstrations about HIV in my community."***

   » ***"Outreach prevention centers"***

3. **Youth/School Outreach.** Twenty percent (n=34) of outreach-related responses focused on youth as the target for such efforts and a number of these responses suggested schools as an appropriate venue for these activities. These responses are characterized by the following quote:

   » ***"Going to schools – Jr. High, High Schools – educating parents, special groups to enforce learning about HIV so children can have HIV prevention."***

   » ***"Much more information- not only obvious information but things that you know in your heart. I talk to young people because they are the future. We must talk to the young people."***

4. **PLWH as Educators.** A small proportion (12%, n=21) of outreach-related responses focused on the role of PLWH in educating others who are not HIV positive and sharing their perspectives as a PLWH. These responses are characterized by the following quotes:

   » ***"Possibly having people with HIV speak to groups (especially teens) and give first hand info on how becoming infected has affected their lives."***

   » ***"More programs involving HIV+ people speaking to youth and at-risk populations."***

5. **Condom Access.** Another 12% (n=21) of outreach-related responses focused on access to condoms, either by making them more widely available or actively distributing them to individuals. These responses are characterized by the following quotes:

   » ***"Having condoms free of cost available to more people, not just addicts and HIV infected."***

   » ***"More information on the disease and condoms available everywhere possible."***

6. **Street Outreach.** While similar to community outreach described above, the category of responses called "street outreach" focused more specifically on proactive, one-on-one strategies to engage individuals in public (street) settings. Ten percent (n=18) of outreach-related responses focused on street-level activities.

These responses are characterized by the following quotes:

- "***More education centers and outreach (in bars and clubs).***"
- ***"Keep teaching on street, half-way [houses], back doors. Just keep a front row seat."***
- ***"Face-to-face resources that are considered credible to my community because of race/income/where they live, etc."***

FUNDER AND CONSUMER RESPONSES

This research project was a collaborative effort among the research team (JSI), funders (MDPH and BPHC), groups representing PLWH (MA Statewide CAB and the Boston EMA HIV Health Services Planning Council), and consumers who participated in the survey. In the spirit of this collaboration, and as a clear indication of the intent to use this study and its results to inform future planning, the project's funders and groups representing PLWH were asked to develop responses to the study and the results. These are presented in this section as a fitting conclusion to this report.

FUNDER RESPONSE

The findings from the Consumer Study reinforce that the majority of PLWH in Massachusetts and the Boston EMA continue to experience stable or improved health and quality of life. In part due to the availability of a full range of clinical and non-clinical support services, and progressive public health policies including the implementation of state health care reform, reported access to medical care and engagement and retention in care is high. Virtually all respondents reported they are engaged in recent medical care, have some form of health insurance coverage, and are accessing antiretroviral treatments; and overall 70% of consumers reported that their current health status was good, very good, or excellent.

While there have been many successes, there continue to be ongoing challenges. There remains a small, but significant group of PLWH who waited more than one year after their HIV diagnosis to enter medical services, and others who experienced barriers to staying on their HIV medications that led to a treatment interruption of a week or more. Furthermore, the most common reason respondents identified for not accessing essential services when they needed them was a lack of information about how and where these services were available and whether they were eligible to receive them.

Additionally, while engaged in primary care and case management, there appears to be an insufficient capacity to meet the substance abuse and mental health care needs of PLWH in the regions. More than half of survey respondents identified serious mental health or substance abuse concerns, yet there are conflicting reports in the survey about the quality and consistency of screening and referral to treatment services. This raises concerns about maintaining an adequately trained and well-resourced case management workforce, and mechanisms to ensure up to date information is available to consumers in an efficient and effective manner.

The Consumer Study is being released as the BPHC, HIV/AIDS Services Division, and the MDPH, Office of HIV/AIDS embark on a collaborative process to revise and improve the service system. The Consumer Study is one component in a series of activities to evaluate the current system, and seek input to improve and enhance system capacities. We anticipate that the changes we will be implement will address many of the gaps identified throughout our planning processes, and respond to the evolving service needs of PLWH that are reflected in this survey.

It is the responsibility of the funders to ensure that consumers experience seamless access to care, accurate and timely information, and high quality and culturally appropriate health and support services. Efforts are underway to co-locate multi-disciplinary care teams in clinical and non-clinical venues to maximize the range of services available in these settings, inclusive of medical, social service, and HIV+ peer staff. These enhancements include improved linkages between HIV prevention, testing, and care programs, and services that address the prevention needs of people living with HIV/AIDS.

There remain some challenges in the road ahead. While the number of PLWH in the Commonwealth and the EMA continues to grow by 5% every year, the availability of resources has not kept pace with the

expanding scope of need. As we face the real prospect of level or decreased funding across the system, we are obligated to maximize the opportunities afforded by state health care reform, and leverage local, state, and federal investments to strengthen the HIV/AIDS services system overall. As people living and newly diagnosed with HIV/AIDS continue to experience health challenges, the system must also respond to the needs of an aging consumer population, the impacts of poverty, and the profound disparities that persist over nearly thirty years into the domestic HIV epidemic. We will continue to engage the consumer and provider community as we formulate creative strategies to meet and overcome these challenges.

Dawn Fukuda
Director, Office of HIV/AIDS
Massachusetts Department of Public Health

Michael Goldrosen
Director, HIV/AIDS Services Division
Boston Public Health Commission

CONSUMER RESPONSE

The Consumer Study was reviewed by many consumer groups, including the Statewide Consumer Advisory Board (SWCAB) and the Boston EMA Part A Planning Council.

The SWCAB has been in existence since 1991 and is a group of up to thirty PLWH. We are a group that is reflective of the epidemic in Massachusetts, and who meet monthly to advise senior staff of MDPH OHA on services and policies affecting the lives of PLWH in Massachusetts.

The Planning Council is an independent, planning body working with the City of Boston to organize, evaluate and prioritize Ryan White HIV funding in the Boston EMA. Ryan White Part A provides emergency funding for urban areas most heavily impacted by the HIV/AIDS epidemic, which in the Boston EMA, covers seven counties in Eastern Massachusetts and three counties in Southern New Hampshire. The Planning Council, in existence since 1990, sets priorities for health and health-related HIV services in the EMA, and decides how federal HIV funds are distributed to each service. The Planning Council is composed of over 40 members, both consumers and providers, who reflect the demographics of the epidemic in the EMA, while also representing diversity in ethnicity, age, gender and geography. The Council and its subcommittees meet on a monthly basis to learn about emerging needs in the region, and to make decisions on services and funding that will improve the lives of PLWH in the EMA; and guides for the Grantee, the BPHC.

Many members of the SWCAB and the Planning Council took an active role in the design and administration of the survey, and were also participants in answering the survey questions. Some of the issues that SWCAB and Council members are interested in exploring further are as follows:

- 30% of consumers reported that their providers/case managers have not discussed medication adherence with them. Perhaps we can use this report to educate providers/case managers to be more proficient at having these conversations, since non-adherence has major consequences for the health and quality of life of consumers.
- 46% of consumers reported that their providers/case managers have not discussed substance use with them. These are concerning statistics since substance use touches the lives of many people living with HIV. Consumers need to be given the opportunity to discuss these challenges with their providers.

Among the small proportion (5%) who missed their most recent medical appointment, 47% (n=23) said it was because of transportation issues. In a service area that includes all of Massachusetts and parts of southern New Hampshire, it is important to continue to assess transportation and access to care.

Many of the “barriers” to care suggest that medical case management services should be more closely studied. We are concerned about many of the high statistics listed in this report regarding the breadth or lack of knowledge that consumers have about services that could be provided to them. Perhaps once the new procurement is in effect we can again review case management and consumer concerns.

The Council also felt that this report unveiled key topics to address, such as the need for more education regarding HIV prevention and HIV/AIDS knowledge, both among consumers and in the general population. Along with sharing the outcomes of this report with providers, it is also critical to share this report and

partner with communities, to educate and offer more outreach to those at highest risk, including youth, elderly, and consumers who are underserved and enduring financial hardships.

