2020-2022
COMMUNITY NEEDS ASSESSMENT

Barriers to care and gaps in service for people living with HIV in the Boston EMA from the perspective of consumers and their care providers

Planning Council Support
Education and Community Engagement Division
Infectious Disease Bureau
Boston Public Health Commission

BOSTON PUBLIC HEALTH COMMISSION

Table of Contents

Authors
Beth Williams, MPH Candidate
Clark Azubuike, MBBS, MPH
Planning Council Support Staff Interns

With the support of
Planning Council Support Staff
pcs@bphc.org

List of Abbreviations

ADAP/HDAP - AIDS Drug Assistance Program/HIV Drugs Assistance Program
AIDS - Acquired Immunodeficiency Syndrome
ART - Antiretroviral therapy
BPHC - Boston Public Health Commission
CARE - Comprehensive AIDS Resources
Emergency
CDC - Centers for Disease Control and Prevention
CEO - Chief Executive Officer
CY - Calendar year
EMA - Eligible Metropolitan Area
FY - Fiscal Year
HAB - HIV/AIDS Bureau (of the Health Resources and Services Administration)
HCC - HIV Care Continuum
HIV - Human Immunodeficiency Virus
HRSA - The Health Resources and Services Administration
IDU - Injection Drug Use (An exposure category used by our epidemiologic profiles)
MA - Massachusetts
MAI - Minority AIDS Initiative
MDPH - Massachusetts Department of Public Health
MSM - Men who have sex with men (An exposure category used by our epidemiologic profiles)
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
PCS - Planning Council Support
PLWH - People living with HIV
RWHAP - Ryan White HIV/AIDS Program
TGA - Transitional Grant Areas
VL- Viral Load

Introduction

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was created in 1990 in response to the growing impact of the HIV/AIDS epidemic. It was amended in 1996 and 2000, then replaced by the Ryan White HIV/AIDS Treatment Modernization Act in 2006, and reauthorized as the Ryan White HIV/AIDS Treatment Extension Act in 2009. The Ryan White CARE Act officially expired in 2013, however, continues to receive funding dependent upon the Federal appropriations process.[1]

The Ryan White HIV/AIDS Program (RWHAP) includes 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 living with HIV/AIDS and their families. This continuum includes core, primary medical care, including HIV specific services, and supportive services which aim to support access to care and enhance quality of life.[2]

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.[3]

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. The Planning Council then also determines allocation proportions for prioritized Part A funded services. BPHC must distribute grant funds according to the priorities established by the Planning Council.[2]

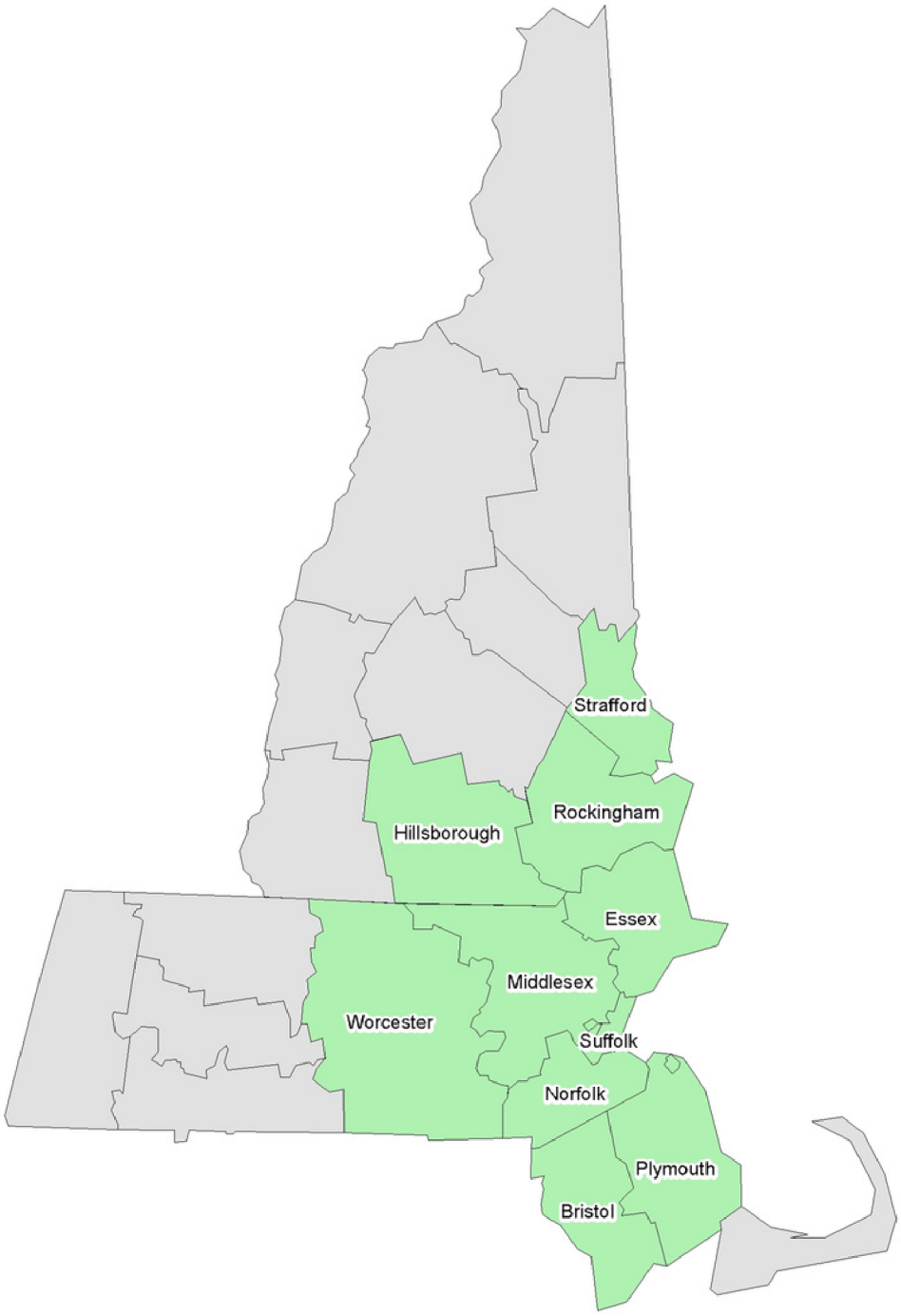
1 Ryan White CARE Act: A Legislative History, Health Resources and Services Administration (HRSA), https://ryanwhite.hrsa.gov/livinghistory/legislation-history, Last Reviewed: February 2022.
2 Part A: Grants to Eligible Metropolitan and Transitional Areas, HRSA, https://ryanwhite.hrsa.gov/about/parts-and-initiatives/part-a, Last Reviewed: November 2022
3 Ryan White HIV/AIDS Program, Part A Manual, HRSA, https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/resources/manual-part.pdf, Last Updated: March 2023

