Ryan White HIV Services, Boston EMA

FY19-20
COMMUNITY NEEDS ASSESSMENT

Ryan White Services Division
Infectious Disease Bureau
Boston Public Health Commission

BOSTON PUBLIC HEALTH COMMISSION

Table of Contents

Rinka Murakami, MPH Candidate
Community Needs Assessment Intern
Boston Public Health Commission
rinkam@bu.edu

Introduction

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 was amended in 1996 and 2000, replaced by the Ryan White HIV/AIDS Treatment Modernization Act of 2006, and reauthorized as the Ryan White HIV/AIDS Treatment Extension Act in 2009. Although the Ryan White CARE Act expired in 2013, the program remains through funding dependent upon the Federal appropriations process.

The Ryan White HIV/AIDS Program (RWHAP) is composed of five parts: A, B, C, D, and F. Funds from Part A provide direct financial assistance to Eligible Metropolitan Areas (EMA) and Transitional Grant Areas (TGA) most severely affected by the HIV epidemic, intending to develop or enhance access to a comprehensive continuum of high quality, community-based care for low-income individuals with HIV/AIDS and their families. This comprehensive continuum should include primary medical care, including HIV specific care, and supportive services which aim to improve access to care, promote health, and enhance quality of life.

The Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB) administers the Ryan White Program using the Part A formula, supplemental components of the grant, and Minority AIDS Initiative (MAI) funds. The formula award is determined according to the most recent HIV/AIDS prevalence data for the geographic region. Supplemental grants are competitively awarded on the basis of demonstrated need and other selection criteria. MAI funding is awarded by formula based on the distribution of living HIV/AIDS cases among racial and ethnic minorities.

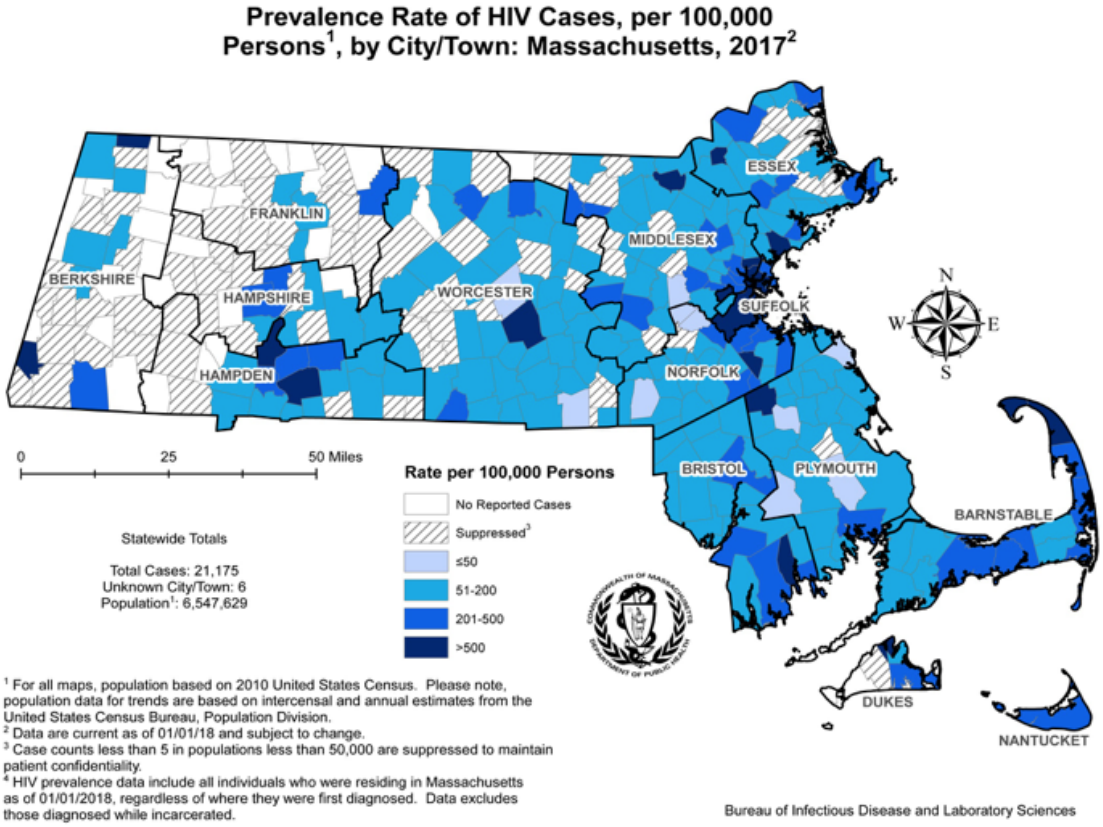
Grants are awarded to each EMA's Chief Elected Official (CEO). The CEO, the Mayor of the City of Boston, then appoints an HIV/AIDS Services Planning Council and designates a Grantee, the Boston Public Health Commission (BPHC). The Planning Council establishes priorities and develops a plan for meeting those priorities. BPHC must distribute grant funds according to the priorities established by the Planning Council.

Background

OVERVIEW OF HIV/AIDS IN THE BOSTON EMA

Data for this section were collected by Massachusetts Department of Public Health (MDPH) and the New Hampshire Department of Health and Human Services (NHDHHS), according to Centers for Disease Control (CDC) surveillance criteria. De-identified data were then provided to the Boston Public Health Commission (BPHC). BPHC collects data on people living with HIV (PLWH) that are enrolled in Ryan White Part A programs in the EMA through e2Boston, an electronic client level data system. Additionally, the BPHC uses information from the Clinical Chart Review (CCR), a report produced by John Snow Inc (JSI). The CCR project reviews a sample of clients receiving clinical care and/or case management among Part A and B funded clinics in MA.

FIGURE 1 | Prevalence Rate of HIV Cases, per 100,000 Persons, by City/Town: MA, 2017

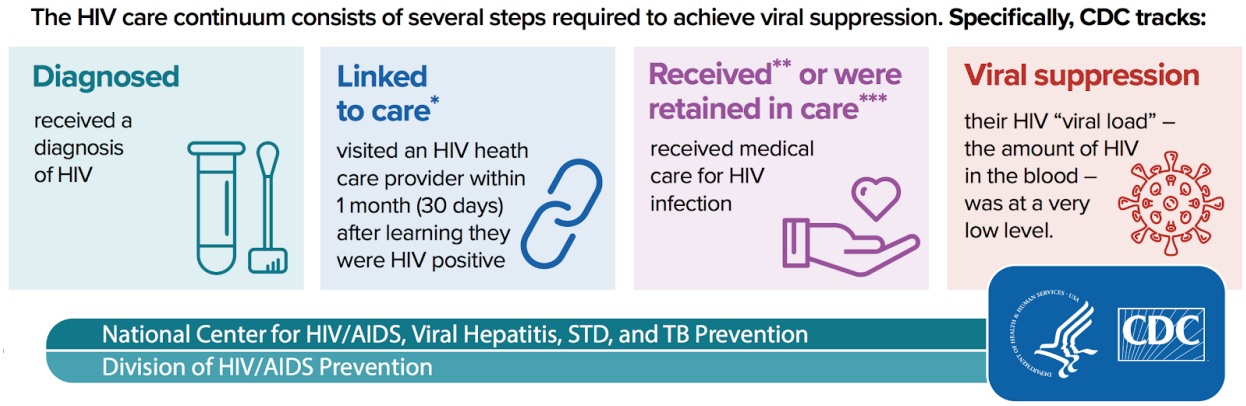


The Boston EMA comprises 308 cities and towns within 10 counties, including seven counties in Massachusetts and three counties in New Hampshire. As of December 31, 2017, there are 18,149 PLWH reported in the Boston EMA. However, in 2017, there were 227 people diagnosed with AIDS, a 27 percent decrease in AIDS diagnoses since 2013.

HIV CARE CONTINUUM (Referenced from the Ryan White Part A Grant prepared by BPHC, Sept. 2019)

To help gauge progress towards national goals on HIV Diagnosis and Care and direct HIV prevention resources most effectively, the CDC developed a tool called the HIV Care Continuum (HCC). The continuum is a series of steps from the time a person receives a diagnosis of HIV through the successful treatment of their infection with HIV medications and achievement of viral suppression.

FIGURE 2 | Understanding the HIV Care Continuum, CDC (July 2019)



The diagnosis-based HIV care continuum shows each step as a percentage of the number of people living with diagnosed HIV. Using the diagnosis-based approach, the BPHC developed its HIV Care Continuum to identify barriers in achieving HIV viral suppression among PLWH in the Boston EMA. Figure 3.1 and 3.2 represent the HCC for the Boston EMA in calendar year (CY) 2017. Table 1 explains how each stage is defined.

FIGURE 3.1 | CY 2017 Diagnosis-based HIV Care Continuum in the Boston EMA

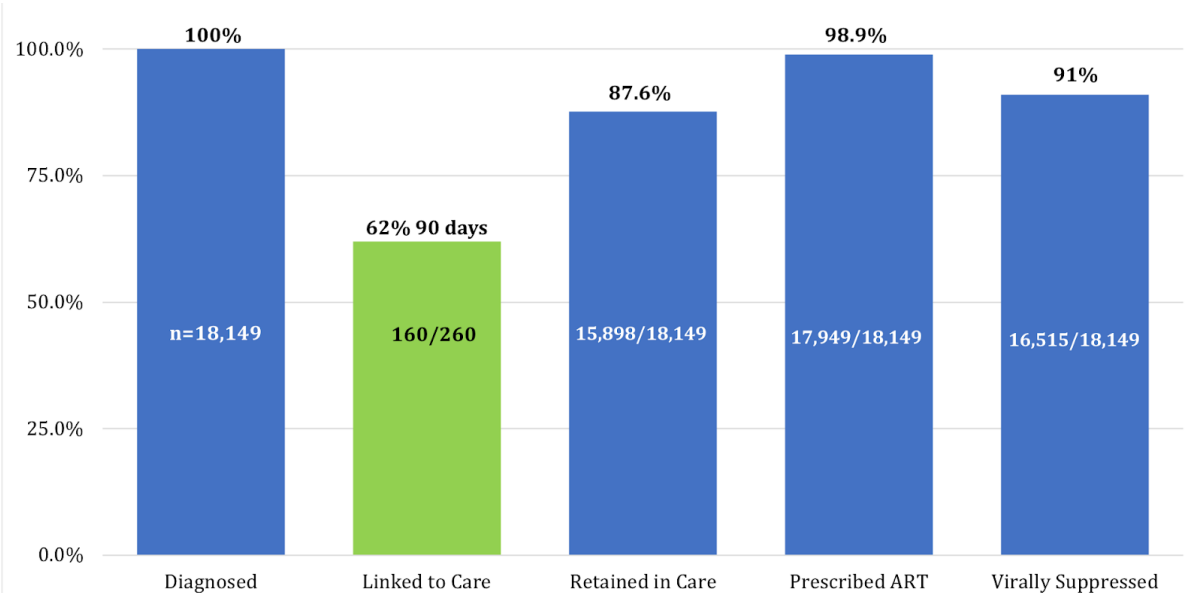


TABLE 1.1 | Figure 3.1 HIV Care Continuum Narrative and Definitions	
Diagnosed	**(18,149/18,149) 100%** **Denominator:** The total number of people diagnosed with HIV in the Boston EMA. **Numerator:** The total number of people diagnosed with HIV in the EMA. *The data is based on surveillance data from the MDPH and NHDHHS for CY17. MDPH and NHDHHS report the number of diagnosed individuals, including persons diagnosed between Jan. 1 2016 and Dec. 31 2016 (vs. prevalent cases).*
Linked to Care	**(160/260): 62%** **Denominator:** The number of clients with a positive HIV test in CY 2017 **Numerator:** The number of clients from the denominator that were linked to medical services within 90 days of diagnosis. *The data to approximate Linkage to Care is estimated from MDPH and NHDHHS EIIHA Data.*
Retention in Care*	**(15,898/18,149) 87.6%** **Denominator:** The number of charts reviewed in the JSI chart review that showed patients with at least one medical visit in the review year 2016. **Numerator:** The number of clients from the denominator who had at least 2 medical visits recorded in their charts during the review year. *The data to approximate the retention in care rate is from a clinical chart review that JSI performs annually for BPHC and MDPH. This chart review randomly selects a set of client charts from clinical sites funded by BPHC and MDPH to collect and analyze outcomes data.*
Prescribed ART*	**(17,949/18,149) 98.9%** **Denominator:** The number of client charts reviewed during CY 2016 that showed a patient to be in care (having had at least one medical appointment) at one of the clinical sites included in the JSI Clinical Chart Review. **Numerator:** The number of client records from the denominator that showed a prescription for anti-retroviral therapy (ART). This amount was 99% from the chart review. We then used this amount to calculate the numerator. *The data to approximate the rate clients using ART medications is from a clinical chart review that JSI performs annually for BPHC and MDPH. This chart review randomly selects a set of client charts from clinical sites funded by BPHC and MDPH to collect and analyze outcomes data.*
Virally Suppressed	**(16,515/18,149) 91%** **Denominator:** The number of client charts reviewed during the CY 2016 review period that showed a patient to be in care (having had at least one medical appointment) at one of the clinical sites included in the JSI Clinical Chart Review.

	Numerator: The percent of client records from the denominator that were virally suppressed (≤200 copies/ml) at their last medical visit. *The data to approximate amount of virally suppressed PLWH in the EMA is from a clinical chart review that JSI performs annually for BPHC and MDPH. This chart review randomly selects a set of client charts from clinical sites funded by BPHC and MDPH to collect and analyze outcomes data.*

* The JSI chart review data does not include PLWH living in the EMA counties of NH. This report is used as a proxy measure for the EMA.

FIGURE 3.2 | CY 2017 Diagnosis-based HIV Care Continuum in the Boston EMA, Part A Services

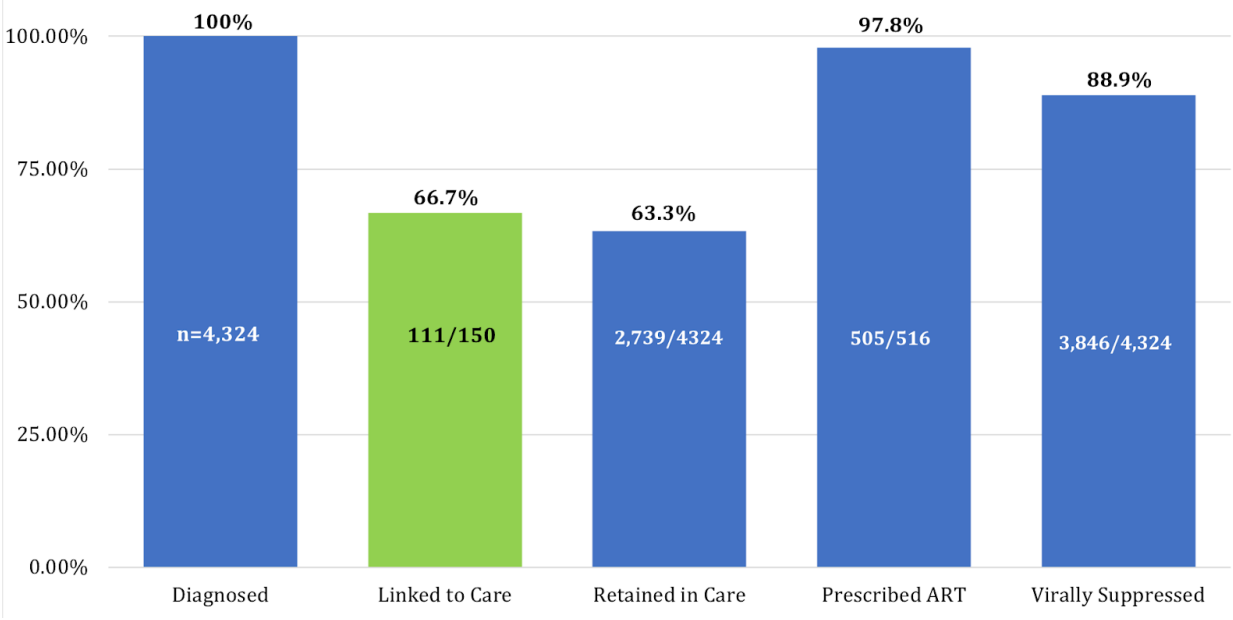


TABLE 1.2 | Figure 3.2 HIV Care Continuum Narrative and Definitions

Diagnosed	**(4,324/4,324) 100%** **Denominator:** The total number of clients with a care engagement** date recorded during FY 2017. **Numerator:** Number of clients from the denominator who have had a diagnosis of HIV/AIDS. *Data for this measure comes from e2Boston- BPHC's cloud-based data reporting system.*
Linked to Care	**(111/150) 66.7%** **Denominator:** The number of clients with a diagnosis of HIV/AIDS recorded during CY 2017. **Numerator:** The number of clients from the denominator that also had a care engagement** date in CY 2017.

	Data for this measure comes from e2Boston's outcomes data which includes engagement in care dates as the dates of medical appointments. These dates are either uploaded from electronic medical records (EMRs) or other forms of medical history or are self-reported by the client.
Retention in Care	**(2,739/4,324) 63.3%** **Denominator:** The number of clients with at least one care engagement** date recorded within FY 2017. **Numerator:** The number of clients from the denominator who also have at least one recorded care engagement** date within FY 2017 *Data for this measure comes from e2Boston's outcomes data which includes engagement in care dates as the dates of medical appointments. These dates are either uploaded from EMRs or other forms of medical history or are self-reported by the client.*
Prescribed ART	**(505/516) 97.9%** **Denominator:** The number of client charts reviewed during CY 2016 that showed a patient to be in care (having had at least one medical appointment) at one of the clinical sites funded by RW Part A included in the JSI Clinical Chart Review. **Numerator:** The number of client records from the denominator that showed a prescription for ART within the same period. *The data for this number was given to BPHC in a separate report that used the JSI Clinical Chart Review data to then drill down on those sites that are funded by Part A. The JSI chart clinical chart review is a project that JSI performs annually for BPHC and MDPH. This chart review randomly selects a set of client charts from clinical sites funded by BPHC and MDPH to collect and analyze outcomes data.*
Virally Suppressed	**(3,846/4324) 88.9%** **Denominator:** The number of clients with a care engagement** date recorded in FY 2017. **Numerator:** The number of clients with a care engagement** date recorded in FY 2017 that had a viral load of <200 copies/mL at their most recent viral load test. *Data for this measure comes from e2Boston's outcomes data which includes engagement in care dates as the dates of medical appointments. These dates are either uploaded from EMRs or other forms of medical history or are self-reported by the client.*

* The JSI chart review data does not include PLWH living in the EMA counties of NH. This report is used as a proxy measure for all Part A funded subrecipients in the EMA.