The SWCAB and the Planning Council appreciate the opportunity to comment on this important survey, to date, the most comprehensive study of PLWH in the region. While the survey is an important step forward to address current issues with consumer services, we realize that some of these important issues that have been noted may change as we move forward with Healthcare Reform and the re-procurement of the way services are funded by the MDPH and BPHC. It is our hope that this survey can be a useful document in the future evaluation, researching and planning of services provided to all PLWH. SWCAB and Planning Council members would be happy to offer their input into upcoming or existing issues that may arise in conjunction with National Health Care Reform and the National HIV/AIDS Strategy.

If you have any questions, please feel free to call Paul B. Goulet, Consumer Office Director/SWCAB Facilitator at 617-624-5389; or Laura Kozek, Planning Council Support Director at 617-534-4559.

Thank You.

SWCAB Members
Boston EMA Part A Planning Council Members

GLOSSARY

Adherence
Closely following (adhering to) a prescribed treatment regimen.

AIDS (Acquired Immune Deficiency Syndrome)
A disease of the body's immune system caused by the human immunodeficiency virus (HIV). AIDS is characterized by the death of CD4 cells (an important part of the body's immune system), which leaves the body vulnerable to life-threatening conditions, such as infections and cancers.

ANOVA (Analysis of Variance)
A common statistical procedure used to test hypotheses that the means (averages) among two or more independent groups are equal. For example, ANOVA would be used to test whether the mean viral load count of men and women were equal or not.

ARV or Antiretroviral
Drug intended for the treatment of diseases caused by retroviruses, such as HIV, by interfering with the ability of the retrovirus to make more copies of itself.

Boston Public Health Commission (BPHC)
An independent public agency providing a wide range of health services and programs for the City of Boston. It is the oldest public health department in the US. BPHC is also the recipient of Ryan White Program Part A funding for HIV services. www.bphc.org

CAGE
A validated series of questions used to assess whether someone may have a problem with alcohol. CAGE is an abbreviation for the four basic questions related to Cutting down on alcohol, experiencing Annoyance from others about alcohol use, feeling Guilty, and using alcohol as an Eye opener. For the Phase II survey described in this report, the CAGE questions were adapted to refer to alcohol and/or drugs and were time limited to the three months prior to the survey. A "yes" response to two or more of the questions was used as an indicator of a possible problem with alcohol or drugs.

CD4 Cell
Also known as helper T cell or CD4 lymphocyte. CD4 is a type of infection fighting white blood cell that carries the CD4 receptor on its surface. CD4 cells coordinate the immune response, which signals other cells in the immune system to perform their special functions. The number of CD4 cells in a sample of blood is an indicator of the health of the immune system. HIV infects and kills CD4 cells, which leads to a weakened immune system.

CD4 Cell Count
A measurement of the number of CD4 cells in a sample of blood. The CD4 count is one of the most useful indicators of the health of the immune system and the progression of HIV/AIDS.

Chi Square
A statistic that compares counts or frequencies of categorical responses (e.g., yes or no) between two (or more) independent groups (e.g., men vs. women) and determines if the distributions of these categorical variables differ significantly from one another.

Disclosure
The process by which a person living with HIV tells their HIV status to another person.

Eligible Metropolitan Area (EMA)
The designation given to urban areas highly-impacted by HIV/AIDS and eligible for Ryan White Program Part A funding.

Epidemiology
The study of the incidence, distribution, and possible control of diseases and other factors relating to health. As used in this report (e.g., "the epidemiology of the HIV epidemic"), this term refers to those living with HIV/AIDS and their characteristics (e.g., race, gender, age, etc.)

Federal Poverty Level
A scale of individual and family income limits set annually by the federal government to determine eligibility for certain benefits and entitlements.

HDAP
The HIV Drug Assistance Program, which provides access to HIV-related medications for residents of Massachusetts. HDAP is program of the Office of HIV/AIDS of the Massachusetts Department of Public Health funded through federal and state sources. Also known as ADAP in other states such as New Hampshire.

Health Resources and Services Administration (HRSA)
The agency of the U.S. Department of Health and Human Services that administers various primary care programs for the medically underserved, including the Ryan White Program.

HIV (Human Immunodeficiency Virus)
The virus that causes Acquired Immune Deficiency Syndrome (AIDS).

HIV prevalence
The number of people living with HIV at a particular point in time. For example, as of October 1, 2009, there were 18,045 people living with HIV in Massachusetts.

Institutional Review Board (IRB)
A committee that has been formally designated to approve, monitor, and review research involving humans with the purpose of protecting the rights and welfare of the research subjects.

JSI Research & Training Institute (JSI)
A public health and health care consulting company headquartered in Boston, hired to conduct the research described in this report. www.jsi.com

Massachusetts Department of Public Health (MDPH)
The public health department for the Commonwealth of Massachusetts. MDPH Office of HIV/AIDS (OHA) is the recipient of Ryan White Program Part B funding for HIV services, including the HDAP program. www.mass.gov/dph

Massachusetts HIV Prevention Planning Group (MPPG)
A group of community members, providers, and state representatives who meet to guide the planning of HIV prevention services in Massachusetts. MPPG advises MDPH Office of HIV/AIDS.

Massachusetts Statewide Consumer Advisory Board (SWCAB)

A formal group that meets monthly to advise senior staff of the MDPH Office of HIV/AIDS on services and policies affecting the lives of people living with HIV/AIDS in Massachusetts.

Medicaid

A medical assistance program funded by federal and state funds for low-income people; coverage of and payment for medical services are determined by individual states. Administered by the Centers for Medicare and Medicaid Services (CMS) of the Department of Health and Human Services.

Medical provider

For the purposes of the study described in this report (and the surveys that were conducted), medical provider refers to the doctor, nurse practitioner, nurse, or physician assistant who manages a person's HIV care.

Medicare

A federally funded program administered by Department of Health and Human Services/Centers for Medicare and Medicaid Services that finances health care services for certain elderly people and people with disabilities (regardless of income and assets).

Planning Council

An independent, planning group that works with the City of Boston to organize, evaluate, and set priorities for Ryan White Program HIV funding in the Boston Eligible Metropolitan Area (EMA). A Planning Council is required for EMAs that receive Ryan White Program funds. www.bostonplanningcouncil.org

Respondent

A person who completed and returned the Phase I and/or Phase II survey as part of this study.

Ryan White Program

A federal program, first authorized in 1990 and most recently by the Ryan White Treatment Extension Act of 2009, that provides funding for HIV-related care and services for those who do not have sufficient health care coverage or financial resources. Named after Ryan White, an Indiana teenager diagnosed with AIDS in 1984 at age 13.

Statistically significant

In statistical analyses, statistically significant refers to a result that is unlikely to have happened by chance.

Stigma

Among people living with HIV, the actual, potential, or perceived social disqualification (less than full social acceptance or social rejection), denial or limitation of opportunity (i.e., in housing, jobs, or services), and/or negative change in social identity (how other see or perceive him/her) resulting from their HIV status.

SurveyMonkey®

A company that provides web-based data collection and survey tools for use by companies and organizations. The SurveyMonkey® platform was used to host the online and phone version of the Phase II survey described in this report.

Teleform

A software application that enables users to create machine-readable data forms and create databases to store the data collected from those forms. Teleform was used for the mail-based Phase I and Phase II surveys described in this report.

Tukey's HSD test

A statistical, multiple comparison procedure that tests all possible pairwise differences in means or proportions when more than two groups are being compared. It identifies which pairs are significantly different and adjusts the p-value accordingly (the p-value for significance is usually 0.05 for a single comparison). For example, if the proportion of respondents that reported a need for a service varied by race/ethnicity (more than two groups), Tukey's HSD indicates which two racial/ethnic groups were significantly different.

Viral load

The amount of HIV RNA in a blood sample, reported as number of HIV RNA copies per milliliter of blood plasma. The VL provides information about the number of cells infected with HIV and is an important indicator of HIV progression and of how well treatment is working.