**A care engagement date includes any visit with a medical doctor including a general visit, viral load test, etc. This date is reported to our subrecipients by the client and is recorded in e2Boston.

PART A APPROVED SERVICES

- AIDS Drug Assistance Program (ADAP/HDAP) (Drug Reimbursement)
- Case Management, Medical
- Early Intervention Services
- Emergency Financial Assistance
- Food Bank/Home-Delivered Meals
- Health Education and Risk Reduction
- Health Insurance Premium and Cost Sharing
- Housing
- MAI Case Management, Medical
- MAI Case Management, Non-Medical
- MAI Psychosocial Support
- Medical Case Management Training & Capacity Building Services
- Medical Nutrition Therapy
- Medical Transportation
- Mental Health
- Oral Health Care
- Outpatient/Ambulatory Medical Care
- Psychosocial Support
- Substance Abuse, Outpatient
- Substance Abuse, Residential

PART A SERVICES MAP: SURROUNDING BOSTON NEIGHBORHOODS

Case Management, Medical

- Beth Israel Deaconess Hospital - Plymouth
- Edward M. Kennedy Community Health Center
- Greater Lawrence Family Health Center
- Lynn Community Health Center

Case Management, Non-Medical

- AIDS Project Worcester
- Making Opportunities Count

Emergency Financial Assistance

- Greater Lawrence Family Health Center
- Making Opportunities Count

Food Bank/Home-Delivered Meals

- AIDS Project Worcester

Health Education - Risk Reduction

- AIDS Project Worcester

Housing

- Father Bill's & MainSpring
- Justice Resource Institute

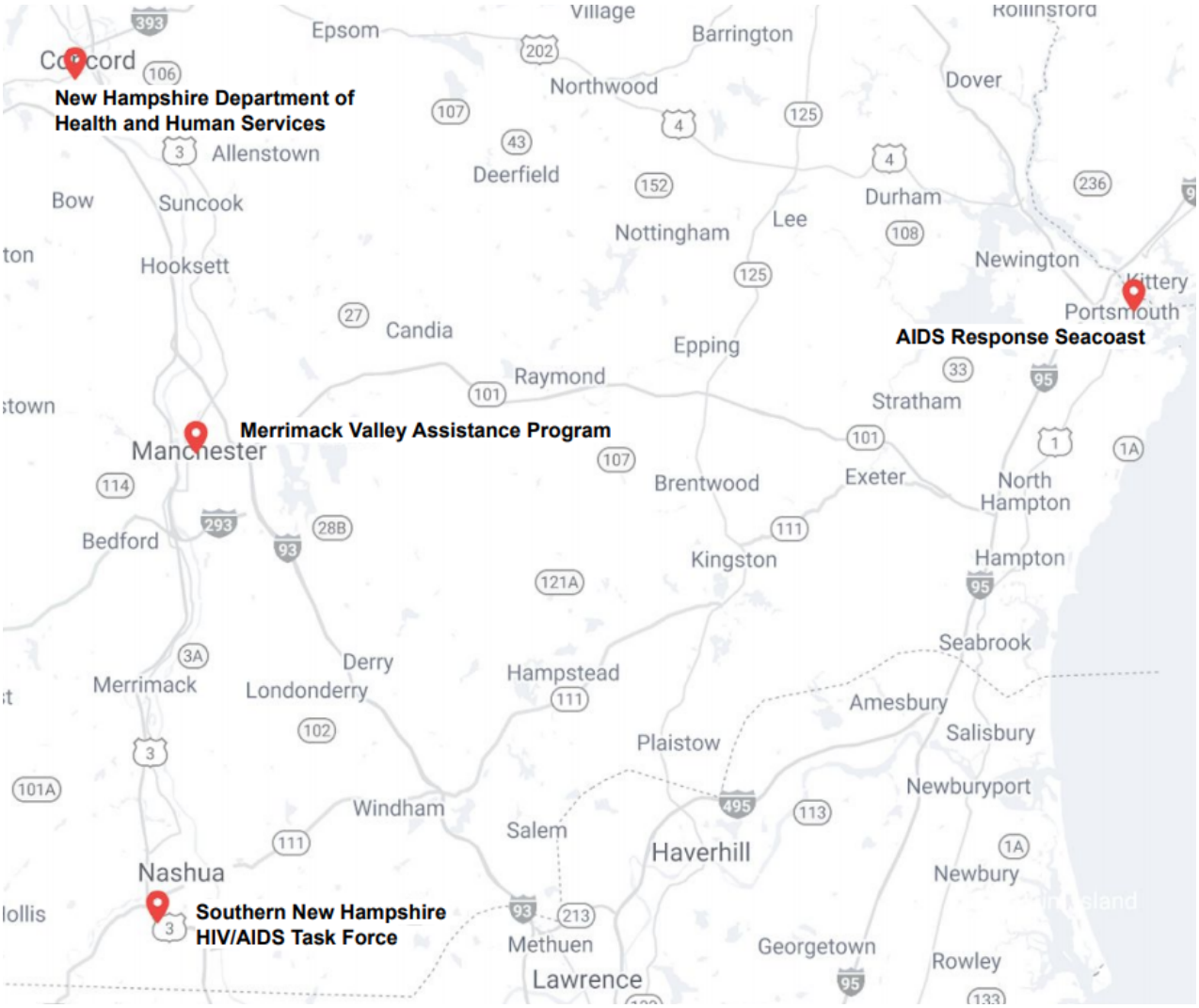
Medical Transportation

- AIDS Project Worcester
- Beth Israel Deaconess Hospital - Plymouth
- Edward M. Kennedy Community Health Center
- Greater Lawrence Family Health Center
- Lynn Community Health Center

Psychosocial Support

- AIDS Project Worcester
- Justice Resource Institute

PART A SERVICES MAP: NEW HAMPSHIRE



AIDS Drug Assistance Program (ADAP/HDAP):

- New Hampshire Department of Health and Human Services

Case Management, Medical

- AIDS Response Seacoast
- Southern New Hampshire HIV/AIDS Task Force

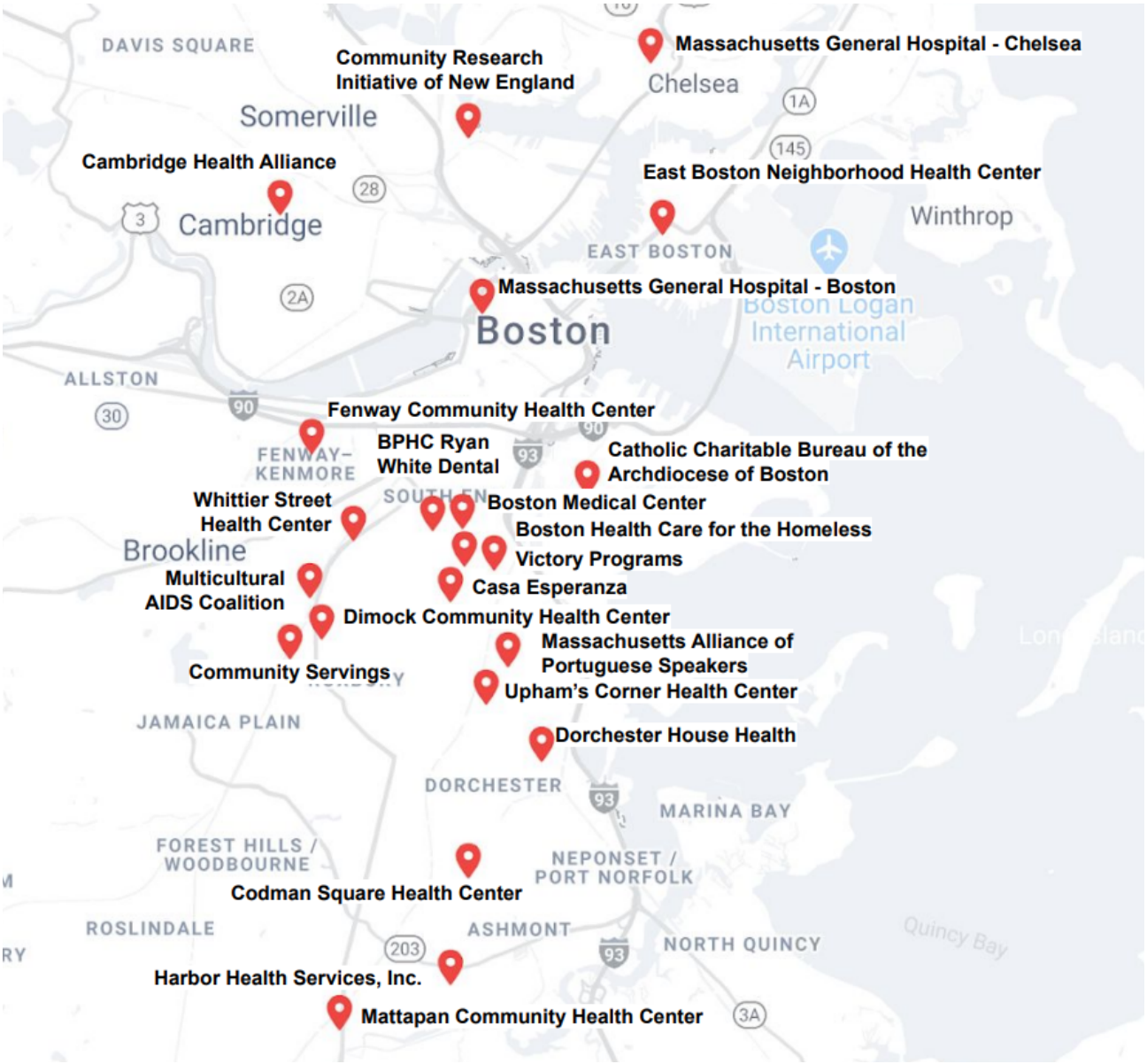
Case Management, Non-Medical

- Merrimack Valley Assistance Program

Psychosocial Support

- Southern New Hampshire HIV/AIDS Task Force

PART A SERVICES MAP: SUFFOLK AND MIDDLESEX COUNTY



MIDDLESEX COUNTY

Case Management, Medical
- Cambridge Health Alliance

MAI Case Management, Non-Medical
- Massachusetts Alliance of Portuguese Speakers

Emergency Financial Assistance
- Massachusetts Alliance of Portuguese Speakers

Health Education - Risk Reduction
- Massachusetts Alliance of Portuguese Speakers

Housing
- Justice Resource Institute

Medical Transportation
- Justice Resource Institute

Psychosocial Support
- Justice Resource Institute

SUFFOLK COUNTY

AIDS Drug Assistance Program (ADAP/HDAP)
- Community Research Initiative of New England Case Management, Medical
- Boston Health Care for the Homeless Program
- Boston Medical Center Corp.
- Codman Square Health Center
- Dorchester House Health
- Mattapan Community Health Center
- Dimock Community Health Center
- Fenway Community Health Center
- Harbor Health Services, Inc.
- Massachusetts General Hospital, Boston/Chelsea

MAI Case Management, Medical
- East Boston Neighborhood Health Center
- Upham's Corner Health Center
- Whittier Street Health Center

Case Management, Non-Medical
- Casa Esperanza, Inc.
- Catholic Charitable Bureau of the Archdiocese of Boston
- Multicultural AIDS Coalition, Inc.
- Victory Programs, Inc.

Emergency Financial Assistance
- Catholic Charitable Bureau of the Archdiocese of Boston
- Fenway Community Health Center
- Multicultural AIDS Coalition, Inc.
- Upham's Corner Health Center
- Whittier Street Health Center

Food Bank/Home-Delivered Meals
- Victory Programs, Inc. Health Education — Risk Reduction
- Boston Children's Hospital
- Casa Esperanza, Inc.
- Multicultural AIDS Coalition, Inc.
- Victory Programs, Inc.

Housing
- Fenway Community Health Center
- Harbor Health Services, Inc.
- Victory Programs, Inc.
- Codman Square Health Center

Medical Nutrition Therapy
- Boston Children's Hospital
- Community Servings, Inc.

Medical Transportation
- Boston Health Care for the Homeless Program
- Boston Medical Center Corp
- Casa Esperanza, Inc.
- Codman Square Health Center
- Dimock Community Health Center
- Fenway Community Health Center
- Massachusetts General Hospital — Boston/Chelsea
- Multicultural AIDS Coalition, Inc.
- Victory Programs, Inc.
- Whittier Street Health Center

Oral Health Care
- BPHC Ryan White Dental Program

Psychosocial Support
- Dimock Community Health Center
- Fenway Community Health Center
- Whittier Street Health Center
- Victory Programs, Inc.

MAI Psychosocial Support
- Codman Square Health Center
- Dorchester House Health
- Mattapan Community Health Center
- East Boston Neighborhood Health Center
- Multicultural AIDS Coalition, Inc.

Substance Abuse, Residential
- Victory Programs, Inc.

Boston EMA Ryan White Planning Council Members

2019-2020

Alves, Adelina

Alves, Justin

Batchelder, Stephen

Barros, Janet

Baum, Patrick

Bennett, Jazzz

Brown, Lamar

Butler, Brian

Callis, Barry

Colon, Gelfi

Corbett, Stephen

Cullinan, Chris

Day, Larry

Diaz, George

Fabiano, John

Flores, Stanley

Gaines, Damon

Giannasca, Robert

Hector, Melissa

Holliday, Brian

Jones, Lorraine

Joseph, Christianan

Keating, Katie

Kirchgasser, Alison

Landrum, Corin

Leblanc, Wendy

Lesley, Christopher

Lituri, Kathy

Lombe, Margaret

Lundy, Gertrude

Nolen, Keith

Olivera, Ericka

Pinheiro, Mahara

Rodriguez, Raymond

Pires, Manuel

Sack, Darren

Shanmugum, Harry

Smith, Carolyn

Smith, Shawnna

Sostre, Jose

Stewart, Jessica

Swaney, Michael

Swanson, Richard

Thomas, Bryan

Winters, Deb

Young, Tim

List of Abbreviations

ADAP/HDAP - AIDS Drug Assistance Program/Housing and Disability Advocacy Program

AIDS - Acquired Immunodeficiency Syndrome

ART - Antiretroviral therapy

ASO - AIDS Service Organization

BPHC - Boston Public Health Commission

CARE - Comprehensive AIDS Resources Emergency

CCR - Clinical Chart Review

CDC - Centers for Disease Control and Prevention

CEO - Chief Executive Officer

CY - Calendar year

EMA - Eligible Metropolitan Area

EMR - Electronic medical records

HAB - The Health Resources and Services Administration's HIV/AIDS Bureau

HCC - HIV Care Continuum

HIV - Human Immunodeficiency Virus

HRSA - The Health Resources and Services Administration

JSI - John Snow Inc.

MA - Massachusetts

MAI - Minority AIDS Initiative

MDPH - Massachusetts Department of Public Health

NH - New Hampshire

NH DHHS - New Hampshire Department of Health and Human Services

NRAC - Needs, Resources, & Allocations Committee (NRAC) of the Boston EMA Ryan White Planning Council

PLWH - People living with HIV

RWHAP - Ryan White HIV/AIDS Program

TGA - Transitional Grant Areas

Consumer Needs Assessment

Grantees of Ryan White funding are required to conduct a HIV Comprehensive Needs Assessment following the Ryan White Treatment Extension Act of 2009. The assessment consists of:

1) Epidemiologic profile describing trends in the HIV epidemic;
2) Assessment of , identifying needs of PLWH specifically related to HIV care;
3) Resource inventory, highlighting the availability of HIV-related services, and services provided to PLWH;
4) Provider capacity profile, describing the extent to which current HIV providers are able to successfully meet the needs of PLWH in their geographic region; and
5) Assessment of unmet need, identifying the barriers to accessing care faced by PLWH who are not currently receiving HIV-related medical care.

The Health Resources and Services Administration (HRSA) guidance recommends a two or three-year needs assessment cycle, with a schedule for collecting updated information to address special areas and support priority-setting and resource allocation activities.

The Boston EMA developed a 3-Year Needs Assessment model (see Table 2) in order to collect the most statistically significant sample of consumer data that could be used to inform allocation decisions. Many components of the assessment were updated annually, such as the epi profile, estimates of those out of care and unaware of their status, and provider information.

TABLE 2 | 3-Year Needs Assessment Model

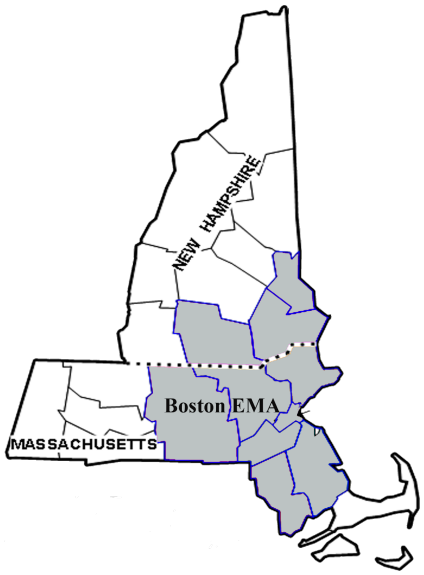
Component	2017-2018	2018-2019	2019-2020
Epidemiologic Profile	Update current information based on State Surveillance data		
Estimates PLWH ● Unaware ● Out of Care	Update current information based on State Surveillance data		
Assessment of Service Needs ● PLWH in care ● PLWH out of care	1) Develop process for agencies interested in conducting a consumer study within the EMA	Design and implement consumer study	Present final results
	2) Select agency to conduct consumer study		
	3) Analyze current reports, Unmet Need Project, E2Boston data	Present results	

Resource Inventory	Gather information from/about services providers	Organize information	Present results
	Update funding stream data		
Profile of Provider • Capacity • Capability	Develop methodology and implement	Analyze results	Present results
Assessment of Unmet Need/ Service Gaps	Summarize data from all other components	Analyze and present results	Create Final Needs Assessment Report (April 2020)

This data collection was conducted between March 2019 and May 2020 through a survey and focus groups of PLWH living in 308 cities and towns within the 10 counties (see Figure 4) that make up the Boston EMA.

FIGURE 4| Map of Counties in Boston EMA

Massachusetts (MA):		New Hampshire (NH):
Bristol	Plymouth	Hillsborough
Essex	Suffolk	Strafford
Middlesex	Worcester	Rockingham
Norfolk		



Methods

To assess service needs and barriers of PLWH in the Boston EMA, the Ryan White Planning Council conducted a survey and a series of semi-structured focus groups. The survey collected data from a larger group of individuals using a series of mostly closed- ended and some open-ended questions. The focus groups offered qualitative data and enabled deeper insight of experiences receiving HIV-related care and services. All data was collected from March 2019 to May 2020. Both quantitative and qualitative data were collected in partnership with the following 21 different AIDS Service Organizations (ASOs) in MA and NH (see Figure 1).

The survey (see Appendix A) was an anonymous tool that included 17 questions about (1) basic demographic information (e.g., age range, racial identity, county of residence, etc.), (2) HIV-related care and services received, and (3) needs and barriers experienced when trying to access services.

Surveys were self-administered and distributed to PLWHA attending an HIV-related care visit at one of the partnering AIDS Service Organizations (ASOs) in the Boston EMA (see Figure 5) or accessed online. * = Also participated in focus group interviews.

1. AIDS Project Worcester*
2. AIDS Response Seacoast
3. Appledore Infectious Disease Clinic
4. Boston Health Care for the Homeless Program
5. Cambridge Health Alliance
6. Codman Square Health Center
7. Community Research Initiative of New England (CRI)
8. Greater Lawrence Family Health Center
9. Greater New Bedford Community Health Center*
10. Harbor Health Services, Inc.
11. Health Imperatives - Sexual & Reproductive Health Services
12. Justice Resource Institute
13. Lynn Community Health Center
14. Maranda's House*
15. Massachusetts General Hospital HIV/AIDS Clinic
16. Southern NH HIV/AIDS Task Force
17. SSTAR Family Healthcare Center
18. Tufts Medical Center - HIV/AIDS Clinic
19. Upham's Corner Health Center *
20. Victory Programs, Inc.
21. Whittier Street Health Center

FIGURE 5 | Needs Assessment Participant ASOs in Boston EMA

The 19-question survey was developed by the Needs, Resources, & Allocations Committee (NRAC) of the Boston EMA Ryan White Planning Council to identify 1) if PLWH are falling out of care and 2) what is causing them to disengage from routine HIV care. Survey questions were pulled and edited from surveys used in previous needs assessments conducted by the John Snow Institute (see Appendix C) and Boston University School of Public Health (see Appendix D).

Surveys were available in paper and online formats in four different languages: English, Spanish, Hatian-Creole, and Portuguese. These languages were chosen because they are the dominant languages spoken by clients accessing Part A funded agencies. No incentives were offered for completing the survey; gift cards were offered to focus group participants for their time and input. Completed paper surveys were sent back to the BPHC by pre-paid mail service. Business cards and posters with QR codes linking to the online version of the survey were also available at the ASOs. 46 responses were received from the online version.

The focus groups were facilitated by Planning Council Services (PCS) members and staff by using a semi-structured guide (see Appendix B). Focus group participants were also given surveys. Participants were asked about their experiences of living with HIV/AIDS in the Boston EMA, their HIV-related service needs, the importance of HIV services, and any challenges experienced when accessing services. Five partnering ASOs hosted focus groups. For each group, one or two PCS members or staff facilitated the discussion and at least one other PCS member or staff took notes. Staff of the partnering ASOs were present in some focus groups. All participants were assured of confidentiality and were asked their consent.

All procedures, tools, and systems related to data collection for these activities were reviewed and approved by the Ryan White Planning Council on February 14, 2019.

Analysis

Descriptive statistics were generated for the assessment of need survey. Proportions and frequencies are reported for categorical variables; means and standard deviations are reported for continuous variables. All quantitative analyses were completed in Excel Version 16.16.22 and RStudio Version 1.1.456.

Notes from the focus group discussions were reviewed and grouped by theme.

Participants

SURVEY RESPONDENTS

Survey respondents were recruited by staff at the partnering ASOs. Of the 18,149 (as of December 31, 2017) PLWH in the Boston EMA, 320 individuals completed the survey.

Table 3 shows characteristics of survey respondents (see Appendix E for more details) in comparison to characteristics of PLWH reported to the MA HIV/AIDS surveillance system as of January 1, 2019.

Some of the questions asked on the survey are not available from reported surveillance data and these are marked as “not available” in the table. In general, characteristics of survey respondents were similar to PLWHA reported to surveillance, except that the respondents were older on average and had been living with HIV for a longer period of time.

TABLE 3 | Comparison of survey respondents in Boston EMA and PLWHA reported to MA HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=320)		MA HIV/AIDS Surveillance Systems (N=22,634)[a]	
	N	%	N	%
Age				
30 years of age or younger	7	2.19%	1,584	7%
50+ years of age or older	205	64.1%	13,128	58%
Gender				
Male	212	66.3%	15,844	70%
Female	96	30.0%	6,564	29%
Transgender Male to Female	3	9.38%	226*	1%*
Transgender Female to Male	2	6.25%		
Gender fluid	1	3.12%	0	0%
Ethnicity				
Hispanic	112	35.0%	6,111**	27% **
Race				
White/Caucasian	148	46.3%	9,280 ***	41% ***
Black or African-American	80	25.0%	6,790 ***	30% ***
American Indian/ Alaskan Native	2	.625%	Not available	
Asian/Pacific Islander	4	1.25%	453	2%
Prefer not to answer	5	1.56%	Not available	
Other	33	10.3%	226	1%
Sexual Identity				
Heterosexual	160	50.0%	Not available	
Gay	109	24.1%		
Lesbian	0	0%		
Bisexual	30	9.38%		
Other	4	1.25%		
Primary Spoken Language				
English	109	65.3%	Not available	
Spanish	60	20.6%		
Cape Verdean Creole	7	2.41%		
Portuguese	21	7.22%		
Haitian Creole	10	3.44%		
French	0	0%		
Swahili	1	.344%		
Other	2	z		
Immigration Status				
U.S. Citizen	256	81.5%	Not available	
Legal Permanent Resident	22	7.01%		
VISA	3	.956%		
Refugee/Asylee	6	1.91%		
Undocumented	20	6.37%		

[a]County level data of PLWH

*Sex at Birth
**Non-Black, Non-White
***Non-Hispanic

Over half of respondents were 50 years or older (64.1%) and male (66.3%). Less than 5 percent of respondents were 30 years of age or younger (2.19%). Half of the respondents identify their sexual orientation as heterosexual, and almost a quarter identify as gay (24.1%).

Most respondents were white (46.3%) and the majority were not Hispanic or Latino/a (65%). Of the respondents who selected "other" (6.7%), most considered their race to be Hispanic and did not identify with another race.

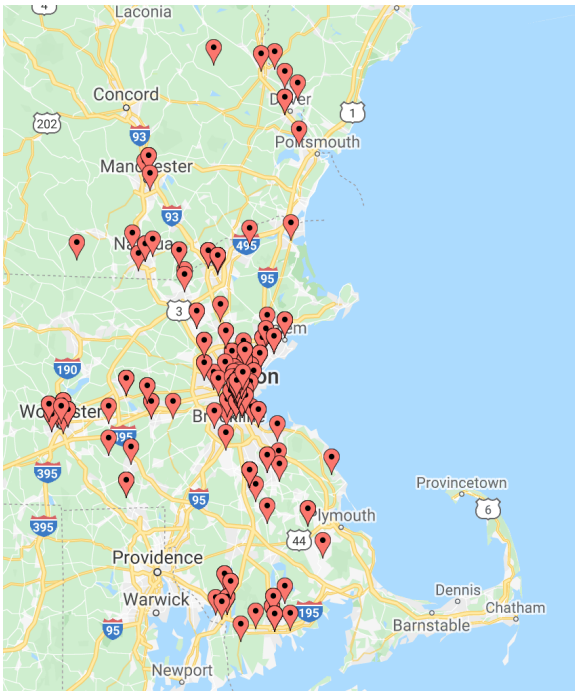
Most respondents reported English as their primary spoken language (65.3%), with Spanish following second (20.6%). Less than 1 percent of respondents primarily speak Swahili (0.344%) or other languages (0.688%) such as Burmese.

TABLE 4| Survey Respondents in Boston EMA by County

County	Boston EMA Survey Respondents (N=320)	
	N	%
Bristol	28	8.83%
Essex	41	12.9%
Hillsborough	18	5.68%
Middlesex	52	16.4%
Norfolk	6	1.90%
Plymouth	22	6.94%
Rockingham	1	0.315%
Strafford	8	2.52%
Suffolk	108	34.1%
Worcester	26	8.20%

Most respondents live in Suffolk County (34.1%), followed by Middlesex and Essex (16.4%, 12.9%). This survey was able to reach one person from Rockingham County.

FIGURE 6 | Survey Respondents in Boston EMA Mapped by Zip Code



FOCUS GROUP PARTICIPANTS

Focus group participants were recruited by staff at the four partnering ASOs: AIDS Project Worcester, Greater New Bedford Health Center, Maranda's House, and Upman's Corner Health Center. During April 2019 and March 2020, there were 52 individuals who participated in the focus groups (see "Methods" for eligibility criteria). Surveys were also distributed participants, which were completed at the end of focus group discussions.

Findings

SURVEY

39.9% of survey respondents were diagnosed in the current zip code they are living at (within the Boston EMA). 60.1% received a diagnosis somewhere else (see Figures 5, 6, and 7).

FIGURE 7 | Zip Code at Time of Diagnosis (Outside of Current Zip Code): MA Map

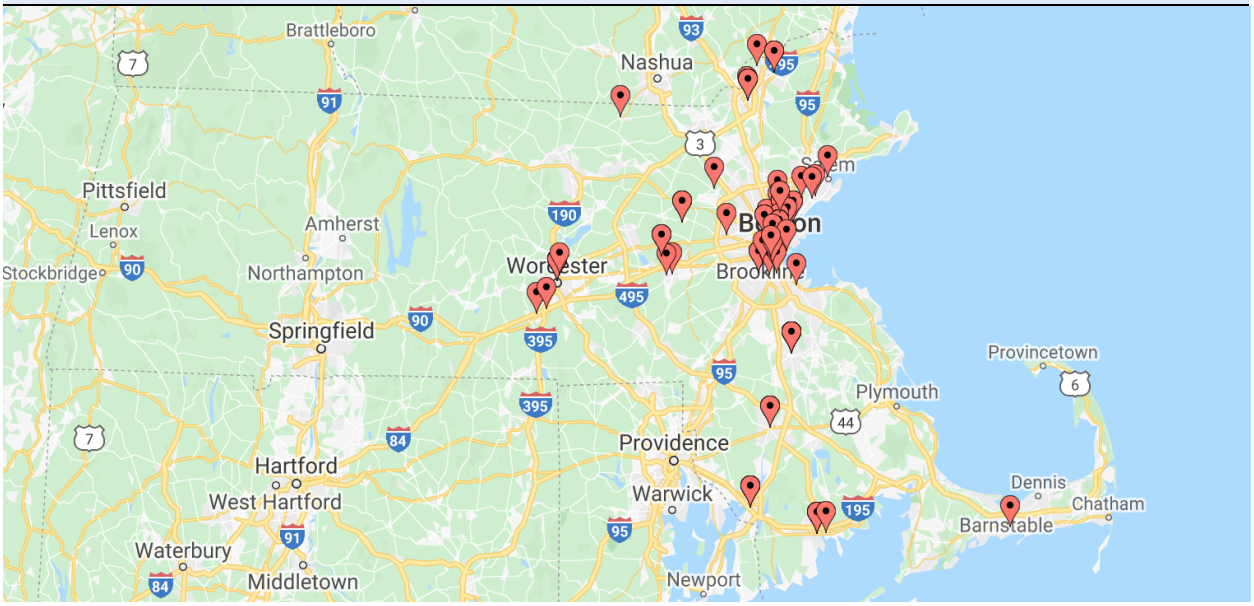


FIGURE 8 | Zip Code at Time of Diagnosis (Outside of Current Zip Code): U.S. Map

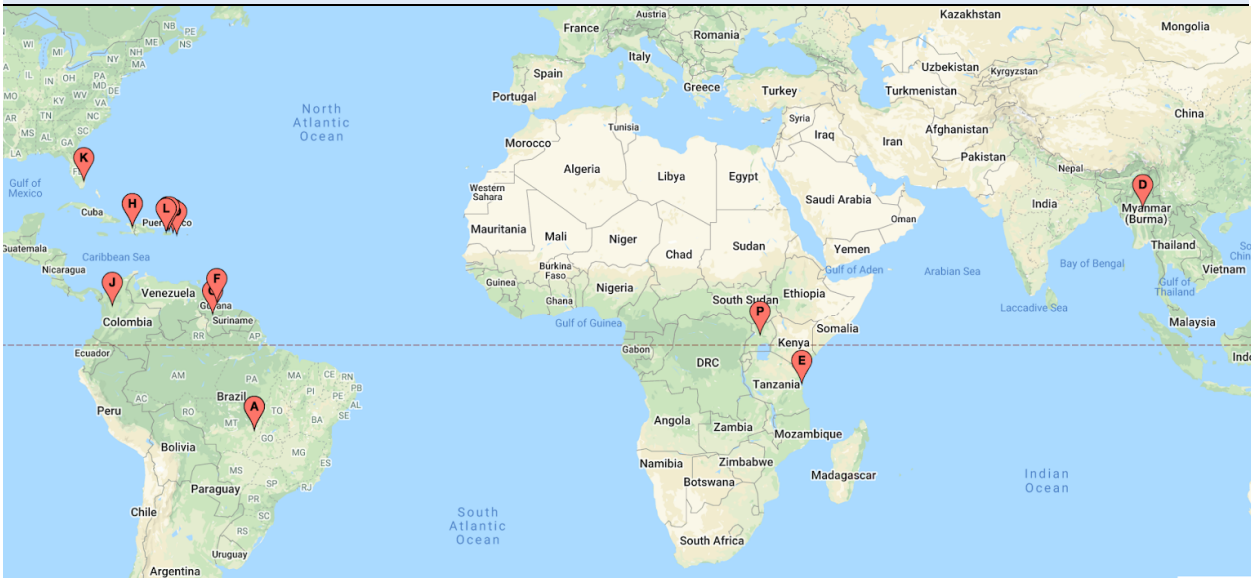
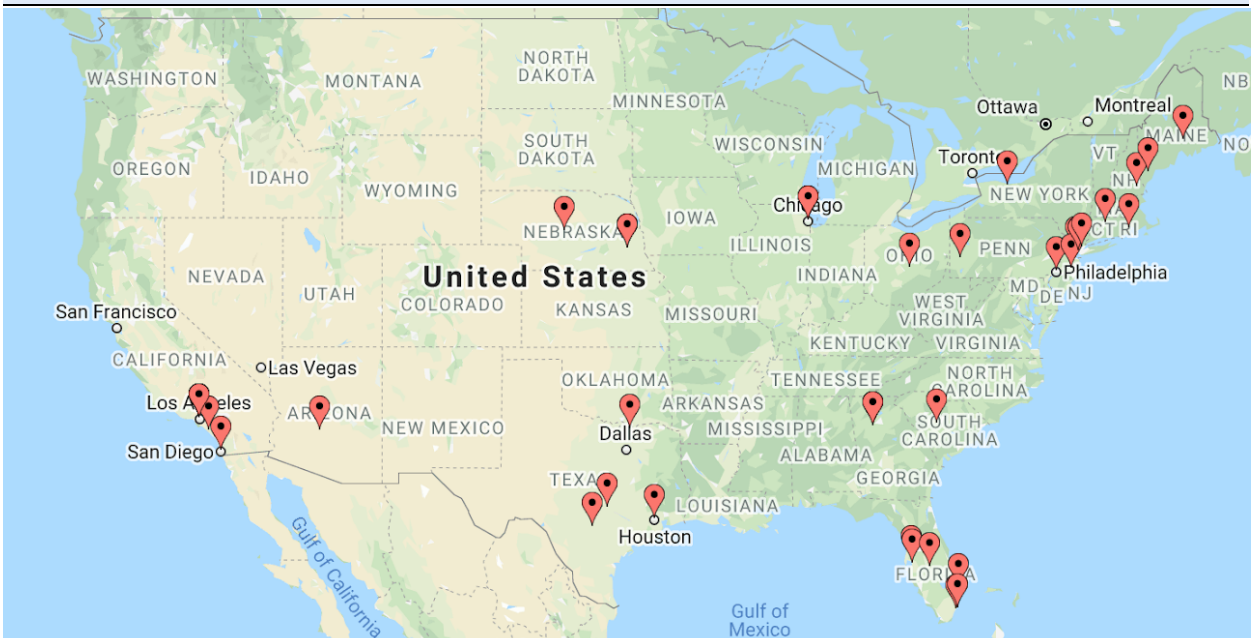


FIGURE 9 | Zip Code at Time of Diagnosis (Outside of Current Zip Code): World Map



The earliest self-reported year of a diagnosis for HIV was in 1980, when 3 people tested positive. The median year was in 2000 and the mean was 2001. The first quartile was in 1992 and the third quartile was in 2009. The most recent year of diagnosis was in 2019 (see Figures 10.1-10.3).

Out of 305 respondents who provided information, 33.4% are long term survivors of HIV (diagnosed in 1995 or earlier).