Viral Load Test

Test that measures the quantity of HIV RNA in the blood. Results are reported as the number of copies of HIV RNA per milliliter of blood plasma.

APPENDIX A: PHASE I SURVEY TOOL

HIV/AIDS Consumer Survey: Part I (Short Form)

Directions: Fill in circles darkly and completely.
INCORRECT MARKS CORRECT MARK

LIST OF SERVICES

For each service below, complete sections A, B, and C

	A. ROLE — WHAT ROLE DOES THIS SERVICE HAVE IN YOUR OVERALL HEALTH? (SELECT 1)			B. NEED — DID YOU NEED THE SERVICE IN THE PAST 6 MONTHS? (SELECT 1)			C. BARRIERS — DID YOU HAVE ANY PROBLEMS GETTING THE SERVICE? (SELECT ALL THAT APPLY)														
	IT IS ESSENTIAL	IT IS NICE, BUT NOT ESSENTIAL	NONE, NO ROLE	DIDN'T NEED & DIDN'T USE	NEEDED & USED	NEEDED, BUT COULDN'T GET	NO PROBLEMS	DIDN'T KNOW EXISTED OR HOW TO GET IT	TRANSPORTATION PROBLEMS	NOT AVAILABLE NEAR MY AREA	HARD TO GET AN APPOINTMENT	DON'T HAVE ENOUGH MONEY	TOLD NOT ELIGIBLE FOR SERVICE	PROVIDER DOESN'T SPEAK MY LANGUAGE	NOT COMFORTABLE WITH PROVIDER	CAN'T TAKE TIME OFF OF WORK	AFRAID PEOPLE WILL FIND OUT I HAVE HIV	NO CHILDCARE	TOO SICK TO GO	CHOSE NOT TO GO	OTHER REASON
1. Help coordinating and planning for HIV care and other services (case management)	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
2. Help getting benefits such as health, social security, or disability	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
3. Regular dental care from a dentist or hygienist	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
4. Regular medical care from a doctor, nurse or ob/gyn including HIV care	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
5. Help paying for or getting drugs for HIV/AIDS and for related health issues	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
6. Help taking medications regularly and dealing with side-effects	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
7. Professional counseling or treatment for a diagnosed mental health issue	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
8. Support from other people living with HIV/AIDS (one-on-one or in groups)	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
9. Services that help deal with alcohol and/or drug use	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
10. Help finding a place to live	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
11. Help paying rent	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
12. Help understanding and planning for nutrition needs	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
13. Meals delivered to my home	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
14. Group meals served somewhere other than my home	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
15. Food vouchers or groceries that can be picked up from a food bank	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
16. Help with legal issues	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
17. Services that help deal with immigration status	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
18. Help finding and keeping a job	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
19. Help taking care of partner, parent, or other adult family member	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○

Draft

Survey ID #

Please return by August 1, 2009 to: Jaya Mathur, JSI, 44 Farnsworth Street, Boston, MA 02210
If you have questions please call 1-866-993-1781or email consumersurvey@jsi.com

Continue on other side of page

Note: Form has been reduced from original size (8 x 14 legal) for purposes of this report.

DEMOGRAPHICS

D1. What is the zipcode where you live now?
(If not permanently housed, enter 99999)

D2. In what YEAR were you born?

D3. Are you of Latino/a or Hispanic ethnicity?
- O Yes
- O No

D4. What is your race? (SELECT ALL THAT APPLY)
- O American Indian/Alaskan Native
- O Asian
- O Black/African American
- O Native Hawaiian/Pacific Islander
- O White
- O Other

D5. What is your gender?
- O Male
- O Female
- O Transgender (male to female)
- O Transgender (female to male)

D6. What is your sexual orientation?
- O Straight (Heterosexual)
- O Gay/Lesbian (Homosexual)
- O Bisexual

D7. What was your HOUSEHOLD income last month?
(To the nearest whole dollar)

$, .00

D8. How many adults (18 years or older) live in your household? adults

D9. How many children (under 18 years old) live in your household? children

D10. Which of the following forms of health insurance do you have? (SELECT ALL THAT APPLY)
- O Commonwealth Care/Choice
- O Medicaid (Mass Health or NH Medicaid)
- O Private insurance such as Blue Cross/Blue Shield, Anthem, Tufts, Harvard Pilgrim (including premiums paid for by HDAP)
- O Medicare
- O New Hampshire Health Plan (NHHP)
- O I don't know
- O I don't have insurance
- O Other, specify: _____

D11. When was the last time you saw a medical or service provider?
- O Less than 6 months ago
- O 6 months to 1 year ago
- O More than 1 year ago
- O Never

D12. In what YEAR were you told by a medical or service provider that you had HIV?
(If you can't remember, please estimate)

D13. Which of the following best describes how you think you got HIV? (SELECT ALL THAT APPLY)
- O Sex with a man
- O Sex with a woman
- O Sex with an injection drug user
- O Sharing injection drug equipment (needles)
- O Blood transfusion or blood products
- O I was born with HIV
- O I don't know
- O Other, specify: _____

Draft

Want to earn $25 more?

Participate in the follow-up survey and receive a $25 gift certificate!

1.) Fill out the enclosed yellow form to take the survey by phone or mail

-or-

2.) Take it online:
www.consumersurvey.jsi.com

To complete a follow-up survey online you will need the **Survey ID #** written in the lower left corner of this survey so that the two surveys can be linked. Your name will not be attached to your answers.

Survey ID #

Thank you for participating!

Please return by August 1, 2009 to: Jaya Mathur, JSI, 44 Farnsworth Street, Boston, MA 02210
If you have questions please call 1-866-993-1781or email consumersurvey@jsi.com

Note: Form has been reduced from original size (8 x 14 legal) for purposes of this report.

APPENDIX B: PHASE II SURVEY TOOL

HIV SERVICE NEEDS ASSESSMENT

Fill in circles darkly and completely.

INCORRECT MARKS CORRECT MARK

For text boxes, please stay within the lines.

INCORRECT MARK CORRECT MARK

A. Demographics

A1. In what YEAR were you born? ☐☐☐☐

A2. Where were you born?

- ○ United States (50 states and DC only)
- ○ Puerto Rico
- ○ Other US Territory (e.g., Guam, US Virgin Islands)
- ○ Brazil
- ○ Cameroon
- ○ Cape Verde
- ○ Dominican Republic
- ○ El Salvador
- ○ Ghana
- ○ Haiti
- ○ Kenya
- ○ Uganda
- ○ Other (specify COUNTRY): _____

A2a. If you were not born in the United States, in what YEAR did you move to the US? ☐☐☐☐

A3. Which of the following best describes your immigration status? SELECT ONLY ONE.

- ○ US citizen
- ○ Legal permanent resident (valid green card)
- ○ Student, work, business, or tourist visa
- ○ Refugee or asylee (approved)
- ○ Other

A4. What language do you speak most of the time at home? SELECT ONLY ONE.

- ○ English
- ○ French
- ○ Haitian-Creole
- ○ Portuguese
- ○ Spanish
- ○ Swahili
- ○ Other (specify): _____

A5. What language do you prefer to speak with service providers (e.g., doctors, nurses, case managers)? SELECT ONLY ONE.

- ○ English
- ○ French
- ○ Haitian-Creole
- ○ Portuguese
- ○ Spanish
- ○ Swahili
- ○ Other (specify): _____

A. Demographics (continued)

A6. What were the sources of <u>your household income</u>? SELECT ALL THAT APPLY.

- ○ My employment (either full time, part time, or temporary/seasonal)
- ○ My spouse/partner's employment
- ○ Child support or alimony
- ○ Support from family members
- ○ Support from other household members not related to me
- ○ Financial aid from school
- ○ Unemployment benefits
- ○ Social Security (either SSI or SSDI)
- ○ TAFDC (Transitional Aid to Families with Dependent Children) or TANF (Temporary Aid to Needy Families)
- ○ EAEDC (Emergency Aid to Elderly, Disabled, and Children) or APTD (Aid to the Permanently and Totally Disabled)
- ○ Other (specify): _____

A7. What was your household income last month? **$ ☐☐,☐☐☐.00**

A8. How many adults (18 years or older) including you live in your household? ☐☐ adults

A9. How many children (under 18 years old) live in your household? ☐☐ children

A10. Which of the following forms of health insurance do you have? SELECT ALL THAT APPLY.