FIGURE 10.1 | Year Respondents First Tested Positive for HIV N=305

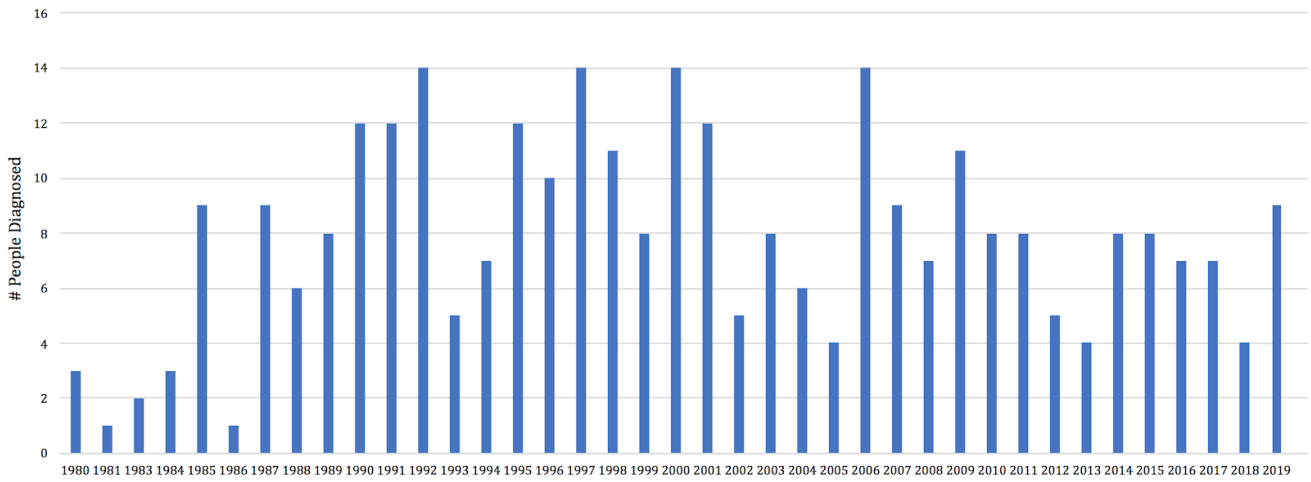


FIGURE 10.2 | Year Respondents First Tested Positive for HIV, Up to Second Quartile

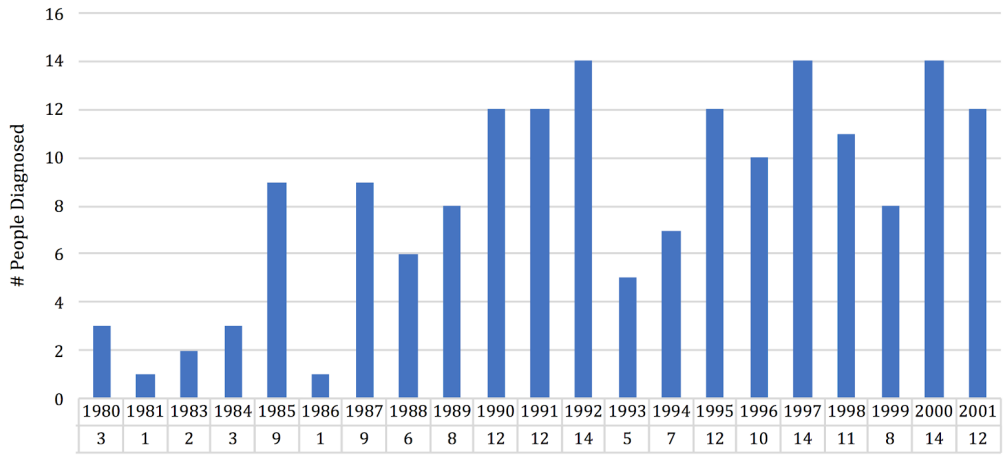
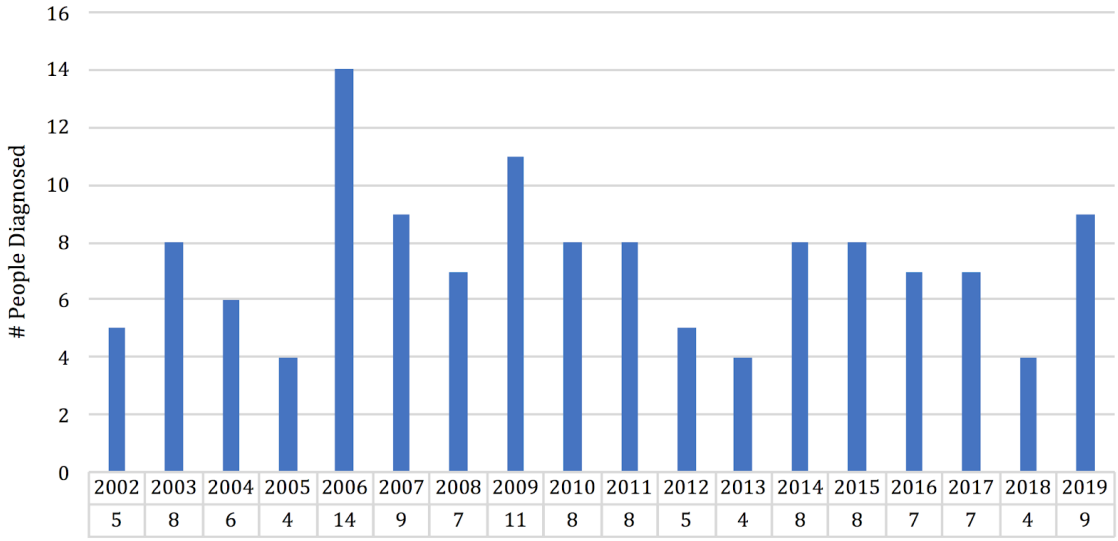


FIGURE 10.3 | Year Respondents First Tested Positive for HIV, Up to Fourth Quartile



The earliest self-reported year a respondent began taking HIV medications was in 1980, where 1 person began medication. The median year was 2002 and the mean was 2003. The first quartile was in 1996 and the third quartile was in 2010. The most recent year HIV medication began was in 2019 (see Figures 11.1-11.3).

It is also important to note the implementation timeline of antiretroviral medications when looking at this self-reported data. Combination therapy with different medications is highly common, which may lead to varying perceptions and opinions of what is considered HIV medication and when medication began. Highly active antiretroviral therapy (HAART) became widely available to people living with HIV/AIDS in 1996. (Source: Living History of Ryan White and Global HIV/AIDS Programs, HRSA)

FIGURE 11.1 | Year Respondents Began Taking HIV Medications N=298

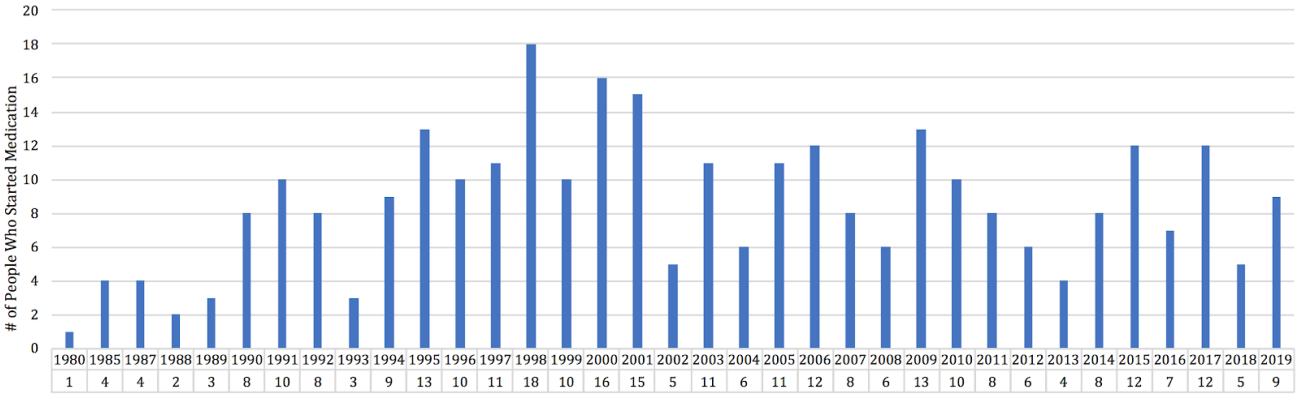


FIGURE 11.2 | Year Respondents Began Taking HIV Medications, Up to Second Quartile

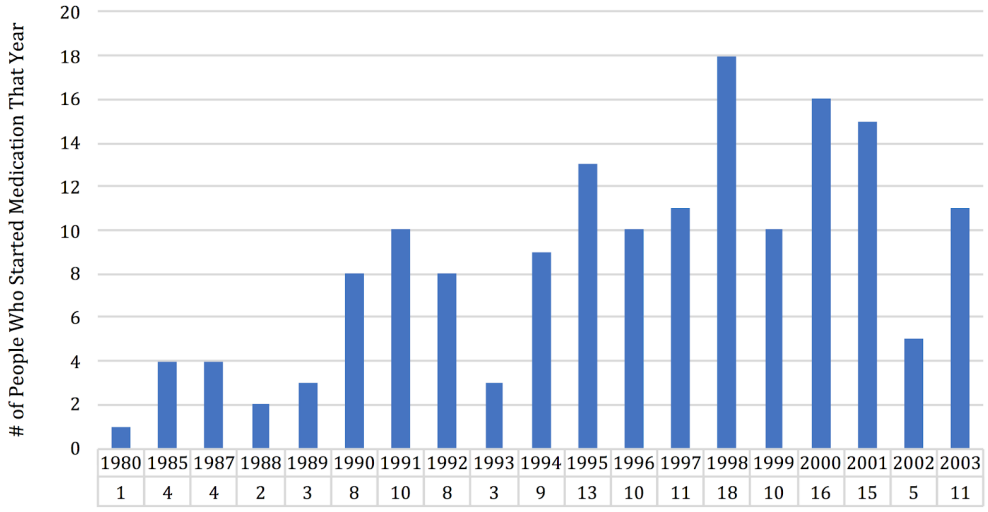
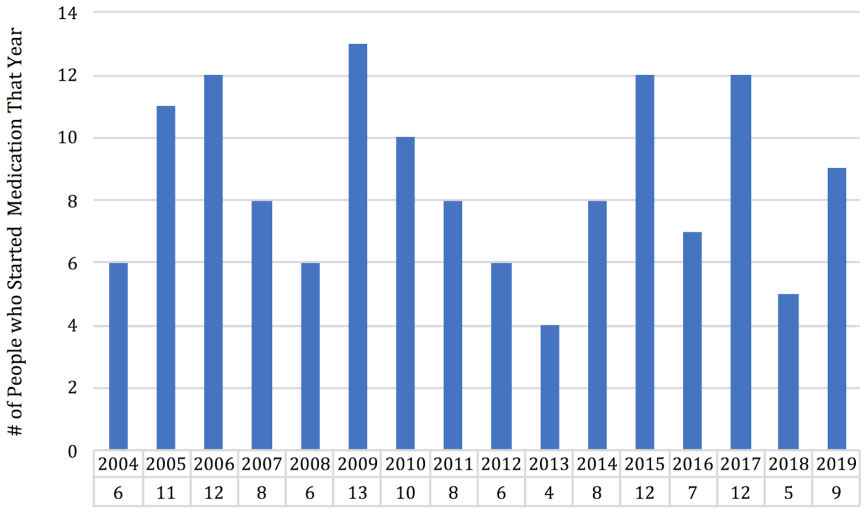


FIGURE 11.3 | Year Respondents Began Taking HIV Medications, Up to Fourth Quartile



Out of 306 respondents who provided information, 17.0% reported they have stopped taking HIV medications for more than a week in the past 6 months. The number one cause of why they stopped taking HIV meds was because respondents forgot to take them (53.7%). Other reasons reported were wanting to avoid side effects, feeling depressed or overwhelmed, feeling too sick, and living on the street or homeless. Those who responded with "Other" experienced delays in the pharmacy to refill their medications, losing their medication, or lack of health insurance.

TABLE 5 | Why did you stop taking HIV medications?

Reason	N=54	
	N	%
Forgot to take them	29	53.7%
Wanted to avoid side effects	10	18.5%
Was busy with other things	4	7.41%
Had problems taking pills	3	5.56%
Could not get to a doctor or clinic	4	7.41%
Felt depressed or overwhelmed	18	33.3%
Felt too sick	6	11.1%
Was living on the street or homeless	10	18.5%
Had too many pills to take	6	11.1%
Could not afford a refill	3	5.56%
Other	10	18.5%

*Not mutually exclusive.

Of those who responded, the majority of respondents are virally undetectable (82.1%). 7.41% were unsure whether they were.

TABLE 6 | Are you virally undetectable?

Response	N=313	
	N	%
Yes	257	82.1%
No	40	18.5%
Don't Know	16	7.41%

Out of 311 respondents who provided information, 51.1% get to their appointments and errands by public transportation. 40.8% used a personal vehicle for transportation. Those who responded with other listed Medicaid transportation, coordinated transportation solutions, and MassHealth PT-1 transportation.

TABLE 7 | How do you get to your appointments or run errands?

Reason	N=311	
	N	%
Public transportation	159	53.7%
Personal vehicle	127	40.8%
Walk	69	22.1%
Friend or family member	25	8.03%
Uber/Lyft/Taxi	41	13.2%
Shuttle service managed by provider	18	5.79%
Bicycle	15	4.82%
Other	14	4.50%

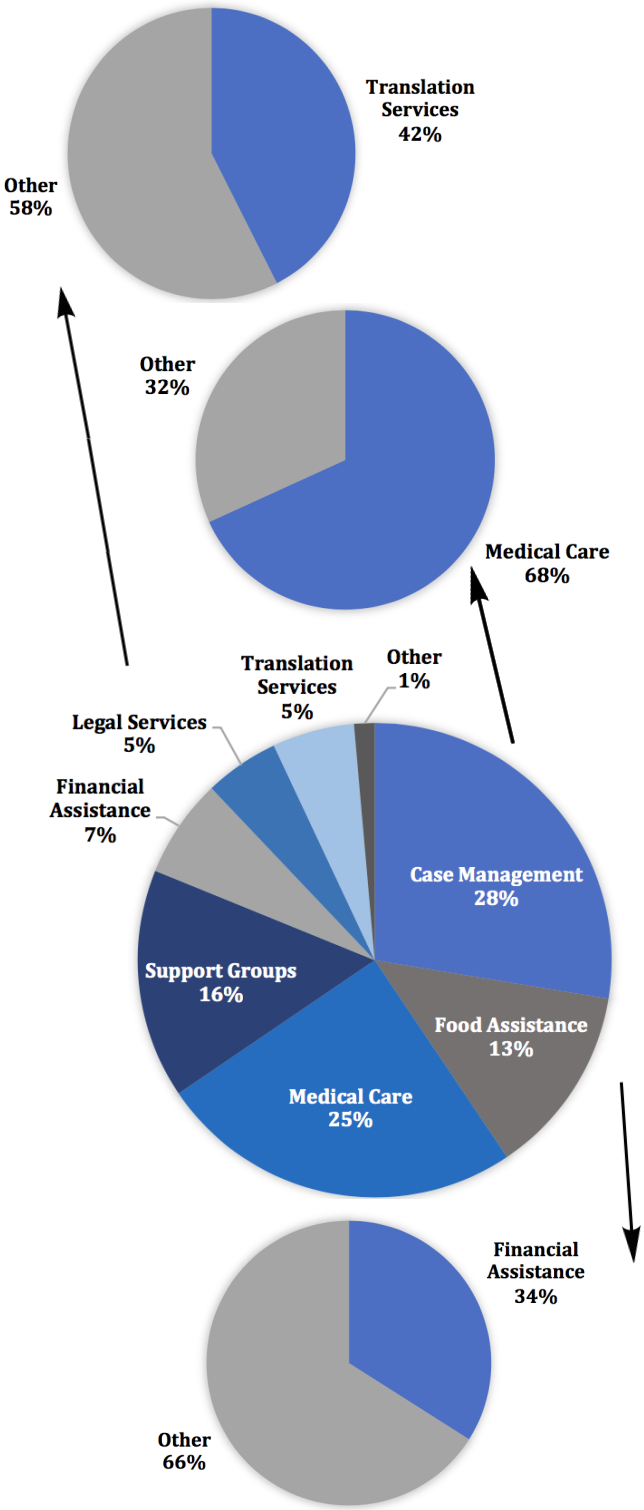
Almost all respondents (88.8%) access HIV services in the community (see Table 3). Most respondents access care through case management (76.4%) and over half (69.0%) are receiving medical care. Support groups (43.3%) and food assistance services (35.9%) are accessed by more than a quarter of respondents. Those who access other services said they are receiving dental services and therapy.

TABLE 8 | What services in the community are you accessing?

Service Category	Of those who are accessing services (N=284)	
	N	%
Case management	217	76.4%
Food assistance	102	35.9%
Medical care	196	69.0%
Support groups	123	43.3%
Financial assistance	53	18.7%
Legal services	40	14.1%
Translation services	44	15.5%
Other	25	3.87%

Of those who are accessing case management services, 68.2% of respondents also receive HIV medical care. Of those who access legal services, 42.5% also use translation services. Of those who access food assistance services, 34.0% also receive financial assistance.

FIGURE 12 | What services in the community are you accessing?



Almost half (48.4%) of respondents reported that they had difficulty accessing or using HIV services (see Table 4). Among those who reported difficulties, the most common barrier preventing respondents from receiving more services were housing status (22.7%), transportation (19.4%), and income or ability to pay (19.0%).

TABLE 9 | If you want to receive more services, what is preventing you?*

Service Category	Of those who experience barriers (N=155)	
	N	%
Transportation	53	19.4%
Income/Ability to pay	52	19.0%
Housing status	62	22.7%
Language barrier	13	4.76%
Child care/Family needs	14	5.13%
Competing priorities	24	8.79%
Fear of stigma	31	11.4%
Immigration status	21	7.69%
Lack of support	28	10.3%
Other	18	6.59%

*Not mutually exclusive.

More than 25% of respondents mentioned 3 or more barriers (25.1%). Of those who said transportation was a barrier, 71.7% mentioned an additional barrier.

When asked if they are frustrated with any of the services they are receiving, 64.4% of respondents said "No." Among those who responded "Yes" (18.1%), 40.4% said their reason for frustration was general dissatisfaction and 36.5% said it was due to wait times. Those who listed "Other" (28.8%) mentioned frustration with housing services and frequently changing case managers.

TABLE 10 | Why are you frustrated?*

Reason	Of those who responded (N=52)	
	N	%
General dissatisfaction	21	40.4%
Hostile environment from health care professionals/providers	10	19.2%
Timely follow up from hospital/clinic staff or providers	13	25.0%
Wait times	19	36.5%
Location/hours of operation	9	17.3%
Other	15	28.8%

*Not mutually exclusive.

Among those who reported additional services they would like to access that are not available, the majority were existing services that consumers did not know of. This reflects a gap in education and knowledge on the types of services available in the Boston EMA. The top existing services respondents said they needed but could not get were:

- Utility assistance
- Financial assistance
- Housing assistance

The top services respondents said they needed but could not get were:

- Educational services
- Support for a healthy lifestyle, such as exercise gyms, health education
- Employment assistance

There was a strong desire for additional services that will help consumers in the long-term, such as guidance for a healthy lifestyle and assistance in returning to school for work or finding new employment.

There are disparities in the needs, services, and barriers by county. See Appendix E to understand county-specific breakdowns.

FOCUS GROUP

Health Education/Support for Healthy Lifestyle

"Having had complications from HIV changed my health. More information on nutrition would be very helpful, [as it's the] cornerstone to how you feel."
- Focus group participant, Southern New Hampshire HIV/AIDS Task Force

An additional service that was commonly desired by survey respondents, health education and support for a healthy lifestyle were also brought up in many focus group discussions. Participants described how complications from HIV change their health as they age, and their growing consciousness of nutrition they did not consider when younger. There is a strong desire for nutritional information from a dietician.

Relationships with Case Managers

" It makes a difference when you are with providers who understand you, that understand HIV, and the struggles and stigma we go through."
- Focus group participant, AIDS Project Worcester

Another common theme in both the survey and focus groups were patient relationships with case managers. Participants describe becoming educated about HIV and receiving support from long-term case managers. However, with the high turnover rate of case managers, participants feel a shift from a "grassroots model to medical model."

Services Cut

*"**Services are cut because they're thought of as small services, but they're lifelines for some of us.** Some of the things we deal with, there are some people who need support, especially those who are recovering."*
- Focus group participant, Southern New Hampshire HIV/AIDS Task Force

Services that were defunded were also a common topic in the survey and focus groups. Many participants expressed their sadness and frustrations with closing ASOs and services. The most common frustration was the closing of drop in care centers, which allowed PLWH to go and get off the street.

Affordable Housing

"Patients don't want to stay in shelters in order to become homeless in order to get housing."
- Provider, Greater New Bedford Community Health Center

Affordable housing was the most important service in patients' lives from the Upham's Corner Health Center focus group. Similarly, other focus groups spoke on how housing is a major issue for PLWH in the Boston EMA.

Participants described it could take five years to receive stable, affordable housing. During that time they must answer every call and requests for information from a potential housing program. This is a barrier for people who may not maintain a phone, have access to a computer, and don't have a stable place to live in the meantime.

Rent assistance was identified as the greatest need related to housing. Participants shared their difficulty with rigid eligibility guidelines.

Transportation

"At that time, drugs were the most important and now it seems transportation is. I have a car and I had no idea. Access to healthcare, medications, and T because people need a ride to get all this."
- Focus group participant, Southern New Hampshire HIV/AIDS Task Force

While 19.4% of survey respondents identified transportation as a barrier, 100% of focus groups discussed transportation as a major barrier to care.

Participants discussed barriers within transportation services, such as those who cannot apply to MassHealth PT-1 medical transportation because of their immigration status.

Stigma

"People are feeling alone, people do not feel comfortable sharing at first, you need to be surrounded by people facing similar struggles to feel comfortable sharing with and understand what you are going through."
- Upham's Corner Health Center

Stigma seemed to be more prevalent in certain communities. Many participants shared their experience with hiding their HIV status due to both physical and emotional harm they experienced. Word on HIV status rapidly spread in the community. Many shared this as a primary reason for not participating in support groups despite the desire for more social support. Some experienced stigma in medical settings as well. When asked for examples of stigma, many participants described issues experienced when visiting the pharmacist.

Comorbidities

"Our clients fall out of care and go missing. They have comorbidities and they are getting older. They are getting sick with other things. They have other health issues, bigger than HIV. "
- Focus group participant, Greater New Bedford Community Health Center

Many participants spoke about comorbidities they are living with. Many of these conditions are related to or common in PLWH. Participants shared their difficulties living with multiple health problems while trying to take care of oneself. Particularly for an aging

population, a patient's HIV status may no longer be the most acute health condition. Additionally, some responses from the survey as well as comments from focus groups expressed a desire for more information on how to best manage the side effects from HIV medication.

Limitations

This needs assessment has some limitations in its data collection. Survey respondents and focus group participants were recruited through a convenient sampling methodology at a select number of ASOs in Massachusetts. While the ASOs were geographically distributed, they do not reflect the full population of PLWHA in the Boston EMA who were currently in care. Additionally, no focus groups were conducted in New Hampshire.

The timing of when individuals were approached may have impacted their decisions to participate and led to bias in their responses. Recruitment of participants mostly occurred at ASOs when individuals were visiting for an HIV-related care appointment.

Self-reported bias or error is possible. To ensure anonymity of the survey, no information is referenced with records. However, people reporting what they remember is important because it is their memory and experience living with HIV.

Selection bias must be accounted for in focus group participation. Individuals who do not feel positive about the ASO they receive services at may have been more likely to decline participation than those who have had more positive experiences with the ASO and its staff.

Social desirability bias is likely as some of the ASO staff were present in the room during focus group facilitation. This would make it more difficult for participants to mention any negative experiences or comments on the ASO.

Focus groups were facilitated using a semi-structured guide, however, there were different topic guides and different questions were asked. Additionally, variations in participants and the conversations led to spending different amounts of time discussing certain topics.

The survey questions on ethnicity/race are vague and do not match the data measures from the Massachusetts Department of Public Health (MDPH) or New Hampshire Department of Health and Human Services (NHDHHS). This makes it difficult to make any comparisons whether the survey data is representative of the larger population.

There is no way to check whether respondents answered the survey more than once due to the anonymous nature of the survey.

There is no method to control how the survey is facilitated in ASOs. Many batches of surveys were written in by one handwriting, likely by case managers. This could also contribute to response bias.

The limited response in the electronic version of the survey is tied to issues of access. Many PWLH accessing Ryan White Part A services may not have the resources to access the electronic version of the needs assessment survey.

Challenges

With the COVID-19 pandemic in the spring of 2020, the community needs assessment efforts became limited to online formats of the survey, which are not easily accessible to all. Focus groups scheduled March 2020 and onward were canceled. Flyers with QR codes to the online survey were distributed on the Boston EMA Ryan White Planning Council homepage, different ASOs in the EMA, and local living centers. Virtual outreach was done through the Boston Public Health Commission and MDPH advisory groups.

Recommendations

Recommendations for future needs assessments include asking additional questions on 1) Place of birth, 2) World region of origin, 3) Method of transmission/ exposure, and 4) Comorbidities. This will resolve issues with the vague and confusing questions around race and ethnicity, and are the same data measures used by MA and NH state public health departments. Method of transmission/exposure will allow for better understanding of injection-drug use, and HIV comorbidities are important to understand.

Another recommendation is to add some way to uniquely code each respondent to prevent more than one response per person. Although there is a notice on the top of the survey (see Appendix A), it is very possible for respondents to have submitted more than one survey when the needs assessment was conducted from April 2019 to May 2020.

It is also suggested to use the same variables as the MDPH and NHDHHS so that data comparisons can be made.

Lastly, outreach for the needs assessment survey should be strengthened and intensified to collect a respondent pool representative of the PLWH in Boston EMA (377 surveys for 18,149 PLWH).

Conclusion

Findings from both the survey and the focus group discussions highlight common themes regarding the needs, services, and barriers of PLWH in the Boston EMA. The data collected is generally representative and reflective of the larger population.

- Most participants/respondents were in care, receiving case management, and experienced some sort of barrier when accessing services;
- Among the barriers for accessing HIV-related care services that were identified, transportation, income or ability to pay, and housing status were the most frequent;
- **More knowledge of what services are available and where was identified as a useful way to better ensure PLWH could identify and access relevant HIV-related services;** and
- Educational services, support for a healthy lifestyle. And employment assistance services are three of the top services PLWH want but are unable to access.

Findings from the survey also highlighted that financial assistance is an important resource for PLWH in the Boston EMA. Participants reported concern on diminishing resources that could jeopardize financial assistance.

Findings from the focus group discussions suggest that PLWH are concerned about aging with HIV and their capacity to manage HIV and other comorbidities. Additionally, focus group participants wanted more social support services, especially financial assistance and affordable housing.

The purpose of this report is to provide important information that can guide HIV service planning in the Boston EMA to ensure a comprehensive, coordinated continuum of care and support services. It can also inform future data collection activities that may explore specific barriers and unmet needs.

Appendix A: Needs Assessment Survey

Consumer Survey

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

- All information you provide in this survey is anonymous. Do not write your name.
- If there are questions you don't feel comfortable answering, you don't have to answer them.
- Completing this survey takes approximately 10-20 minutes.
- **Disclaimer: This study began in March 2019. If you filled out this survey in 2019, please do not submit another.**

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

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

If you have any questions about this project or if you would like assistance in completing this survey, please contact Liz Rios at (617) 534-2413 or 617-947-4299, email: erios@bphc.org.

---

1. **What is your age?**
   - ☐ 18-25
   - ☐ 26-30
   - ☐ 31-40
   - ☐ 41-50
   - ☐ 51-60
   - ☐ 61-69
   - ☐ 70+

2. **What is your gender?**
   - ☐ Male
   - ☐ Female

- ☐ Transgender (male to female)
- ☐ Transgender (female to male)
- ☐ Gender fluid
- ☐ Other (specify):_____

3. **What is your sexual orientation?**
   - ☐ Heterosexual
   - ☐ Gay
   - ☐ Lesbian
   - ☐ Bisexual
   - ☐ Unsure
   - ☐ Other (specify):_____

4. **Are you Latinx, Hispanic or Spanish?**
   - ☐ Yes
   - ☐ No

5. **What is your race?** *[Select all that apply]*
   - ☐ American Indian/Alaskan Native
   - ☐ Asian
   - ☐ Black/African American
   - ☐ Native Hawaiian/Pacific Islander
   - ☐ White/Caucasian
   - ☐ Prefer not to answer
   - ☐ Other (specify):_____

6. **Which WRITTEN and/SPOKEN language do you PREFER to use for any legal matters (documents, contracts, motor vehicle registry, banking, etc.)?**
   - ☐ English
   - ☐ Spanish
   - ☐ Portuguese
   - ☐ Haitian Creole
   - ☐ French
   - ☐ Swahili
   - ☐ Other (specify):_____

7. **Which SPOKEN language do you speak most of the time (with friends and family)?**
   - ☐ English
   - ☐ Spanish
   - ☐ Cape Verdean Creole
   - ☐ Portuguese
   - ☐ Haitian Creole
   - ☐ French
   - ☐ Swahili

☐ Other (specify):_____

8. **What is the best description of your immigration status?**
   - ☐ US Citizen
   - ☐ Legal Permanent Resident (valid "green card")
   - ☐ VISA: Student, Work, Business or Tourist
   - ☐ Refugee/Asylee (legal/approved)
   - ☐ Undocumented
   - ☐ Prefer not to answer
   - ☐ Other (specify):_____

9. **What is your current zip code?** ___ ___ ___ ___ ___
   a. **Were you living at this zip code when you were diagnosed?**
   - ☐ Yes
   - ☐ No

   b. **If NO, where were you living (city/state/country) when you were diagnosed?**
   _____

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

11. **What year, if applicable, did you first start taking HIV medications?**
    ___ ___ ___ ___ **(yyyy)**

12. **If you are you currently taking HIV medications, during the past 6 months, have you ever stopped taken any of them for more than a week (i.e. 7 days in a row or longer)?**
    - ☐ No, I have not stopped taking any my HIV medications for more than 7 days.

    If YES, why? *[Select all that apply]*
    - ☐ Forgot to take them
    - ☐ Wanted to avoid side effects
    - ☐ Was busy with other things
    - ☐ Had problems taking pills
    - ☐ Could not get to a doctor or clinic
    - ☐ Felt depressed or overwhelmed
    - ☐ Felt too sick
    - ☐ Was living on the street or homeless
    - ☐ Had too many pills to take
    - ☐ Could not afford a refill
    - ☐ My medical provider told me to stop
    - ☐ Other (specify): _____

13. **At your last viral load blood test, did your provider tell you that you were you virally undetectable?**
    - ☐ Yes
    - ☐ No

- ☐ Don't Know

14. How do you get to your appointments or run errands? *[Select all that apply]*

- ☐ Public transportation
- ☐ Personal vehicle
- ☐ Walk
- ☐ Friend or family member
- ☐ UBER/LYFT/Taxi
- ☐ Shuttle service managed by provider
- ☐ Bicycle
- ☐ Other: _____

15. What services in the community are you accessing? *[Select all that apply]*

- ☐ Case Management
- ☐ Food banks/Assistance with food
- ☐ Medical care
- ☐ Support groups
- ☐ Financial assistance
- ☐ Legal services
- ☐ Translation services
- ☐ None
- ☐ Other: _____

16. If you want to receive more services, what is preventing you? *[Select all that apply]*

- ☐ Transportation
- ☐ Income/Ability to pay
- ☐ Housing status
- ☐ Language barrier
- ☐ Child care needs/Family needs
- ☐ Competing priorities
- ☐ Fear of stigma
- ☐ Immigration status
- ☐ Lack of support
- ☐ N/A
- ☐ Other:_____

17. What additional services would you like to access that are not available?

18. If you have accessed services in the past that you are no longer, what made you stop?

19. Are you frustrated with any of the services you are receiving?

- ☐ Yes
- ☐ No
- ☐ N/A

If YES, why? *[Select all that apply]*

- ☐ General dissatisfaction
- ☐ Hostile environment from health care professionals or providers
- ☐ Timely follow up from hospital/clinic staff or providers
- ☐ Wait times
- ☐ Location/hours of operation
- ☐ Other:_____

Thank you for taking the time to complete the survey.

Please send the survey to:
Boston Public Health Commission
Attn: Boston EMA Planning Council
1010 Massachusetts Ave, 2nd Fl
Boston, MA 02118
OR
Fax: 617-419-1588

Appendix B: Focus Group Materials

Introductions and guiding script – RW Planning Council 2020 Needs Assessment Focus Groups

Introduction:

Welcome, and thank you for hosting us. We are representing the RW Planning Council and we are facilitating focus groups to learn more about PLWH in MA and NH. Everyone here represents people that access HIV services and we want their opinions to be collected in order to improve, change, or keep services.

Our goal is to collect information from people in 10 counties, because that is the region where the Part A grant provides services. This is our first focus group in Bristol county.

A little about RW Planning Council: The council is a group of volunteers from the community, many of whom are living with HIV and use Part A services. They are in charge of deciding what Part A services should be available, how much money should be invested in them, and how they should be delivered. The council gives their recommendations to the BPHC, and the BPHC takes the lead on procuring and contracting services. Part of the work of council is also to collect the opinions and feedback of the people who use the services, and to use that information in decision making processes.

If you are interested in becoming a member of council, we can give you more info!

Structure of today:

Our objective today is to ask you questions about the types of HIV services you use, both medical services and supports like this peer group, transportation, etc. We want to understand what makes it easy or difficult for a person to get connected to services, use them, and ultimately achieve positive results.

We will be taking notes. We will not use your name or identity without your permission. You should feel comfortable to tell us anything you like, and to participate in a way that works for you.

We do want to enforce basic ground rules. We want everyone to feel respected. We don't want people to distract, interrupt, or discourage anyone else. If you have to use your phone or step out, please do so quietly. If you disagree with something you hear, please express that with respect. This group is in charge of the information that you communicate to us, and our job is to capture that information and portray it accurately. The information we learn here today is one piece of data that helps us tell the story of what PLWH are experiencing. It will not result is instant changes, rather it will help inform change over time.

Each person will receive a $5 DD gift card for participating today. Each person will also be asked to complete a paper survey.

Appendix B: Focus Group Materials

Boston EMA Assessment of Service Needs for PLWH

Focus Group - Topic Guide

Background

- Years living w HIV
- Experience living w HIV
    - Change over time?

Service Needs

- Change in needs?
    - Now vs past?
    - Need now
    - Don't need anymore

Service Gaps Remaining

- Getting a new service
    - Able to or not?
    - Why?
        - Access
        - Unaware of services/how to connect
        - Other priorities?

Barriers to Care or Adherence

- Challenges to taking meds
    - What helps?
- Keeping up w appointments
    - Challenges?
    - What helps?
- Previously out of care?
- What keeps you in care?
- Friends/peers who don't get services
    - Reasons why?
    - Barriers?

Appendix C: John Snow Institute Needs Assessment Survey

HIV SERVICE NEEDS ASSESSMENT

Fill in circles darkly and completely.	
INCORRECT MARKS	CORRECT MARK
	●

Demographics

1. Where were you born?

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

2. Which of the following best describes your immigration status? (select one)

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

3. What language do you speak at home?

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

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

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

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

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

7. What was your total household income in 2008? _____

8. What were the sources of this income? (select all that apply)

- ○ My own employment (full time, part time, or temporary/seasonal)
- ○ My spouse/partner's employment
- ○ Child support
- ○ Support from family members
- ○ Unemployment benefits
- ○ Social Security (either SSI or SSDI)
- ○ TAFDC (Transitional Aid to Families with Dependent Children)
- ○ EAEDC (Emergency Aid to Elderly, Disabled, and Children)
- ○ Financial aid from school
- ○ Other, specify: _____

9. Which of the following forms of health insurance do you have?

- ○ Commonwealth Care/ Choice
- ○ Medicaid (MassHealth or NH Medicaid)
- ○ Private insurance (Blue Cross/Blue Shield, Harvard Pilgrim, Anthem, Tufts, etc.)
- ○ Medicare
- ○ New Hampshire Health Plan (NHHP)
- ○ I don't know
- ○ Other, specify: _____

HIV Diagnosis

1. When were you first told by a medical provider that you were HIV positive? Month [ ][ ] YEAR [ ][ ][ ][ ]

2. Where were you tested when you had your first positive HIV test?

- ○ Private doctor's office
- ○ Hospital
- ○ Emergency room
- ○ Community health center or clinic
- ○ HIV Counseling, testing, and referral site
- ○ Family planning clinic
- ○ STD clinic
- ○ Mobile test site (health dept. van, needle exchange site, etc.)
- ○ Jail or prison
- ○ Don't remember/don't know

3. After you tested positive for HIV, how long did you wait before seeking HIV medical care?

- ○ I didn't wait; I sought medical care immediately
- ○ Less than a month
- ○ Between 1 and 3 months
- ○ Between 4 and 6 months
- ○ Between 7 and 12 months
- ○ Between 13 months and 3 years
- ○ More than 3 years
- ○ I have not yet sought HIV medical care

4. After you tested positive for HIV, how long did you wait before seeking HIV services other than medical care? (peer support, transportation, food, etc.)