- ○ Commonwealth Care/ Choice
- ○ Medicaid (MassHealth or NH Medicaid)
- ○ Medicare
- ○ New Hampshire Health Plan (NHHP)
- ○ Private insurance such as Blue Cross/Blue Shield, Harvard Pilgrim, Anthem, Tufts (including premiums paid for by HDAP)
- ○ I do not know
- ○ I do not have health insurance
- ○ Other (specify): _____

B. HIV Diagnosis

B1. When was the first time a medical or service provider told you that you were HIV positive? If you do not remember, please estimate.

Month ☐☐ / Year ☐☐☐☐

B2. Where were you tested when you were first told you were HIV positive?

- ○ Private doctor's office
- ○ Hospital or hospital clinic (not emergency room)
- ○ Emergency room
- ○ Community health center or clinic
- ○ Family planning clinic
- ○ STD clinic
- ○ AIDS service organization (ASO) or other community-based organization (CBO)
- ○ HIV counseling, testing, and referral site
- ○ Mobile test site (e.g., a health department van)
- ○ Jail or prison
- ○ Don't remember/don't know
- ○ Other (specify): _____

B3. After you first tested positive for HIV, how long did you wait before getting <u>HIV medical care</u>?

- ○ I did not wait; I got HIV medical care immediately (within 30 days)
- ○ Between 1 month and 6 months
- ○ Between 6 months and 12 months (less than 1 year)
- ○ Between 1 year and 3 years
- ○ Between 3 years and 5 years
- ○ More than 5 years
- ○ I have not yet gotten HIV medical care

B4. What would have helped you (or would help you now) THE MOST get <u>HIV medical care</u> sooner? CHOOSE THE BEST ANSWER.

- ○ I did not wait; I got HIV medical care immediately (within 30 days)
- ○ Nothing would have helped me get care sooner
- ○ I needed/need time to deal with my diagnosis
- ○ Talk or counseling when I got my diagnosis
- ○ Someone with HIV to help me talk about or deal with the diagnosis
- ○ More information about what might happen if I did not get care
- ○ More information about where to go to get services
- ○ Information about free or low cost services
- ○ Help making an appointment
- ○ Someone to go with me on my first visit
- ○ Someone coming to my home to provide services
- ○ Help dealing with drug or alcohol issues/addiction
- ○ Legal services to help me with my immigration status
- ○ Other (specify): _____

B5. After you first tested positive for HIV, how long did you wait before getting HIV services other than medical care (such as peer support, transportation, food, etc.)?

- ○ I did not wait; I got HIV services other than medical care immediately (within 30 days)
- ○ Between 1 month and 6 months
- ○ Between 6 months and 12 months (less than 1 year)
- ○ Between 1 year and 3 years
- ○ Between 3 years and 5 years
- ○ More than 5 years
- ○ I have not yet gotten HIV services

B6. What would have helped you (or would help you now) get HIV services other than medical care sooner? SELECT ALL THAT APPLY.

- ○ I did not wait; I got HIV services other than medical care immediately (within 30 days)
- ○ Nothing would have helped me get services sooner
- ○ I needed/need time to deal with my diagnosis
- ○ Talk or counseling when I got my diagnosis
- ○ Someone with HIV to help me talk about or deal with the diagnosis
- ○ More information about what might happen if I did not get care
- ○ More information about where to go to get services
- ○ Information about free or low cost services
- ○ Help making an appointment
- ○ Someone to go with me on my first visit
- ○ Someone coming to my home to provide services
- ○ Help dealing with drug or alcohol issues/addiction
- ○ Legal services to help me with my immigration status
- ○ Other (specify): _____

B7. After you found out you have HIV, who helped you THE MOST to get HIV medical care or other HIV services? CHOOSE THE BEST ANSWER.

- ○ I am not getting HIV care or using HIV services
- ○ Husband, wife, partner, or significant other
- ○ Family member
- ○ Friend
- ○ Medical provider (doctor, nurse practitioner, nurse, physician's assistant)
- ○ Case Manager
- ○ Outreach worker
- ○ The person who gave me my test results
- ○ Another person with HIV
- ○ No one
- ○ I don't know/remember
- ○ Other (not the person's name, but his/her job or relationship to you): _____

C. Health Status

C1. What were the results of your most recent T-cell (CD4) test?

- ○ Less than 200
- ○ 200 to 350
- ○ More than 350
- ○ I have only had one T-cell test and I am currently waiting for results
- ○ I have never had a T-cell test
- ○ I do not know if I have ever had a T-cell test or I do not know what a T-cell test is
- ○ I cannot remember my T-cell results

C2. What were the results of your most recent viral load test?

- ○ Undetectable or less than 400
- ○ 400 to 4,999
- ○ 5,000 to 10,000
- ○ 10,001 to 100,000
- ○ More than 100,000
- ○ I have only had one viral load test and I am currently waiting for results
- ○ I have never had a viral load test
- ○ I do not know if I have ever had a viral load test or I do not know what a viral load test is
- ○ I cannot remember my viral load results

C3. Have you ever had a baseline resistance test (genotypic or phenotypic) that helps find out which medications are best for treating your HIV? ○ Yes ○ No ○ Don't Know

C4. Regarding your HIV status, have you ever had...

C4a. A T-cell (CD4) count under 200? ○ Yes ○ No ○ Don't Know

C4b. An opportunistic infection (OI)? ○ Yes ○ No ○ Don't Know

Note: An opportunistic infection may include pneumocystis carinii pneumonia (PCP), Kasposi's sarcoma (KS), cytomegalovirus (CMV), mycobacterium avian complex (MAC or MAI), and tuberculosis (TB), among others.

C5. In addition to HIV, do you currently have any of the following conditions? SELECT ALL THAT APPLY.

- ○ Arthritis
- ○ Asthma
- ○ Cancer
- ○ Chronic obstructive pulmonary disease (COPD)
- ○ Diabetes
- ○ Heart disease
- ○ Hemophilia/blood disorder
- ○ Hepatitis B
- ○ Hepatitis C
- ○ High blood pressure
- ○ High cholesterol
- ○ Liver disease
- ○ Lung disease (not tuberculosis)
- ○ Memory problems
- ○ Neuropathy
- ○ Osteoporosis
- ○ Sexually transmitted infection (e.g. Chlamydia, gonorrhea, syphilis, herpes)
- ○ Tuberculosis (TB)
- ○ Other (specify): _____
- ○ None of the above

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C. Health Status (continued)

C6. Has your medical provider ever told you that you have AIDS?

○ Yes ○ No ○ Don't Know

C7. Do you have any of the following disabilities? SELECT ALL THAT APPLY.

○ Blindness or visual impairment (not correctable with glasses)
○ Deafness or loss of hearing
○ Physical disability that requires me to use a wheelchair
○ Physical disability that requires me to use a walker, crutches, or leg braces
○ Pulmonary (lung) condition that affects my mobility
○ Cardiac (heart) condition that affects my mobility
○ Neurological or psychiatric disability
○ None of the above

C8. Would you say in general your health is...

○ Excellent ○ Very good ○ Good ○ Fair ○ Poor

C9. Compared to 6 months ago, would you say your general health now is...

○ Better ○ About the same ○ Worse

D. Primary Care

Instructions: For the following questions "**HIV medical provider**" means your main doctor, nurse practitioner, nurse, or physician's assistant who manages your HIV care. If you have more than one medical provider, think about the one you see most of the time.

D1. Where do you usually go to get HIV medical care?