- ○ I didn't wait; I sought medical care immediately
- ○ Less than a month
- ○ Between 1 and 3 months
- ○ Between 4 and 6 months
- ○ Between 7 and 12 months
- ○ Between 13 months and 3 years
- ○ More than 3 years
- ○ I have not yet sought HIV medical care

5. What made you wait to seek medical care or other HIV services? (select all that apply)

- ○ I didn't wait; I sought care immediately
- ○ I didn't feel sick
- ○ I didn't know where to go
- ○ I was depressed
- ○ I didn't want anyone to know I had HIV
- ○ I thought I was going to die, so I didn't think it would matter
- ○ I was afraid to start medications
- ○ I don't like or trust doctors
- ○ I was dealing with drug or alcohol issues/addiction
- ○ I was worried about my immigration status
- ○ I couldn't find a doctor
- ○ I didn't think I could afford it
- ○ Other, specify: _____

6. What would have helped you seek medical care or other HIV services sooner? (select all that apply)

- ○ I did not wait; I sought care and services immediately
- ○ Nothing, I needed time to deal with my diagnosis
- ○ Talk/counseling when I was first diagnosed
- ○ Someone with HIV to help me talk about/deal with the diagnosis
- ○ More information about what might happen if I didn't get care
- ○ More information about where to go to get services
- ○ Someone to go with me on my first visit
- ○ Help dealing with drug or alcohol issues/addiction
- ○ Legal services to help me with my immigration status
- ○ Information about free or low cost services

7. Who helped you the most to get into medical care or other HIV services (after you found out you have HIV)?

- ○ Spouse, partner/significant other
- ○ Family member
- ○ Friend
- ○ Medical provider (doctor, nurse, physician's assistant, etc.)
- ○ Outreach worker
- ○ The person who gave me my test results
- ○ Another person with HIV
- ○ No one
- ○ Don't know/remember
- ○ Other, specify: _____

Appendix C: John Snow Institute Needs Assessment Survey

Health Status

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

- ○ I've only had one T-cell test and I'm currently waiting for results
- ○ Less than 200
- ○ Between 200 and 350
- ○ Over 350
- ○ I've never had a T-cell test
- ○ I don't know if I've ever had a T-cell test or what a T-cell test is
- ○ I can't remember the results

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

- ○ I've only had one viral load test and I'm currently waiting for results
- ○ Undetectable or below 400
- ○ Between 400 and 4,999
- ○ Between 5,000 and 10,000
- ○ Between 10,001 and 100,000
- ○ Over 100,000
- ○ I've never had a viral load test
- ○ I don't know if I've ever had a viral load test or what a viral load test is
- ○ I can't remember my viral load results

10. 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

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

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

An opportunistic infection (pneumocystis pneumonia or PCP)? ○ Yes ○ No ○ Don't Know

12. In addition to HIV, do you currently have any of the following conditions? (select all that apply)

- ○ Arthritis
- ○ Asthma
- ○ Cancer
- ○ COPD (chronic obstructive pulmonary disease)
- ○ Diabetes
- ○ Heart disease
- ○ Hemophilia/blood disorder
- ○ Hepatitis B
- ○ Hepatitis C
- ○ High blood pressure
- ○ High cholesterol
- ○ Liver disease
- ○ Lung disease
- ○ Memory problems
- ○ Neuropathy
- ○ Osteoporosis
- ○ Sexually transmitted infection (chlamydia, gonorrhea, syphilis)
- ○ Tuberculosis
- ○ Other, specify: _____

13 Has your medical provider ever told you that you have AIDS? ○ Yes ○ No ○ Don't Know

14. Do you have either of the following conditions? (select all that apply)

○ A mental health condition

○ An alcohol of drug addiction

15. 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 use of a wheelchair

○ Physical disability that requires use of a walker, crutches, or leg braces

○ Severe pulmonary (lung) condition that affects my mobility

○ Severe cardiac (heart) condition that affects my mobility

○ Neurological or psychiatric disability

16. How would you rate your health status?

○ Excellent
○ Very good
○ Good
○ Fair
○ Poor

Primary Care

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

1. Where do you get HIV medical care?

○ Private doctor's office
○ Hospital/hospital clinic
○ Emergency room
○ Community health center or clinic
○ VA hospital/clinic
○ I don't get medical care (Skip to X)
○ Other, specify: _____

2. How long ago did you last see your HIV Medical Provider?

○ Less than a month
○ Between 1 and 3 months
○ Between 4 and 6 months
○ Between 7 and 12 months
○ Between 13 months and 3 years
○ More than 3 years
○ I don't have a doctor (SKIP TO X)
○ I haven't ever seen my doctor (SKIP to X)
○ I don't know or don't remember

3. Overall how satisfied are you with the care you receive from your HIV Medical Provider?

- ○ Very satisfied
- ○ Satisfied
- ○ Neither satisfied nor dissatisfied
- ○ Dissatisfied
- ○ Very dissatisfied

4. During your last visit with your HIV Medical Provider, whith which of the following people did you meet to discuss your health and care? (select all that apply)

- ○ A doctor (physician)
- ○ A physician's assistant
- ○ A nurse practitioner
- ○ A medical case manager

Please indicate 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.

5. My HIV Medical Provider...	**Always**	**Sometimes**	**Never**	**NA**
Spends enough time with me during visits	○	○	○	○
Listens to me during visits	○	○	○	○
Is easy to reach when I need to	○	○	○	○
Is easy to schedule an appointment with	○	○	○	○
Encourages me to participate in my own care	○	○	○	○
Makes sure I get the care I need, including referralsto specialty care	○	○	○	○
Understands the needs of people my age	○	○	○	○
Understands my culture or community	○	○	○	○
Understands how to treat HIV/AIDS	○	○	○	○
Is able to help me deal with other health issues besides HIV/AIDS	○	○	○	○
Screens me for other diseases like Hepatitis C or TB	○	○	○	○
Treats me with respect	○	○	○	○

Appendix C: John Snow Institute Needs Assessment Survey

HIV/AIDS Medications and Adherence

1. Are you currently taking HIV medications (antiretrovirals) prescribed by your medical provider to treat HIV or AIDS? ○ Yes ○ No

If prescribed HIV medications:

1a. If yes, when did you start taking medications for the first time? YEAR ☐☐☐☐

1b. If yes, how do you cover the cost of your medications? (select all that apply)

- ○ HDAP/ADAP (HIV or AIDS Drug Assistance 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 the total cost myself
- ○ I don't know

1c. If yes, during the past six months, have you ever stopped taking your medications for more than a week?

○ Yes ○ No

1c1. If yes, why?

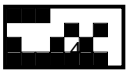
- ○ Forgot to take them
- ○ Wanted to avoid side effects
- ○ Was busy with other things
- ○ Had a change in daily routine
- ○ Had problems taking pills at specified times
- ○ Couldn't get to a doctor or clinic
- ○ Felt depressed or overwhelmed
- ○ Was on the street
- ○ Had too many pills to take
- ○ Couldn't afford a refill
- ○ My medical provider told me to stop
- ○ I've chosen not to take them
- ○ Other, specify: _____

1d. If yes, how often have you missed a dose of your HIV medication in the past 2 week?

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

1e. In the past three months, have you discussed the importance of taking your HIV medications regularly with any of the following people? (select all that apply)

- ○ Medical provider
- ○ Case manager
- ○ An outreach /community health worker
- ○ Other HIV services provider
- ○ Peer leader
- ○ Mental health counselor
- ○ Substance abuse counselor
- ○ Support group member(s)
- ○ Other people living with HIV that I know
- ○ Family/friends
- ○ I have talked to no one about this issue



If not currently prescribed HIV medications:

2. Why not? (select all that apply) E2

- ○ I can't afford them
- ○ I don't feel sick
- ○ I use alternative medicine
- ○ My medical provider has not prescribed them
- ○ The side effects are too hard to manage
- ○ Too much paperwork
- ○ I don't want to go to the pharmacy to get them
- ○ I've decided with my medical provider to wait to start medications
- ○ I've chosen not to take them
- ○ I don't have a medical provider

Housing Status

1. How would you describe your current living situation (past 30 days)?

- ○ Living on the street, in a shelter, in a vehicle, or some other temporary
- ○ Living in someone else's house or apartment temporarily because I have no place else to go
- ○ Living in a home or apartment of my own
- ○ Living in a residential program
- ○ Living in jail or prison
- ○ Other, specify: _____

2. Has your living situation changed in the past six months? ○ Yes ○ No

If yes, what was your most common living situation in the past six months?

- ○ Living on the street, in a shelter, in a vehicle, or some other temporary
- ○ Living in someone else's house or apartment temporarily because I have no place else to go
- ○ Living in a home or apartment of my own
- ○ Living in a residential program
- ○ Living in jail or prison
- ○ Other, specify: _____

3. Have you had any problems accessing or retaining housing due to any of the following? (select all that apply)

- ○ CORI (criminal record information)
- ○ Waiting lists
- ○ Difficulty paying rent or mortgage
- ○ 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
- ○ Other, specify: _____
- ○ I have not had any problems accessing or retaining housing

Appendix C: John Snow Institute Needs Assessment Survey

Access

1. For each of the following HIV services, select the items that are important for helping you to use the service when you need it (select all that apply)

2. Overall, 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
- ○ All of the paperwork
- ○ Travelling to and from appointments
- ○ Finding time to go to appointments
- ○ Having to go to different places to get different services
- ○ Managing all of my service providers and their requirements
- ○ Getting services because of my immigration status
- ○ Being seen accessing services
- ○ Finding service providers that understand the needs of people living with HIV/AIDS

Employment

1. Are you currently employed? ○ Yes ○ No

1a. If NO, why aren't you working? (select all that apply)

- ○ I'm unable to find a job
- ○ I don't know how to apply or interview for a job
- ○ I'm afraid I will earn too much and lose government benefits (e.g., SSI/SSDI, Section 8, food stamps, etc.)
- ○ I'm afraid I will lose access to HIV services
- ○ I am worried that people will know I have HIV
- ○ I don't have the energy
- ○ I am worried about getting sick on the job
- ○ I don't have enough training or skills
- ○ I am worried about medications side effects in the workplace
- ○ I am currently getting training/education so I can get a job
- ○ I don't have someone to take care of my kids or family
- ○ I'm retired
- ○ I'm disabled as a result of AIDS
- ○ I'm disabled as a result of some other condition
- ○ Other, specify: _____

1b. If you are working, what challenges do you experience as a person living with HIV/AIDS and working? (select all that apply)

- ○ None, I don't experience any challenges
- ○ My energy level sometimes makes it hard to get through the day
- ○ I worry about or get sick on the job
- ○ I worry about or experience medications side effects on the job
- ○ I don't feel I can be open about my HIV status in the workplace
- ○ It's difficult to get away during the workday to attend HIV medical and service appointments
- ○ Finding or paying for childcare
- ○ Other, specify: _____

2. Do you do any volunteer work? ○ Yes ○ No

Education

1. What is the highlest level of education you have completed?

- ○ 8th grade or less (primary school)
- ○ 9th to 12th grade, but did not graduate (some secondary school)
- ○ Graduated high school (or got GED, completed secondary school)
- ○ Vocational/technical school/Associates degree
- ○ Some college, but no degree
- ○ College degree
- ○ Graduate degree
- ○ Don't know

2. Are you currently in school, college, or a vocational training program? ○ Yes ○ No

2a. If no, do you want to go to school, college, or a vocational training program? ○ Yes ○ No

2a1. If yes, what is keeping you from going to school or college?

- ○ I can't afford it
- ○ I don't know if I can handle school
- ○ I am worried about people knowing I have HIV
- ○ I am not sure I have the energy
- ○ I am worried about getting sick at school
- ○ I am worried about medication side effects
- ○ I don't have someone to take care of my kids or family
- ○ Don't know where to go
- ○ Nothing, I just haven't done it

Appendix C: John Snow Institute Needs Assessment Survey

Substance Use

1. In the past six months, have you talked with any of the following people about alcohol or drug use? (select all that apply)

- ○ Medical provider
- ○ Case manager
- ○ An outreach /community health worker
- ○ Other HIV services provider
- ○ Peer leader
- ○ Mental health counselor
- ○ Substance abuse counselor
- ○ Support group member(s)
- ○ Other people living with HIV that I know
- ○ Family/friends
- ○ I have talked to no one about this issue

One drink of alcohol equals a bottle or can of beer (12 oz.), one wine cooler (12 oz.), a glass of wine (5 oz.) or a shot of hard liquor (1.5 oz.).

2. In the past 30 days, have you had at least one drink of alcohol? ○ Yes ○ No

3. In the past 30 days, have you had five or more drinks on any one occasion? ○ Yes ○ No

4. In the past 30 days, have you taken any drugs not prescribed by your doctor? ○ Yes ○ No

IF YES TO ANY OF THE THREE QUESTIONS ABOVE:

5. Have you ever felt you ought to cut down on your drinking or drug use? ○ Yes ○ No

6. Have people annoyed you by criticizing you drinking or drug use? ○ Yes ○ No

7. Have you ever felt guilty about your drinking or drug use? ○ Yes ○ No

8. Have you ever had a drink or used drugs first thing in the morning to steady your nerves, get rid of a hangover, or as an eye opener? ○ Yes ○ No

9. Have you ever used a need or syringe to inject any drugs not prescribed by your doctor into your body? ○ Yes ○ No

10. Have you used a needle or syringe in the past 30 days to inject any drugs not prescribed by your doctor? ○ Yes ○ No

10a. If yes, in the past 30 days have you shared needles or works with someone else? ○ Yes ○ No

10b. Do you access clean needles or works, either through a needle exchange, syringe access, or at a pharmacy? ○ Yes ○ No

Appendix C: John Snow Institute Needs Assessment Survey

Mental Health

1. In the past six months, have you talked with any of the following people about <u>mental health issues</u>? (select all that apply)

- ○ Medical provider
- ○ Case manager
- ○ An outreach /community health worker
- ○ Other HIV services provider
- ○ Peer leader
- ○ Mental health counselor
- ○ Substance abuse counselor
- ○ Support group member(s)
- ○ Other people living with HIV that I know
- ○ Family/friends
- ○ I have talked to no one about this issue

Please indicate 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.

2. In the past 30 days, how often have you...	Never	Rarely	Sometimes	Frequently
Felt anxious, depressed or confused	○	○	○	○
Felt sad or hopeless	○	○	○	○
Worried so much that it has kept you from doing activities you woul d have liked to do	○	○	○	○
Found it difficult to enjoy yourself when engaging in activities you have enjoyed in the past	○	○	○	○
Had any significant difficulties sleeping	○	○	○	○
Found yourself reliving bad experiences from the past (flashbacks, feeling as if you are re-experiencing the event	○	○	○	○

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

○ Yes ○ No

Insert statement about where to get help

Appendix C: John Snow Institute Needs Assessment Survey

Support

1. Other than your medical and support service providers, who do you depend on for support? (select all that apply)

- ○ Spouse/partner/significant other
- ○ Other family members
- ○ Friend(s)
- ○ Co-worker(s)
- ○ Religious leader(s)
- ○ Support group members
- ○ Another HIV-positive person
- ○ I have no one else

Disclosure

1. Other than yourself, does anyone know you are living with HIV/AIDS? ○ Yes ○ No

1a. IF YES, WHO? (select all that apply)

- ○ My doctor/nurse
- ○ My case manager
- ○ My ob/gyn provider
- ○ My dentist
- ○ Other service providers
- ○ Spouse/partner/significant other
- ○ Other family members
- ○ Friends
- ○ Coworker(s)
- ○ Religious figures
- ○ No one else knows

1b. IF NO, WHY HAVEN'T YOU TOLD ANYONE ELSE? (select all that apply)

- ○ I'm afraid of how others will react
- ○ I'm afraid for my safety
- ○ It's my own business and no one else needs to know
- ○ I'm afraid people will judge me
- ○ I'm afraid I will lose my job
- ○ I'm still coming to terms with my status myself
- ○ Other, specify:

2. What would help you let people know you are living with HIV? _____

_____

3. Do you and your partner discuss HIV?

- ○ Yes, always
- ○ Yes, sometimes
- ○ Never

Appendix C: John Snow Institute Needs Assessment Survey

Positive Prevention

1. In the past six months, have you talked with any of the following peopel about your sexual health, such as reducing you and your partern's risk of sexually transmitted diseases (STDs) or Hepatitis? (select all that apply)

- ○ Medical provider
- ○ Case manager
- ○ An outreach /community health worker
- ○ Other HIV services provider
- ○ Peer leader
- ○ Mental health counselor
- ○ Substance abuse counselor
- ○ Support group member(s)
- ○ Other people living with HIV that I know
- ○ Family/friends
- ○ I have talked to no one about this issue

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 often.

2.	Agree	Disagree	I don't have a Case Manager
My Case Manager is comfortable discussing sex with me.	○	○	○
I am comportable discussing sex with my case manager.	○	○	○
My Case Manager is comfortable discussing alcohol and/or drug use with me.	○	○	○
I am comfortable discussing alcohol and/or drug use with my Case Manager.	○	○	○
My Case Manager knows a lot about different types of sexual activities.	○	○	○
My Case Manager knows a lot about "street" or recreational drug use.	○	○	○

Appendix C: John Snow Institute Needs Assessment Survey

HIV Knowledge /Literacy

1. Please indicate whether you agree or disagree with each of the following statements

True or false -- a T-cell (CD4) test measures the amount of HIV virus in an HIV-positive person's body. ○ True ○ False

True or false -- it is possible for an HIV-positive person to have sex without transmitting HIV to his/her sex partner. ○ True ○ False

True or false -- if an HIV-positive person's viral load is "undetectable," it means he/she is cured of HIV. ○ True ○ False

True or false, the use of recreational drugs can impact the effectiveness of HIV medications. ○ True ○ False

True or false, a woman living with HIV cannot give birth to children without infecting them ○ True ○ False

.

Aging

1. 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
- ○ 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 a higher education
- ○ Maintaining access to or getting the HIV services I need
- ○ Telling people about my HIV status
- ○ Taking care of my partner/significant other or other family members
- ○ Staying healthy
- ○ Planning for the end of my life (making a will, long term care, etc.)
- ○ Being a burden
- ○ None of the above
- ○ Other, specify:

Appendix C: John Snow Institute Needs Assessment Survey

Other

1. In the past 3 months, have you done any of the following to help manage your HIV and/or side effects of medications (Select all that apply)

- ○ Taken vitamin/nutritional supplements
- ○ Taken herbal treatments
- ○ Followed a healthy diet
- ○ Exercised regularly
- ○ Used massage
- ○ Used chiropractic care
- ○ Used acupuncture
- ○ Meditated
- ○ Other, specify:

2. Have you 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

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

Appendix D: Boston University School of Public Health Needs Assessment Survey

CONSUMER SURVEY

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

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

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

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

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

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

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

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

Write Unique Code Here: ____ ____ ____ ____

BE SURE TO SUBMIT THIS PAGE WITH YOUR SURVEY

Appendix D: Boston University School of Public Health Needs Assessment Survey

PART 1: DEMOGRAPHIC AND BACKGROUND INFORMATION

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

2. **What is your gender?**
   - ☐ Male
   - ☐ Female
   - ☐ Transgender (male to female)
   - ☐ Transgender (female to male)

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

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

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

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

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

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

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

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

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

11. **Do you have health insurance?**
   - ☐ No → go to 11A
   - ☐ Yes → Skip to 12
   - ☐ Don't know → Skip to 12

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

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

PART 2: SERVICE NEEDS & GAPS

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

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

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

Appendix D: Boston University School of Public Health Needs Assessment Survey

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

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

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

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

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

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

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

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

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

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

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

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

Appendix D: Boston University School of Public Health Needs Assessment Survey

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

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

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

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

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

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

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

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

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

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

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

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

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

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

O. Did you need legal support for immigration issues?

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

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

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

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

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

R. Did you need job training/employment assistance?

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

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

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

T. Did you need assistance connecting with medical specialists?

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

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

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

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

- ☐ No → Go to 14.
- ☐ Yes → **Specify:** _____

↓

Did you receive this service in the last 6 months?

- ☐ No → **Why Not?**_____
- ☐ Yes

Part 3: Medical Care and Medications

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

- ☐ Yes → Go to 15.
- ☐ No → Go to 16.

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

- ☐ Yes → Go to 15A.
- ☐ No → Go to 15B.

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

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

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

16. When was your last viral load blood test drawn?

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

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

A. At your last viral load blood test drawing, were you virally suppressed (less than 200 copies/mL)?
- ☐ Yes
- ☐ No
- ☐ I don't know

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

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

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

☐ None → Go to 19.
☐ At least one time → Please specify the number of times: _____ → Go to 18A.
☐ Don't know → Go to 19.

A. Why did you miss your appointments? _____

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

☐ Heart disease
☐ High blood pressure
☐ Lung disease
☐ Diabetes
☐ Ulcer or stomach disease
☐ Kidney disease
☐ Hepatitis C
☐ Other liver disease
☐ Anemia or other blood disease
☐ Cancer
☐ Depression
☐ Osteoporosis, degenerative arthritis
☐ Back pain
☐ Rheumatoid arthritis
☐ Other, specify: _____

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

_____
_____
_____
_____

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

_____
_____
_____
_____

END OF SURVEY

Appendix D: Boston University School of Public Health Needs Assessment Survey

If you have completed the survey and would like to enter the raffle to win a $100 gift card to Stop & Shop, please take the following steps:

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

2) Remove this page and keep for your records.

3) Submit completed survey by using the stamped and self-addressed envelope.

4) Call Alexander de Groot at (617) 638-1930 and provide your unique ID and the best way to reach you (this will not be linked to your survey responses in any way).

Appendix E: Assessment Of Need Survey Data Table

Table A-1: Age

Age	Count	Percent (N=318)
18-25	2	0.62%
26-30	5	1.57%
31-40	42	13.2%
41-50	64	20.1%
51-60	109	34.3%
61-69	77	24.2%
70+	19	5.97%

Table A-2: Gender

Gender	Count	Percent (N=314)
Male	212	67.5%
Female	96	30.6%
Transgender Male to Female	3	.955%
Transgender Female to Male	2	.637%
Gender fluid	1	.318%
Other	0	0%

Table A-3: Sexual Orientation

Gender	Count	Percent (N=304)
Heterosexual	160	52.6%
Gay	109	35.9%
Lesbian	0	0%
Bisexual	30	9.87%
Unsure	0	0%
Other	4	1.31%

Appendix E: Assessment Of Need Survey Data Table

Table A-4: Ethnicity

Ethnicity	Count	Percent (N=312)
Hispanic/Latinx/Spanish	200	64.1%
Not Hispanic/Latinx/Spanish	112	35.9%

Table A-5: Race*

Ethnicity	Count	Percent (N=295)
American Indian/Alaskan Native	2	.625%
Asian	4	1.25%
Black/African-American	80	25.0%
Native Hawaiian/Pacific Islander	0	0%
White/Caucasian	148	46.3%
Prefer not to answer	5	1.56%
Other	13	10.3%

*Not mutually exclusive

Table A-5: Written/Spoken Language for Legal Matters*

Language	Count	Percent (N=312)
English	222	71.2%
Spanish	74	23.7%
Portuguese	23	7.37%
Haitian Creole	12	3.85%
French	4	1.28%
Swahili	1	.321%
Other	6	1.92%

*Not mutually exclusive

Appendix E: Assessment Of Need Survey Data Table

Table A-6: Spoken Language with Family/Friends*

Language	Count	Percent (N=313)
English	209	62.2%
Spanish	79	23.5%
Cape Verdean Creole	10	2.98%
Portuguese	22	6.55%
Haitian Creole	11	3.27%
French	0	0%
Swahili	3	.893%
Other	2	.595%

*Not mutually exclusive

Table A-7: Immigration Status

Language	Count	Percent (N=317)
U.S. Citizen	256	81.1%
Legal Permanent Resident	22	6.94%
VISA	3	0.95%
Refugee/Asylee	6	1.89%
Undocumented	20	6.31%
Prefer Not to Answer	4	1.26%
Other	6	1.89%

Table A-8: Diagnosed in Current Zip Code

Response	Count	Percent (N=306)
Yes	122	39.9%
No	184	60.1%

Appendix E: Assessment Of Need Survey Data Table

Table A-9: County of Residence

Language	Count	Percent (N=310)
Bristol	28	9.03%
Essex	41	31.2%
Hillsborough	18	5.81%
Middlesex	52	16.8%
Norfolk	6	1.94%
Plymouth	22	7.10%
Rockingham	1	0.323%
Strafford	8	2.58%
Suffolk	108	34.8%
Worcester	26	8.39%

Table A-10: Year Respondent First Tested Positive for HIV

Language	Count	Percent (N=305)
1980-89	42	13.8%
1990-99	105	34.4%
2000-2009	90	29.5%
2010-2019	68	22.3%

Table A-11: Year Respondent Started Taking HIV Medications

Language	Count	Percent (N=298)
1980-89	14	4.70%
1990-99	100	34.6%
2000-2009	103	34.6%
2010-2019	81	27.2%

Appendix E: Assessment Of Need Survey Data Table

Table A-12: Have You Ever Stopped Taking HIV Medications?*

Response	N=306	
	N	%
Yes	52	17.0%
No	254	83.0%

*For more than a week in the past 6 months.

Table A-13: Why Did You Stop Taking HIV Medications?*

Language	Count	Percent (N=54)
Forgot to take them	29	53.7%
Wanted to avoid side effects	10	18.5%
Was busy with other things	4	7.41%
Had problems taking pills	3	5.56%
Could not get to a doctor or clinic	4	7.41%
Felt depressed or overwhelmed	18	33.3%
Felt too sick	6	11.1%
Was living on the street or homeless	10	18.5%
Had too many pills to take	6	11.1%
Could not afford a refill	3	5.56%
Other	10	18.5%

*Not mutually exclusive

Table A-14: Long Term Survivors

Response	N=306	
	N	%
Yes, diagnosed in or before 1995	103	33.7%
No, diagnosed after 1995	203	66.3%

Table A-15: Are You Virally Undetectable?

Response	N=313	
	N	%
Yes	257	82.1%
No	40	18.5%
Don't Know	16	7.41%

Table A-16: How Do You Get To Your Appointments Or Run Errands?*

Method	N=311	
	N	%
Public transportation	159	53.7%
Personal vehicle	127	40.8%
Walk	69	22.1%
Friend or family member	25	8.03%
Uber/Lyft/Taxi	41	13.2%
Shuttle service managed by provider	18	5.79%
Bicycle	15	4.82%
Other	14	4.50%

*Not mutually exclusive.

Appendix E: Assessment Of Need Survey Data Table

Table A-17: What Services In The Community Are You Accessing?*

Service Category	N=284	
	N	%
Case management	217	76.4%
Food assistance	102	35.9%
Medical care	196	69.0%
Support groups	123	43.3%
Financial assistance	53	18.7%
Legal services	40	14.1%
Translation services	44	15.5%
Other	25	3.87%

*Not mutually exclusive

Table A-18: If You Want To Receive More Services, What Is Preventing You?*

Service Category	N=155	
	N	%
Transportation	53	19.4%
Income/Ability to pay	52	19.0%
Housing status	62	22.7%
Language barrier	13	4.76%
Child care/Family needs	14	5.13%
Competing priorities	24	8.79%
Fear of stigma	31	11.4%
Immigration status	21	7.69%
Lack of support	28	10.3%
Other	18	6.59%

*Not mutually exclusive.

Table A-19: Are You Frustrated With Any of the Services You Are Receiving?

Response	N=306	
	N	%
Yes	58	67.3%
No	206	19.0%
N/A	39	12.7%

Table A-20: Why Are You Frustrated?*

Reason	N=52	
	N	%
General dissatisfaction	21	40.4%
Hostile environment from health care professionals/providers	10	19.2%
Timely follow up from hospital/clinic staff or providers	13	25.0%
Wait times	19	36.5%
Location/hours of operation	9	17.3%
Other	15	28.8%

*Not mutually exclusive.

Appendix F: Assessment Of Need Survey Data Table: Bristol County

TABLE 1 | Comparison of survey data and MA HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=28)		MA HIV/AIDS Surveillance Systems (N=1,405)[a]	
	N	%	N	%
Age				
30 years of age or younger	1	3.57%	79	6%
50 years of age or older	27	96.4%	1326	94%
Gender				
Male	19	67.9%	93*	67%*
Female	9	32.1%	468*	33%*
Ethnicity				
Hispanic	9	32.1%	335**	24%**
Race				
American Indian/ Alaskan Native	0	0%	Not available	
Asian/Pacific Islander	0	0%	11	1%
Black or African-American	3	10.7%	249***	18%***
White/Caucasian	13	46.4%	797***	57%***
Prefer not to answer	1	3.57%	Not available	
Other	8	28.6%	13	1%
Sexual Orientation				
Heterosexual	15	53.6%	Not available	
Gay	10	35.7%		
Bisexual	1	3.57%		
Primary Spoken Language				
English	20	71.4%	Not available	
Spanish	7	25%		
Cape Verdean Creole	1	3.57%		
Portuguese	1	3.57%		
Haitian Creole	0	0%		
French	0	0%		
Swahili	0	0%		
Other	0	0%		
Immigration Status				
U.S. Citizen	26	92.9%	Not available	
Legal Permanent Resident	1	3.57%		
VISA	0	0%		
Refugee/Asylee	0	0%		
Undocumented	1	3.57%		
Other	0	0%		

[a]County level data of PLWH
*Sex at Birth
**Non-Black, Non-White
***Non-Hispanic

Data from Massachusetts Department of Public Health, Bureau of Infectious Disease and Laboratory Sciences. 2018 Massachusetts HIV/AIDS Epidemiologic Profile: Regional HIV/AIDS Epidemiologic Profile of Bristol County, Massachusetts. Published September 2018. Numbers as of 1/1/18.

Appendix F: Assessment Of Need Survey Data Table: Bristol County

What services in the community are you accessing?

1. Case Management - 29.2%
2. Medical Care - 23.1%
3. Support Groups - 20%
4. Food Banks/Assistance - 12.3%
5. Financial Assistance - 7.7%

If you want to receive more services, what is preventing you?

1. N/A - 29%
2. **Income/Ability to Pay - 19.4%**
3. Housing Status, **Transportation - Each 16.1%**
4. Lack of Support, Competing Priorities, Language Barrier - Each 6.5%

What additional services would you like to access that are not available?

- Holistic therapies such as acupuncture or massage
- More social activities like camping, movie nights, board games, "feel like a family"

If you have accessed services in the past that you are no longer, what made you stop?

- Services that have been cut due to funding

Appendix F: Assessment Of Need Survey Data Table: Essex County

TABLE 1 | Comparison of survey data and MA HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=41)		MA HIV/AIDS Surveillance Systems (N=2006)[a]	
	N	%	N	%
Age				
30 years of age or younger	2	4.88%	13	6%
50 years of age or older	39	95.1%	1993	94%
Gender				
Male	24	58.5%	1,354*	67%*
Female	16	39%	652*	33%*
Transgender MTF	1	2.44%	Not available	
Ethnicity				
Hispanic	24	58.5%	730**	36%**
Race				
American Indian/ Alaskan Native	0	0%	Not available	
Asian/Pacific Islander	1	2.44%	31	2%
Black or African-American	7	17.1%	370***	18%***
White/Caucasian	22	53.7%	856***	43%***
Prefer not to answer	1	2.44%	Not available	
Other	3	7.32%	19	1%
Sexual Orientation				
Heterosexual	31	75.6%	Not available	
Gay	6	14.6%		
Bisexual	3	7.32%		
Primary Spoken Language				
English	22	53.7%	Not available	
Spanish	23	56.1%		
Cape Verdean Creole	0	0%		
Portuguese	0	0%		
Haitian Creole	0	0%		
French	0	0%		
Swahili	1	2.44%		
Other	0	0%		
Immigration Status				
U.S. Citizen	33	80.5%	Not available	
Legal Permanent Resident	2	4.88%		
VISA	1	2.44%		
Refugee/Asylee	1	2.44%		
Undocumented	1	2.44%		
Other	2	4.88%		

[a]County level data of PLWH
*Sex at Birth
**Non-Black, Non-White
***Non-Hispanic

Data from Massachusetts Department of Public Health, Bureau of Infectious Disease and Laboratory Sciences. 2018 Massachusetts HIV/AIDS Epidemiologic Profile: Regional HIV/AIDS Epidemiologic Profile of Essex County, Massachusetts. Published September 2018. Numbers as of 1/1/18.

Appendix F: Assessment Of Need Survey Data Table: Essex County

What services in the community are you accessing?

1. Case Management - 48.9%
2. Medical Care -18.2%
3. Food Banks/Assistance - 11.4%
4. Support Groups, **Translation Services - Each 5.7%**
5. **Legal Services, None - Each 2.3%**

If you want to receive more services, what is preventing you?

1. N/A - 45.9%
2. **Housing Status - 13.5%**
3. **Fear of Stigma, Income/Ability to Pay - Each 10.8%**
4. **Transportation - 8.1%**
5. Lack of Support - 5.4%

What additional services would you like to access that are not available?

- Housing
- Educational services, computer training, exercise programs
- Utility assistance
- Gym/exercise area, support team to support healthy lifestyle
- Drop in center / consumer meeting
- Support group, interratial preferred
- Gift certificates

If you have accessed services in the past that you are no longer, what made you stop?

- Changes in the program
- Discontinued
- Unfunded

Appendix F: Assessment Of Need Survey Data Table: Hillsborough County

TABLE 1 | Comparison of survey data and NH HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=18)		NH HIV/AIDS Surveillance Systems (N=305)[a]	
	N	%	N	%
Age				
51 years of age or older	17	94.4%	Not available	
45 years of age or older	Not available		174	57.0%
Gender				
Male	16	88.9%	227*	74.4%*
Female	1	5.56%	78*	25.6%
Ethnicity				
Hispanic	24	58.5%	56	18.4%
Race				
American Indian/ Alaskan Native	1	5.56%	1	.328%
Asian/Pacific Islander	0	0%	0	0%
Black or African-American	2	11.1%	43	14.1%
White/Caucasian	14	77.8%	190	62.3%
Multi-Race	Not available		11	3.60%
Prefer not to answer	1	5.56%	Not available	
Other	1	5.56%	2	.656%

[a]County level data of PLWH
*Sex at Birth

Characteristics	Boston EMA Survey Respondents (N=18)		NH HIV/AIDS Surveillance Systems (N=305)[a]
	N	%	N
Sexual Orientation			
Heterosexual	2	11.1%	Not available
Gay	11	61.1%	
Bisexual	4	22.2%	
Primary Spoken Language			
English	17	94.4%	Not available
Spanish	1	5.56%	
Cape Verdean Creole	0	0%	
Portuguese	0	0%	
Haitian Creole	0	0%	
French	0	0%	
Swahili	0	0%	
Other	0	0%	
Immigration Status			
U.S. Citizen	17	94.4%	Not available
Legal Permanent Resident	0	0%	
VISA	1	5.56%	
Refugee/Asylee	0	0%	
Undocumented	0	0%	
Other	0	0%	

Data from New Hampshire HIV/STD/Viral Hepatitis Surveillance Program, provided to the Boston Public Health Commission's Ryan White Data Request. Numbers as of 7/11/19.

Appendix F: Assessment Of Need Survey Data Table: Hillsborough County

What services in the community are you accessing?

1. Case Management - 30%
2. Medical Care - 22%
3. Food Banks/Assistance - 18%
4. Support Groups - 14%
5. Financial Assistance, **Other - Each 6%**

If you want to receive more services, what is preventing you?

1. N/A - 29%
2. **Income/Ability to Pay - 19.2%**
3. Fear of Stigma, **Other - Each 15.4%**
4. Transportation - 11.5%
5. Lack of support, Housing status - Each 7.7%

What additional services would you like to access that are not available?

- Peer support groups
- Monthly coverage for a cellular phone for job related and medical care related items
- Drug trials (therapeutic vaccines, etc)
- Housing assistance
- More social support for non-LGBTQ+
- Support groups investigating side effects to HIV drugs
- Mental health
- Utility assistance
- Peer advocacy/social support/occupational support (job within community of HIV)

If you have accessed services in the past that you are no longer, what made you stop?