○ Private doctor's office
○ Hospital/hospital clinic
○ Emergency room
○ Community health center or clinic
○ VA hospital/clinic
○ I do not get medical care (Skip to page 8, "HIV/AIDS Medication and Adherence")
○ Other (specify): _____

D2. How long ago did you last see your HIV medical provider?

○ Less than 6 months
○ Between 6 months and 12 months (less than 1 year)
○ Between 1 year and 3 years
○ Between 3 and 5 years
○ More than 5 years

D. Primary Care (continued)

D3. Did you keep your last HIV medical appointment?

- ○ Yes
- ○ No

D3a. If NO, why not? SELECT ALL THAT APPLY.

- ○ I was not able to get there
- ○ My medical provider does not speak my language
- ○ I am not comfortable with my medical provider
- ○ I did not have child care
- ○ I was too sick to go
- ○ I was not able to take time away from work
- ○ I was feeling well or did not think it was necessary to go
- ○ Other (specify): _____

Instructions: Please choose how often the following statements are true about your **HIV medical provider.** If you have more than one medical provider, think about the one you see most often.

My HIV medical provider...	Always	Sometimes	Never	NA
D4a. Spends enough time with me during visits	○	○	○	○
D4b. Listens to me during visits	○	○	○	○
D4c. Is easy to reach when I need to	○	○	○	○
D4d. Is easy to schedule an appointment with	○	○	○	○
D4e. Encourages me to participate in my own care	○	○	○	○
D4f. Makes sure I get the care I need, including referrals to specialty care	○	○	○	○
D4g. Seems to understand the needs of people my age	○	○	○	○
D4h. Seems to understand my culture or community	○	○	○	○
D4i. Seems to understand how to treat HIV/AIDS	○	○	○	○
D4j. Is able to help me deal with other health issues besides HIV/AIDS	○	○	○	○
D4k. Offers me testing for other diseases like Hepatitis B or C, TB, STIs or other health condtions	○	○	○	○
D4l. Treats me with respect	○	○	○	○
D4m. Works with me to help me keep my appointments	○	○	○	○
D4n. Meets with my sexual and drug-using partners upon my request	○	○	○	○
D4o. Refers me to mental health or substance abuse services if I need them	○	○	○	○

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E. HIV/AIDS Medications and Adherence

E1. Are you currently taking HIV medications (antiretrovirals), prescribed by your HIV medical provider, to treat HIV or AIDS?

○ Yes ➡

○ No

If YES, you are currently taking HIV medications:

E1a. In what year did you start taking HIV medications for the first time?
If you do not remember, please estimate.

E1b. How do you cover the cost of your medications? SELECT ALL THAT APPLY.

○ HDAP/ADAP (HIV or AIDS Drug Assistance Program) or NH CARE Program
○ Medicaid (MassHealth or NH Medicaid)
○ Medicare
○ Commonwealth Care/Choice
○ New Hampshire Health Plan (NHHP)
○ Private insurance (Blue Cross/Blue Shield, Tufts, Anthem, Harvard Pilgrim)
○ I pay for all of it (on my own or with help from family/friends)
○ I don't know

E1c. During the past 6 months, have you ever stopped taking your HIV medications for more than a week (7 days)?

○ Yes ➡

○ No

If YES: Why? SELECT ALL THAT APPLY.

○ Forgot to take them
○ Wanted to avoid side effects
○ Was busy with other things
○ Had a change in daily routine
○ Had problems taking pills at a specified time
○ 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
○ I have chosen not to take them
○ Other (specify): _____

E1d. How often have you missed a dose of any of your HIV medications in the past 2 weeks?

○ Never ○ 1 to 2 times ○ 3 to 4 times ○ 5 or more times

E1e. In the past 3 months, have any of the following people talked to you about taking your HIV medications as prescribed? SELECT ALL THAT APPLY.

○ Medical provider (doctor, nurse practitioner, nurse, physician's assistant)
○ Case manager
○ Other HIV services provider or outreach/community health worker
○ Peer leader
○ Mental health counselor (like a therapist or psychiatrist)
○ Substance abuse counselor
○ Support group member(s)
○ Other people living with HIV that I know
○ Family/friends
○ No one has talked to me about this issue

E1f. In the past 3 months, have you used any of the following therapies to help manage your HIV and/or side effects of medications? SELECT ALL THAT APPLY.

○ Vitamin/nutritional supplements
○ Herbal treatments
○ A healthy diet
○ Regular exercise
○ Massage
○ Chiropractic care
○ Acupuncture
○ Meditation
○ Other (specify): _____

GO TO NEXT PAGE - E2

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E. HIV/AIDS Medications and Adherence (continued)

If NO, you are not currently taking HIV medications:

E2. Why are you not taking HIV medications? SELECT ALL THAT APPLY.

- ○ My medical provider and I have decided to wait to start medications
- ○ My medical provider has not prescribed them
- ○ I cannot afford them
- ○ I do not feel sick
- ○ I use alternative medicine (like herbs, vitamins, or acupuncture)
- ○ I had side effects
- ○ I felt there was too much paperwork
- ○ I do not want to go to the pharmacy to get them
- ○ I chose not to take them
- ○ I am temporarily taking a break from them (a "drug holiday")
- ○ I do not have a medical provider
- ○ I do not have stable housing
- ○ Other (specify): _____

F. Housing Status

F1. Where are you living currently (past 30 days)?

- ○ On the street, in a shelter, in a car, or some other temporary place
- ○ In someone else's house or apartment for a short time because I have no place else to go
- ○ In a home or apartment of my own
- ○ In a residential program
- ○ In jail or prison
- ○ Other (specify): _____

F2. Are you living in subsidized housing? ○ Yes ○ No ○ Don't know

F3. Has your living situation changed in the past 6 months?

○ Yes

○ No

F3a. If YES, where did you live most of the time in the past 6 months?

○ On the street, in a shelter, in a car, or some other temporary place
○ In someone else's house or apartment for a short time because I have no place else to go
○ In a home or apartment of my own
○ In a residential program
○ In jail or prison
○ Other (specify): _____

F4. In the past 6 months, have you had any problems getting housing due to any of the following? SELECT ALL THAT APPLY.

○ I have not had any problems getting housing
○ CORI (criminal record information)
○ Waiting lists
○ Meeting eligibility requirements for subsidies (e.g., Section 8) or other public housing programs
○ Finding a place to live that will accept my rental subsidy (Section 8)
○ Credit problems
○ History of drug or alcohol use
○ Problems with my immigration status
○ Other (specify): _____

F5. In the past 6 months, have you had any problems keeping your housing due to any of the following? SELECT ALL THAT APPLY.

○ I have not had any problems keeping my housing
○ Difficulty paying rent, mortgage, or utilities
○ Drug or alcohol use
○ Credit problems
○ Eviction
○ Problems with my immigration status
○ Legal problems
○ Other (specify): _____

You're half way there!!!

G. Access

Choose which things are most important to you when you need to use each of the following HIV services. SELECT ALL THAT APPLY.	I do not use this service	It is located **outside** of my community and I will not see anyone I know there	It is located **in** my community and I know people there	I can get there easily	The staff speak my language	The staff understand my culture and community	It is easy to reach someone	It is easy to make an appointment	Services are free or low-cost	They take my insurance	There are no waiting lists	I can get other services while I am there	The staff understand the needs of people living with HIV/AIDS	None of these
G1a. Primary care	○	○	○	○	○	○	○	○	○	○	○	○	○	○
G1b. Case management	○	○	○	○	○	○	○	○	○	○	○	○	○	○
G1c. Substance abuse services	○	○	○	○	○	○	○	○	○	○	○	○	○	○
G1d. Mental health services	○	○	○	○	○	○	○	○	○	○	○	○	○	○
G1e. Dental care	○	○	○	○	○	○	○	○	○	○	○	○	○	○
G1f. Housing/ residential support	○	○	○	○	○	○	○	○	○	○	○	○	○	○
G1g. Peer support	○	○	○	○	○	○	○	○	○	○	○	○	○	○
G1h. Food services	○	○	○	○	○	○	○	○	○	○	○	○	○	○
G1i. Client advocacy/ legal services	○	○	○	○	○	○	○	○	○	○	○	○	○	○

G2. In general, what do you find most difficult about using HIV services? SELECT ALL THAT APPLY.

○ Nothing - I find it fairly easy to use the services I need

○ Too much paperwork

○ Getting to and from appointments

○ Finding time to go to appointments

○ Having to go to different places to get different services

○ Dealing with all of the things my different providers ask of me

○ Getting services because of my immigration status

○ I do not want people to see me getting HIV services

○ Feeling uncomfortable or unwelcome at some service providers

○ Finding service providers that understand the needs of people living with HIV/AIDS

H. Employment

H1. Do you have a job right now?

- ○ Yes
- ○ No

H1a. If NO, why don't you have a job right now? SELECT ALL THAT APPLY.

- ○ I am unable to find a job
- ○ I got fired or laid off
- ○ I do not know how to apply or interview for a job
- ○ I am afraid I will earn too much and lose government benefits (e.g., SSI/SSDI, Section 8, food stamps)
- ○ I am afraid I will lose access to HIV services
- ○ I am worried that people will find out I have HIV
- ○ I do not have the energy
- ○ I am worried about getting sick on the job
- ○ I do not have enough training or skills
- ○ I am worried about medication side effects in the workplace
- ○ I am currently getting training or education so I can get a job
- ○ I do not have someone to take care of my kids or family
- ○ I have immigration or visa issues
- ○ I am retired
- ○ I am disabled as a result of AIDS
- ○ I am disabled as a result of some other condition
- ○ I have issues with drug or alcohol use
- ○ I am not interested in working
- ○ Other

H1b. If YES, what challenges do you experience as a person living with HIV/AIDS who is working? SELECT ALL THAT APPLY.

- ○ None, I do not experience any challenges
- ○ My energy level sometimes makes it hard to get through the day
- ○ I worry about getting or have gotten sick on the job
- ○ I worry about or have medications side effects on the job
- ○ I do not feel I can be open about my HIV status in the workplace
- ○ It is difficult to get away during the workday to go to HIV medical and service appointments.
- ○ I cannot find or pay for someone to take care of my kids or family
- ○ Other (specify): _____

H2. In the past 6 months, have you done any volunteer work? ○ Yes ○ No

Draft

I. Education

I1. What is the highest level of school you have completed?

- ○ I have never attended school
- ○ 8th grade or less (primary school)
- ○ 9th to 12th grade, but did not graduate from high school (some secondary school)
- ○ Graduated high school (or got GED, completed secondary school)
- ○ Vocational/Technical school/Associates degree
- ○ Some college or university, but did not finish
- ○ College or university degree
- ○ Graduate degree (such as Masters or PhD)
- ○ Don't know

I2. Are you currently in school, college, or a vocational training program?

- ○ Yes
- ○ No

I2a. If NO, do you want to go to school, college, or a vocational training program?

- ○ Yes
- ○ No

If you DO want to go to school, college, or a vocational training program, what is keeping you from going? SELECT ALL THAT APPLY.

- ○ Nothing, I just have not done it
- ○ It costs too much or I am worried about getting or repaying loans
- ○ I do not know if I can handle the work
- ○ I am worried about people knowing I have HIV
- ○ I do not think I have the energy
- ○ I am worried about getting sick at school
- ○ I am worried about medication side effects
- ○ I am worried about taking medications at school
- ○ I do not have someone to take care of my kids or family
- ○ I do not know where to go or how to apply
- ○ I am worried about my immigration status
- ○ I have heard that I could lose my disability status

GO TO NEXT PAGE - J1.

GO TO NEXT PAGE - J1.

J. Substance Use

J1. In the past 6 months, have any of the following people talked with you about alcohol or recreational drug use? SELECT ALL THAT APPLY.

- ○ Medical provider (doctor, nurse practitioner, nurse, physician's assistant)
- ○ Case manager
- ○ Other HIV services provider or outreach/community health worker
- ○ Peer leader
- ○ Mental health counselor (like a therapist or psychiatrist)
- ○ Substance abuse counselor
- ○ Support group member(s)
- ○ Other people living with HIV that I know
- ○ Family/friends
- ○ No one has talked to me about this issue

Note: When thinking about drug use, include illegal drug use and the use of prescription drugs other than as prescribed.

J2. Do you drink alcohol?

- ○ Yes
- ○ No

J3. Have you ever experimented with drugs?

- ○ Yes
- ○ No

Instructions:

If you answered YES to either J2 or J3 above, please answer the questions ***below***.

IF NO to both J2 and J3, skip to question J4 on the next page.

IF YES to EITHER J2 OR J3....	
In the last 3 months, have you felt you should cut down or stop drinking or using drugs?	○ Yes ○ No
In the last 3 months, has anyone annoyed you or gotten on your nerves by telling you to cut down or stop drinking or using drugs?	○ Yes ○ No
In the last 3 months, have you felt guilty or bad about how much you drink or use drugs?	○ Yes ○ No
In the last 3 months, have you been waking up wanting to have an alcoholic drink or use drugs?	○ Yes ○ No

J. Substance Use (continued)

J4. Have you <u>ever</u> used a needle or syringe to inject any drugs or hormones into your body? ○ Yes ○ No

J5. <u>In the past 30 days</u>, have you used a needle or syringe to inject any drugs or hormones into your body?

○ Yes →

○ No ↓

If YES ...		
J5a. Were these drugs or hormones prescribed by your doctor?	○ Yes	○ No
J5b. In the past 30 days have you shared needles or works with someone else?	○ Yes	○ No
J5c. Are you able to get clean needles or works when you need them, either through needle exchange, syringe access, or a pharmacy?	○ Yes	○ No

J6. Have you ever been diagnosed with an alcohol or drug problem? ○ Yes ○ No

J7. Have you ever used any of the following drug or alcohol services? SELECT ALL THAT APPLY.

○ I have never used any drug or alcohol services
○ 12 step meetings (such as Alcoholics Anonymous, Narcotics Anonymous, etc.)
○ Detox programs or rehab
○ Inpatient services
○ Methadone
○ Needle exchange
○ Outpatient services
○ Residential or halfway house
○ Suboxone or Subutex (Buprenorphine)
○ Services or treatment in a shelter
○ Other medications to treat drug or alcohol addiction
○ Other (specify): _____

Note: Please see the last page of this survey for more details on obtaining information and services related to substance use.

K. Mental Health

K1. In the past 6 months, have any of the following people talked with you about <u>mental health topics</u>? SELECT ALL THAT APPLY.

○ Medical provider (doctor, nurse practitioner, nurse, physician's assistant)
○ Case manager
○ Other HIV services provider or outreach/community health worker
○ Peer leader
○ Mental health counselor (like a therapist or psychiatrist)
○ Substance abuse counselor
○ Support group member(s)
○ Other people living with HIV that I know
○ Family/friends
○ No one has talked to me about this issue

K2. In the past 30 days, have you...

K2a. Felt anxious, depressed, or confused?	○ Yes	○ No
K2b. Felt sad or hopeless?	○ Yes	○ No
K2c. Worried so much that it has kept you from doing activities you would have liked to do?	○ Yes	○ No
K2d. Found it difficult to enjoy yourself when engaging in activities you have enjoyed in the past?	○ Yes	○ No
K2e. Had any significant difficulties sleeping?	○ Yes	○ No
K2f. Found yourself reliving bad experiences from the past (flashbacks, feeling as if you are re-experiencing the event)?	○ Yes	○ No

K3. In the past 3 months, have you been diagnosed with any of the following mental health conditions? SELECT ALL THAT APPLY.

○ I have not been diagnosed with a mental health condition in the past 3 months
○ Anxiety
○ Bipolar disorder
○ Attention deficit/hyperactivity disorder (ADHD)
○ Depression
○ Panic disorder
○ Post-traumatic stress disorder (PTSD)
○ Schizophrenia
○ Other

Great job!
You're almost done.