- Transportation

Appendix F: Assessment Of Need Survey Data Table: Middlesex County

TABLE 1 | Comparison of survey data and MA HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=52)		MA HIV/AIDS Surveillance Systems (N=3,879)[a]	
	N	%	N	%
Age				
30 years of age or younger	13	25%	231	6%
50 years of age or older	28	53.8%	2253	58.1%
Gender				
Male	33	63.5%	2264*	69%*
Female	17	32.7%	1215*	31%*
Transgender MTF	1	1.92%	Not available	
Transgender FTM	1	1.92%		
Ethnicity				
Hispanic	30	57.7%	760**	20%**
Race				
American Indian/ Alaskan Native	1	1.92%	Not available	
Asian/Pacific Islander	0	0%	160	4%
Black or African-American	21	40.4%	1335 ***	34% ***
White/Caucasian	29	55.8%	1595 ***	41% ***
Prefer not to answer	0	0%	Not available	
Other	4	7.69%	29	1%
Sexual Orientation				
Heterosexual	31	59.6%	Not available	
Gay	12	23.1%		
Bisexual	6	11.5%		
Other	1	1.92%		
Primary Spoken Language				
English	19	36.5%	Not available	
Spanish	9	17.3%		
Cape Verdean Creole	2	3.85%		
Portuguese	17	32.7%		
Haitian Creole	2	3.85%		
French	0	0%		
Swahili	1	1.92%		
Other	1	1.92%		
Immigration Status				
U.S. Citizen	26	50%	Not available	
Legal Permanent Resident	8	15.4%		
VISA	1	1.92%		
Refugee/Asylee	2	3.85%		
Undocumented	12	23.1%		
Prefer not to answer	1	1.92%		
Other	2	3.85%		

[a]County level data of PLWH
*Sex at Birth
**Non-Black, Non-White
***Non-Hispanic

Data from Massachusetts Department of Public Health, Bureau of Infectious Disease and Laboratory Sciences. 2018 Massachusetts HIV/AIDS Epidemiologic Profile: Regional HIV/AIDS Epidemiologic Profile of Bristol County, Massachusetts. Published September 2018. Numbers as of 1/1/18.

Appendix F: Assessment Of Need Survey Data Table: Middlesex County

What services in the community are you accessing?

1. Case Management - 29.7%
2. Medical Care - 24.3%
3. **Translation Services - 13.5%**
4. **Food Banks/Assistance - 9.5%**
5. **Support Groups - 7.4%**

If you want to receive more services, what is preventing you?

1. N/A - 34%
2. **Immigraton Status - 14%**
3. **Transportation - 12%**
4. **Fear of Stigma - 10%**
5. **Language Barrier - 8%**

What additional services would you like to access that are not available?

- Help with accessing affordable financing for home purchase, purchase of vital things like transportation/motor vehicles
- Legal counsel
- Fuel assistance
- Giftcards, cash
- Transportation
- Heating
- Support groups
- Home care attending
- Financial support to buy food

If you have accessed services in the past that you are no longer, what made you stop?

- Supplemental security income
- Dental
- Defunded
- Updated information on immigration and immigration support/assistance

Appendix F: Assessment Of Need Survey Data Table: Norfolk County

TABLE 1 | Comparison of survey data and MA HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=6)		MA HIV/AIDS Surveillance Systems (N=1308)[a]	
	N	%	N	%
Age				
30 years of age or younger	1	16.7%	73	5.58%
50 years of age or older	5	83.3%	860	65.7%
Gender				
Male	4	66.7%	935*	71%*
Female	2	33.3%	373*	29%*
Ethnicity				
Hispanic	0	0%	160**	12%**
Race				
American Indian/ Alaskan Native	0	0%	Not available	
Asian/Pacific Islander	1	16.7%	46	4%
Black or African-American	2	33.3%	434 ***	33% ***
White/Caucasian	3	50%	652 ***	50% ***
Prefer not to answer	0	0%	Not available	
Other	1	16.7%	16	1%
Sexual Orientation				
Heterosexual	3	50%	Not available	
Gay	2	33.3%		
Bisexual	1	16.7%		
Primary Spoken Language				
English	6	100%	Not available	
Spanish	0	0%		
Cape Verdean Creole	0	0%		
Portuguese	0	0%		
Haitian Creole	0	0%		
French	0	0%		
Swahili	0	0%		
Other	0	0%		
Immigration Status				
U.S. Citizen	6	100%	Not available	
Legal Permanent Resident	0	0%		
VISA	0	0%		
Refugee/Asylee	0	0%		
Undocumented	0	0%		
Other	0	0%		

[a]County level data of PLWH
*Sex at Birth
**Non-Black, Non-White
***Non-Hispanic

Data from Massachusetts Department of Public Health, Bureau of Infectious Disease and Laboratory Sciences. 2018 Massachusetts HIV/AIDS Epidemiologic Profile: Regional HIV/AIDS Epidemiologic Profile of Bristol County, Massachusetts. Published September 2018. Numbers as of 1/1/18.

Appendix F: Assessment Of Need Survey Data Table: Norfolk County

What services in the community are you accessing?

1. Case Management - 27.3%
2. Medical Care - 22.7%
3. Support Groups - 18.2%
4. Food Banks/Assistance - 13.6%
5. Financial Assistance - 9.1%

If you want to receive more services, what is preventing you?

N/A, Fear of Stigma, Housing Status, **Transportation, Income/Ability to Pay - Each 20%**

What additional services would you like to access that are not available?

No response

If you have accessed services in the past that you are no longer, what made you stop?

- Program shut down
- Transportation

Appendix F: Assessment Of Need Survey Data Table: Plymouth County

TABLE 1 | Comparison of survey data and MA HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=22)		MA HIV/AIDS Surveillance Systems (N=999)[a]	
	N	%	N	%
Age				
30 years of age or younger	0	0%	56	5.6%
50 years of age or older	14	63.6%	648	64.9%
Gender				
Male	15	68.2%	626*	63%*
Female	7	31.8%	373*	37%*
Gender Fluid	1	4.54%	Not available	
Ethnicity				
Hispanic	0	0%	117**	12%**
Race				
American Indian/ Alaskan Native	0	0%	Not available	
Asian/Pacific Islander	0	0%	11	1%
Black or African-American	6	27.3%	430 ***	43% ***
White/Caucasian	11	50%	429 ***	43% ***
Prefer not to answer	0	0%	Not available	
Other	4	18.2%	12	1%
Sexual Orientation				
Heterosexual	10	45.5%	Not available	
Gay	7	31.8%		
Bisexual	3	13.6%		
Primary Spoken Language				
English	18	100%	Not available	
Spanish	4	18.2%		
Cape Verdean Creole	0	0%		
Portuguese	0	0%		
Haitian Creole	1	4.55%		
French	0	0%		
Swahili	0	0%		
Other	0	0%		
Immigration Status				
U.S. Citizen	19	86.4%	Not available	
Legal Permanent Resident	1	4.55%		
VISA	0	0%		
Refugee/Asylee	0	0%		
Undocumented	1	4.55%		
Other	1	4.55%		

[a]County level data of PLWH
*Sex at Birth
**Non-Black, Non-White
***Non-Hispanic

Data from Massachusetts Department of Public Health, Bureau of Infectious Disease and Laboratory Sciences. 2018 Massachusetts HIV/AIDS Epidemiologic Profile: Regional HIV/AIDS Epidemiologic Profile of Bristol County, Massachusetts. Published September 2018. Numbers as of 1/1/18.

Appendix F: Assessment Of Need Survey Data Table: Plymouth County

What services in the community are you accessing?

1. **Medical Care - 26.9%**
2. Case Management, Support Groups - Each 25%
3. Food Banks/Assistance - 9.6%
4. Legal Services, Financial Assistance - 5.8%
5. Other - 1.9%

If you want to receive more services, what is preventing you?

1. N/A - 26.1%
2. **Housing Status - 17.4%**
3. Income/Ability to Pay - 13%
4. **Transportation, Lack of Support - Each 8.7%**
5. Fear of Stigma, **Immigration Status, Language Barrier, Competing Priorities - Each 4.3%**

What additional services would you like to access that are not available?

- Utility assistance
- Going back to school, access to learn more about electronics
- Community building
- Counseling
- Food, food stamps
- More meetings
- Help with income and finances

If you have accessed services in the past that you are no longer, what made you stop?

- No longer in school, work was interfering with school
- Food cards
- Defunded
- Support group
- CAB (Cabotegravir)

Appendix F: Assessment Of Need Survey Data Table: Rockingham County

TABLE 1 | Comparison of survey data and NH HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=1)		NH HIV/AIDS Surveillance Systems (N=107)[a]	
	N	%	N	%
Age				
51 years of age or older	*1*	*100%*	Not available	
45 years of age or older	*Not available*		77	72%
Gender				
Male	*1*	*100%*	92*	86%*
Female	*0*	*0%*	15*	14%*
Ethnicity				
Hispanic	*0*	*0%*	4	3.74%
Race				
American Indian/ Alaskan Native	*0*	*0%*	0	0%
Asian/Pacific Islander	*0*	*0%*	1	.935%
Black or African-American	*0*	*0%*	6	5.61%
White/Caucasian	*1*	*100%*	95	88.8%
Multi-Race	*Not available*		1	.935%
Prefer not to answer	*0*	*0%*	Not available	
Other	*0*	*0%*	0	0%
Sexual Orientation				
Heterosexual	*0*	*0%*	Not available	
Gay	*1*	*100%*		
Bisexual	*0*	*0%*		
Primary Spoken Language				
English	*1*	*100%*	Not available	
Spanish	*0*	*0%*		
Cape Verdean Creole	*0*	*0%*		
Portuguese	*0*	*0%*		
Haitian Creole	*0*	*0%*		
French	*0*	*0%*		
Swahili	*0*	*0%*		
Other	*0*	*0%*		
Immigration Status				
U.S. Citizen	*1*	*100%*	Not available	
Legal Permanent Resident	*0*	*0%*		
VISA	*0*	*0%*		
Refugee/Asylee	*0*	*0%*		
Undocumented	*0*	*0%*		
Other	*0*	*0%*		

[a]County level data of PLWH
*Sex at Birth

⚠ ***DATA BASED ON ONE SURVEY RESPONDENT***

Data from New Hampshire HIV/STD/Viral Hepatitis Surveillance Program, provided to the Boston Public Health Commission's Ryan White Data Request. Numbers as of 7/11/19.

Appendix F: Assessment Of Need Survey Data Table: Rockingham County

What services in the community are you accessing?

Case Management, Medical Care, Financial Assistance, Food Banks/Assistance, Other - Each 50%

If you want to receive more services, what is preventing you?

Income/Ability to Pay, Lack of Support - Each 50%

What additional services would you like to access that are not available?

- Hospital/ER/psych copays

If you have accessed services in the past that you are no longer, what made you stop?

No response

Appendix F: Assessment Of Need Survey Data Table: Strafford County

TABLE 1 | Comparison of survey data and NH HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=8)		NH HIV/AIDS Surveillance Systems (N=58)[a]	
	N	%	N	%
Age				
51 years of age or older	3	37.5%	Not available	
45 years of age or older	Not available		36	62.1%
Gender				
Male	7	87.5%	50*	86.2%*
Female	1	12.5%	8*	13.8%*
Ethnicity				
Hispanic	0	0%	3	5.17%
Race				
American Indian/ Alaskan Native	0	0%	0	0%
Asian/Pacific Islander	0	0%	0	0%
Black or African-American	3	37.5%	5	8.62%
White/Caucasian	5	62.5%	46	79.3%
Multi-Race	Not available		3	5.17%
Prefer not to answer	0	0%	Not available	
Other	0	0%	1	1.72%
Sexual Orientation				
Heterosexual	1	12.5%	Not available	
Gay	6	75%		
Bisexual	1	12.5%		
Primary Spoken Language				
English	8	100%	Not available	
Spanish	0	0%		
Cape Verdean Creole	0	0%		
Portuguese	0	0%		
Haitian Creole	0	0%		
French	0	0%		
Swahili	0	0%		
Other	0	0%		
Immigration Status				
U.S. Citizen	8	100%	Not available	
Legal Permanent Resident	0	0%		
VISA				
Refugee/Asylee	0	0%		
Undocumented	0	0%		
Other	0	0%		

[a]County level data of PLWH
*Sex at Birth

Data from New Hampshire HIV/STD/Viral Hepatitis Surveillance Program, provided to the Boston Public Health Commission's Ryan White Data Request. Numbers as of 7/11/19.

Appendix F: Assessment Of Need Survey Data Table: Strafford County

What services in the community are you accessing?

Case Management, Medical Care - Each 50%

If you want to receive more services, what is preventing you?

N/A - 100%

What additional services would you like to access that are not available?

- Legal services
- Transportation services for daily errands and maybe bus ticket (on a fixed
- income and cannot afford the taxi and uber fares, too expensive)
- Financial assistance
- Medical assistance (state) - 2 yearly misc assistances have been taken away unless an
- emergency arises
- Dental for root canals, wisdom teeth. NH only has 1 provider
- Hearing aid, eye care

If you have accessed services in the past that you are no longer, what made you stop?

- Discontinued
- No longer eligible unless there is an additional financial burden or emergency

Appendix F: Assessment Of Need Survey Data Table: Suffolk County

TABLE 1 | Comparison of survey data and MA HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=108)		MA HIV/AIDS Surveillance Systems (N=6,145)[a]	
	N	%	N	%
Age				
30 years of age or younger	2	1.85%	6	6%
50 years of age or older	73	67.6%	3687	60%
Gender				
Male	78	72.2%	4727*	77%*
Female	27	25%	1418*	23%*
Transgender FTM	1	.925%	Not available	
Gender Fluid	1	.925%		
Ethnicity				
Hispanic	27	25%	1457**	24%**
Race				
American Indian/ Alaskan Native	1	.925%	Not available	
Asian/Pacific Islander	1	.925%	128	2%
Black or African-American	36	33.3%	2326 ***	38% ***
White/Caucasian	45	41.7%	2174 ***	35% ***
Prefer not to answer	1	.925%	Not available	
Other	21	19.4%	60	1%
Sexual Orientation				
Heterosexual	44	40.7%	Not available	
Gay	48	44.4%		
Bisexual	11	10.2%		
Other	1	.925%		
Primary Spoken Language				
English	78	72.2%	Not available	
Spanish	23	21.3%		
Cape Verdean Creole	5	4.63%		
Portuguese	3	2.78%		
Haitian Creole	3	2.78%		
French	0	0%		
Swahili	1	.925%		
Other	0	0%		
Immigration Status				
U.S. Citizen	92	85.2%	Not available	
Legal Permanent Resident	9	8.33%		
VISA	0	0%		
Refugee/Asylee	2	1.85%		
Undocumented	3	2.78%		
Prefer not to answer	1	.925%		
Other	1	.925%		

[a]County level data of PLWH
*Sex at Birth
**Non-Black, Non-White
***Non-Hispanic

Data from Massachusetts Department of Public Health, Bureau of Infectious Disease and Laboratory Sciences. 2018 Massachusetts HIV/AIDS Epidemiologic Profile: Regional HIV/AIDS Epidemiologic Profile of Bristol County, Massachusetts. Published September 2018. Numbers as of 1/1/18.

Appendix F: Assessment Of Need Survey Data Table: Suffolk County

What services in the community are you accessing?

1. **Medical Care - 25.3%**
2. Case Management - 20.9%
3. Support Groups - 19.8%
4. Food Banks/Assistance - 11%
5. Financial Assistance, **Legal Services - Each 7.3%**
6. **Translation Services - 5.1%**

If you want to receive more services, what is preventing you?

1. N/A - 28.9%
2. **Transportation - 13.3%**
3. **Housing Status - 11.9%**
4. **Income/Ability to Pay - 9.6%**
5. Lack of Support - 6.7%

What additional services would you like to access that are not available?

- Drop in spots
- Affordable housing, rent assistance
- More transportation assistance
- Education to return to work
- Financial assistance
- Immigration support
- Legal assistance
- More services for LTS
- Over 50 support groups and events
- Housing for homeless
- Music, creative classes
- Employment, job assistance
- Community action and protest coordination
- Education on nonviolence
- Gym, exercise
- Spanish information

If you have accessed services in the past that you are no longer, what made you stop?

- No translator
- No longer available
- No longer needed
- Income/financial issues
- Health concerns
- Taking some time off
- Immigration services
- Lost contacts

Appendix F: Assessment Of Need Survey Data Table: Worcester County

TABLE 1 | Comparison of survey data and MA HIV/AIDS Surveillance Systems[a]

Characteristics	Boston EMA Survey Respondents (N=26)		MA HIV/AIDS Surveillance Systems (N=1,933)[a]	
	N	%	N	%
Age				
30 years of age or younger	0	0%	97	5%
50 years of age or older	18	69.2%	1179	61%
Gender				
Male	10	38.5%	1212	63%*
Female	15	57.7%	721	37%*
Transgender MTF	1	3.85%	Not available	
Ethnicity				
Hispanic	11	42.3%	601**	31%**
Race				
American Indian/ Alaskan Native	1	3.85%	Not available	
Asian/Pacific Islander	1	3.85%	35	2%
Black or African-American	7	26.9%	521 ***	27% ***
White/Caucasian	11	42.3%	758 ***	39% ***
Prefer not to answer	1	3.85%	Not available	
Other	3	11.5%	18	1%
Sexual Orientation				
Heterosexual	19	73.1%	Not available	
Gay	5	19.2%		
Other	2	7.69%		
Primary Spoken Language				
English	17	65.4%	Not available	
Spanish	7	26.9%		
Cape Verdean Creole	0	0%		
Portuguese	0	0%		
Haitian Creole	2	7.69%		
French	0	0%		
Swahili	0	0%		
Other	1	3.85%		
Immigration Status				
U.S. Citizen	23	88.5%	Not available	
Legal Permanent Resident	1	3.85%		
VISA	0	0%		
Refugee/Asylee	0	0%		
Undocumented	2	7.69%		
Prefer not to answer	0	0%		
Other	0	0%		

[a]County level data of PLWH
*Sex at Birth
**Non-Black, Non-White
***Non-Hispanic

Data from Massachusetts Department of Public Health, Bureau of Infectious Disease and Laboratory Sciences. 2018 Massachusetts HIV/AIDS Epidemiologic Profile: Regional HIV/AIDS Epidemiologic Profile of Bristol County, Massachusetts. Published September 2018. Numbers as of 1/1/18.

Appendix F: Assessment Of Need Survey Data Table: Worcester County

What services in the community are you accessing?

1. Case Management - 21.9%
2. Medical Care - 20.5%
3. Support Groups - 19.2%
4. Food Banks/Assistance - 16.4%
5. Financial Assistance - 8.2%

If you want to receive more services, what is preventing you?

1. N/A - 20.8%
2. **Fear of Stigma - 14.6%**
3. Income/Ability to Pay, Transportation - 12.5%
4. Housing Status - 10.4%
5. **Language Barrier - 8.3%**

What additional services would you like to access that are not available?

- More support groups
- LGBTQ+ services within the community
- Massage, reiki
- More housing for PLWH
- Housing assistance
- Fuel assistance
- Dental
- Case management
- More information about available benefits

If you have accessed services in the past that you are no longer, what made you stop?

- Lack of participation in the city (support groups are very small)
- Defunded