K4. In the past 3 months, have you gotten professional mental health treatment or counseling?

○ Yes ○ No

Note: Please see the last page of this survey for more details on obtaining information and services related to mental health.

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L. Support

L1. Other than your medical and support service providers, who do you depend on for support? SELECT ALL THAT APPLY.

- ○ Husband, wife, partner, or significant other
- ○ Other family members
- ○ Friend(s)
- ○ Co-worker(s)
- ○ Religious or spiritual leader(s)
- ○ Support group members
- ○ Another HIV-positive person
- ○ I depend on no one else

M. Stigma and Disclosure

Please choose how strongly you agree or disagree with each of the following statements.

	Strongly Agree	Agree	Disagree	Strongly Disgree	Don't Know
M1a. Having HIV makes me feel like I am a bad person.	○	○	○	○	○
M1b. I have lost friends or family by telling them I have HIV.	○	○	○	○	○
M1c. I feel set apart or isolated from the rest of the world.	○	○	○	○	○
M1d. I work hard to keep my HIV a secret from others.	○	○	○	○	○
M1e. People with HIV can lose their jobs when employers find out.	○	○	○	○	○
M1f. I feel guilty because I have HIV.	○	○	○	○	○
M1g. Most people believe a person with HIV deserves it for how he/she lived.	○	○	○	○	○
M1h. I worry that people who know I have HIV will tell others.	○	○	○	○	○
M1i. I have stopped hanging out with some people because of their reactions to my having HIV.	○	○	○	○	○
M1j. Most people are uncomfortable around someone who has HIV.	○	○	○	○	○
M1k. People's attitudes make me feel worse about myself.	○	○	○	○	○
M1l. It is hard for people living with HIV to have long term relationships.	○	○	○	○	○

M. Stigma and Disclosure (continued)

M2. Other than yourself (and your HIV medical provider if you have one), does anyone else know you are living with HIV/AIDS?

○ Yes

○ No

M2a. If YES, who? SELECT ALL THAT APPLY.

- ○ Case manager
- ○ Ob/gyn provider
- ○ Other medical provider
- ○ Dentist
- ○ Other service providers
- ○ Husband, wife, partner, or significant other
- ○ My children
- ○ Other family members
- ○ Friends
- ○ Co-worker(s)
- ○ Manager, supervisor or human resources person at work
- ○ Religious or spiritual leader(s)
- ○ No one else knows

M2b. If NO, why haven't you told anyone else? SELECT ALL THAT APPLY.

- ○ I am afraid of how others will react
- ○ I am afraid for my safety
- ○ It is my own business and no one else needs to know
- ○ I am afraid people will judge me
- ○ I am afraid I will lose my job
- ○ I am still coming to terms with my status myself
- ○ I feel like I can manage on my own
- ○ I am afraid because of my immigration status
- ○ Other (specify): _____

M3. What would help you share your HIV status with others?

_____

_____

_____

N. Positive Prevention

N1. In the past <u>6 months</u>, have any of the following people talked to you about your <u>sexual health</u>, such as reducing your and your partner's risk of sexually transmitted diseases (STDs) or Hepatitis? SELECT ALL THAT APPLY.

- ○ Medical provider (doctor, nurse practitioner, nurse, physician's assistant)
- ○ Case manager
- ○ Other HIV services provider or outreach/community health worker
- ○ Peer leader
- ○ Mental health counselor (like a therapist or psychiatrist)
- ○ Substance abuse counselor
- ○ Support group member(s)
- ○ Other people living with HIV that I know
- ○ Family/friends
- ○ No one has talked to me about this issue

N2. In the past 6 months, have you needed…

N2a. Help figuring out ways to be sexually active and stay healthy?

○ Yes → **If yes, have you gotten this kind of help in the past 6 months?**

○ Yes ○ No

○ No

N2b. Help figuring out ways to stay healthy if using drugs and how to use drugs more safely?

○ Yes → **If yes, have you gotten this kind of help in the past 6 months?**

○ Yes ○ No

○ No

N2c. Help figuring out if, when, and how to tell people about your HIV status?

○ Yes → **If yes, have you gotten this kind of help in the past 6 months?**

○ Yes ○ No

○ No

GO TO NEXT PAGE - N3.

N. Positive Prevention (continued)

Please indicate whether you agree or disagree with the following statements about your medical provider. Remember, "medical provider" means your main doctor, nurse practitioner, nurse, or physician's assistant who manages your HIV care. If you have more than one medical provider, think about the one you see most of the time.

	Agree	Disagree	I do not have a medical provider
N3a. My medical provider seems comfortable discussing sex with me, including ways to keep my partner(s) and me healthy	○	○	○
N3b. I am comfortable discussing sex with my medical provider, including ways to keep my partner(s) and me healthy.	○	○	○
N3c. My medical provider seems comfortable discussing alcohol and/or drug use with me.	○	○	○
N3d. I am comfortable discussing alcohol and/or drug use with my medical provider.	○	○	○

Please indicate whether you agree or disagree with the following statements about your case manager. Remember, "case manager" means the person who helps you develop a care plan, coordinates your care and services, and helps link you to care and other services. If you have more than one case manager, answer the questions based on the one you see most of the time.

	Agree	Disagree	I do not have a case manager
N4a. My case manager seems comfortable discussing sex with me, including ways to keep my partner(s) and me healthy	○	○	○
N4b. I am comfortable discussing sex with my case manager, including ways to keep my partner(s) and me healthy.	○	○	○
N4c. My case manager seems comfortable discussing alcohol and/or drug use with me.	○	○	○
N4d. I am comfortable discussing alcohol and/or drug use with my case manager.	○	○	○

O. HIV Knowledge /Literacy

Please indicate whether you believe each of the following statements is TRUE or FALSE.

O1a. A T-cell (CD4) test measures the amount of HIV virus in an HIV-positive person's body.	○ True	○ False	○ Don't know/not sure
O1b. Using a condom is an effective way to prevent HIV transmission during sex.	○ True	○ False	○ Don't know/not sure
O1c. If an HIV-positive person's viral load is "undetectable," it means he/she is cured of HIV.	○ True	○ False	○ Don't know/not sure
O1d. The use of recreational drugs can impact the effectiveness of HIV medications.	○ True	○ False	○ Don't know/not sure
O1e. An HIV-positive woman can give birth to a child without giving HIV to the baby.	○ True	○ False	○ Don't know/not sure

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P. Aging

P1. As you grow older living with HIV/AIDS, which of the following do you think or worry about? SELECT ALL THAT APPLY.

- ○ Finding or having a place to live
- ○ Finding or having someone to share my life with
- ○ Finding retirement or nursing home providers who understand HIV
- ○ Finding medical providers who understand HIV and aging
- ○ Dating
- ○ Managing HIV and other conditions that come with aging
- ○ The impact of HIV on my quality of life
- ○ Going to work or having a job
- ○ Long term impacts of HIV medications
- ○ Having a family
- ○ Retiring
- ○ Getting more education
- ○ Maintaining access to or getting the HIV services I need
- ○ Telling people about my HIV status
- ○ Taking care of my husband, wife, partner, significant other, or other family members
- ○ Staying healthy
- ○ Maintaining healthy behaviors or practices (such as safer sex) over time
- ○ Planning for the end of my life (making a will, long term care, etc.)
- ○ Being a burden on friends, family, or people who take care of me
- ○ None of the above
- ○ Other (specify): _____

Q. Other

Q1. Have you ever participated in any of the following groups either as a member or guest? SELECT ALL THAT APPLY.

- ○ Massachusetts Statewide Consumer Advisory Board (Statewide CAB)
- ○ Boston Ryan White HIV Planning Council
- ○ Massachusetts Prevention Planning Group (MPPG)
- ○ New Hampshire HIV Community Planning Group (NHCPG)
- ○ A Consumer Advisory Board (CAB) for an organization that provides HIV services
- ○ Massachusetts Service Coordination Collaborative (SCCs)
- ○ I have participated in one or more of these activities, but prefer not to say which
- ○ None

Q2. In your opinion, what can be done to help people in your community to stay HIV negative?

_____

_____

_____

_____

YOU HAVE FINISHED THE SURVEY - THANK YOU!

Draft

APPENDIX C: RESPONDENT DEMOGRAPHIC TABLE

Respondent Demographic Table

	MA HIV Prevalence 2009	EMA HIV Prevalence 2009	All Short Form[1] n =1791	All MA Short Form[1] n =1649	All EMA Short Form[1] n=1339	All LINKED Short & Long Form[2] n=1029	All MA LINKED Short& Long Form[2] n=958	All EMA LINKED Short & Long Form[2] n=763
Age (for the state)								
<20	1%	1%	0%	0%	0%	0%	0%	0%
20-29	5%	6%	2%	2%	2%	2%	2%	2%
30-39	15%	16%	12%	11%	11%	12%	11%	11%
40-49	40%	39%	41%	41%	41%	41%	41%	41%
50-59	29%	38%*	36%	35%	35%	36%	36%	36%
≥60	9%		10%	11%	11%	10%	10%	10%
	*Includes all PLWH 50 and older							
Age (to compare with the EMA)								
<20		1%	0%	0%	0%	0%	0%	0%
20-44		45%	31%	30%	32%	31%	30%	31%
45+		53%	69%	70%	68%	69%	70%	69%
Age (alternate categories)								
18 - 39			14%	13%	13%	14%	13%	13%
40 - 49			41%	41%	41%	41%	41%	41%
50+			46%	46%	46%	46%	46%	46%
Race/Ethnicity								
Non-Hispanic White	45%	47%	47%	46%	48%	50%	49%	52%
Non-Hispanic Black	28%	30%	18%	19%	20%	19%	19%	21%
Hispanic	25%	20%	23%	24%	19%	22%	22%	18%
Asian/P.I.	1%	2%	1%	1%	1%	<1%	<1%	1%
Other	1%	<1%	6%	6%	7%	6%	6%	6%
Unknown			5%	4%	5%	3%	3%	3%
Place of birth								
US born						78%	78%	80%
Puerto Rico/Other US territories						14%	14%	10%
Foreign born						8%	8%	10%
Gender								
Male	71%	71%	65%	65%	65%	65%	65%	65%
Female	29%	29%	34%	34%	34%	34%	34%	35%
Transgender (MTF)			<1%	<1%	<1%	<1%	<1%	<1%
Transgender (FTM)			<1%	<1%	<1%	0%	0%	0%

	MA HIV Prevalence 2009	EMA HIV Prevalence 2009	All Short Form[1]	All MA Short Form[1]	All EMA Short Form[1]	All LINKED Short & Long Form[2]	All MA LINKED Short& Long Form[2]	All EMA LINKED Short & Long Form[2]
			n =1791	n =1649	n=1339	n=1029	n=958	n=763
Sexual Orientation								
Heterosexual			54%	54%	54%	50%	50%	51%
Homosexual			40%	40%	39%	43%	43%	42%
Bisexual			6%	6%	7%	7%	7%	7%
Transmission Risk								
Heterosexual	14%	24%	34%	34%	35%	33%	33%	33%
Presumed heterosexual	16%							
IDU	24%	18%	16%	16%	16%	16%	16%	16%
MSM	35%	38%	38%	38%	38%	41%	41%	41%
MSM/IDU	3%	3%	1%	1%	1%	2%	2%	2%
Other	3%	3%	5%	5%	5%	3%	4%	3%
Unknown	6%	14%	5%	5%	5%	5%	5%	4%
State of Residence								
New Hampshire		6%	5%		7%	5%		7%
Massachusetts		94%	93%	100%	93%	94%	100%	93%
Homeless		2%	2%			1%		
County of Residence								
Barnstable, Dukes, Nantucket	4%		7%	8%		7%	8%	
Berk., Fran., Hamp., Hampshire	12%		16%	17%		17%	18%	
Bristol, Norfolk, Plymouth	14%	17%	16%	17%	21%	16%	17%	21%
Essex, Middlesex	24%	29%	19%	20%	25%	19%	20%	25%
Suffolk	32%	38%	25%	27%	33%	24%	25%	32%
Worcester	9%	11%	11%	11%	14%	11%	12%	15%
NH (Strafford, Rock., Hills.)		6%	5%		7%	5%		7%
Homeless			2%			1%		

	MA HIV Prevalence 2009	EMA HIV Prevalence 2009	All Short Form[1] n =1791	All MA Short Form[1] n =1649	All EMA Short Form[1] n=1339	All LINKED Short & Long Form[2] n=1029	All MA LINKED Short& Long Form[2] n=958	All EMA LINKED Short & Long Form[2] n=763
Health Service Region								
Boston/Metrowest	45%		35%	37%	46%	34%	36%	45%
Central	9%		10%	11%	14%	11%	11%	15%
Northeast	15%		10%	11%	13%	10%	10%	14%
Southeast	14%		23%	24%	20%	22%	24%	20%
Western	12%		16%	17%		17%	18%	
Resides in EMA								
In the EMA	79%	100%	77%	76%	100%	76%	74%	100%
Poverty Status								
Living in poverty (at or below FPL)			47%	47%	45%	47%	48%	45%
Insurance Status (could choose more than one)								
Commonwealth Care/Choice			5%	5%	5%	5%	4%	3%
Medicaid (MA or NH)			66%	68%	65%	68%	71%	67%
Private Insurance			27%	28%	28%	27%	28%	29%
Medicare			29%	29%	31%	31%	34%	33%
NH Health Plan			<1%	<1%	<1%	<1%	<1%	<1%
Other			7%	6%	7%	7%	7%	7%
Uninsured			1%	<1%	1%	1%	<1%	1%
Don't know			<1%	<1%	<1%	<1%	<1%	<1%
Last Time Saw Med/Service Provider								
Less than 6 months ago			96%	96%	96%	97%	97%	96%
6 months to 1 year			3%	3%	3%	3%	3%	3%
Over 1 year ago			1%	1%	1%	1%	1%	1%
Never			<1%	<1%	<1%	<1%	0%	<1%
Total NOT IN CARE			*1% (16)*	*1% (14)*	*1% (13)*	*1% (7)*	*1% (6)*	*1% (6)*
Years Living with HIV								
Less than 1 year			2%	2%	3%	3%	2%	3%
>1 to 5 years			13%	13%	13%	11%	11%	11%
>5 to 10 years			19%	19%	20%	20%	20%	21%
>10 years			65%	66%	64%	66%	67%	65%

	MA HIV Prevalence 2009	EMA HIV Prevalence 2009	All Short Form[1]	All MA Short Form[1]	All EMA Short Form[1]	All LINKED Short & Long Form[2]	All MA LINKED Short& Long Form[2]	All EMA LINKED Short & Long Form[2]
			n =1791	n =1649	n=1339	n=1029	n=958	n=763
Survey Language								
English			86%	86%	89%	88%	88%	91%
Spanish			11%	12%	8%	11%	11%	7%
Portuguese			<1%	1%	1%	<1%	1%	1%
Haitian-Creole			<1%	1%	2%	<1%	1%	1%

[1] These columns describe all respondents who submitted a short form survey. The data comes from the short form responses.

[2] These columns describe all respondents who submitted both a short form and long form survey. The data presented comes from the participants' short form response. This allows for more clear and accurate comparison throughout the table.

JSI RESEARCH & TRAINING INSTITUTE, INC.

44 Farnsworth St.
Boston, MA 02210
www.jsi.com

MASSACHUSETTS DEPARTMENT OF
PUBLIC HEALTH OFFICE OF HIV/AIDS

250 Washington Street, 3rd Floor
Boston, MA 02108
www.mass.gov/dph/aids

Building a Healthy Boston

BOSTON PUBLIC HEALTH COMMISSION
HIV/AIDS SERVICES DIVISION

1010 Massachusetts Avenue, 2nd Floor
Boston, MA 02118
www.bphc.org/aids