Background & Epidemiologic Profile

OVERVIEW OF HIV/AIDS IN THE BOSTON EMA

The Boston EMA comprises 308 cities and towns within 10 counties. Seven counties are in Massachusetts (Suffolk, Essex, Worcester, Middlesex, Norfolk, Plymouth, and Bristol), and three in New Hampshire (Hillsborough, Rockingham, and Strafford).

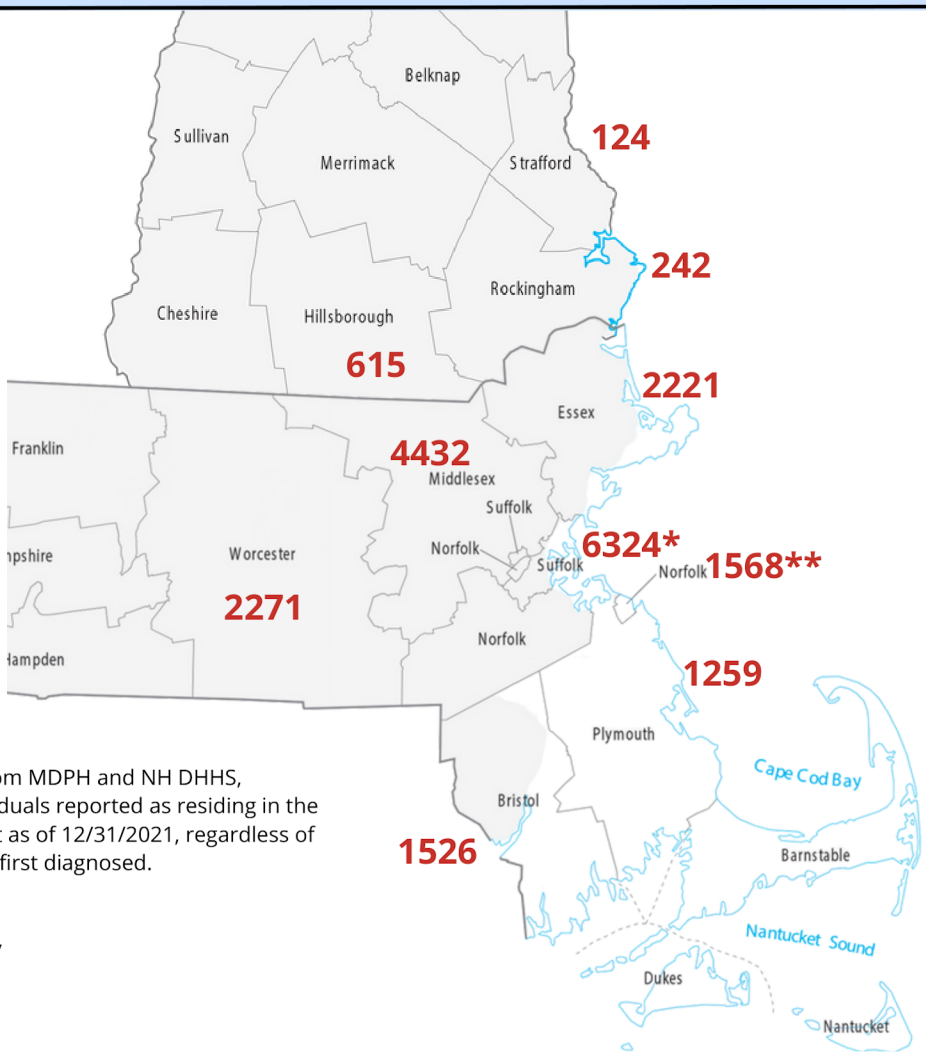
FIGURE 1 | Map of Boston EMA



De-identified data from MDPH and NH DHHS were provided to PCS staff for the purposes of writing this report and creating an epidemiologic profile of the HIV epidemic in the EMA.[4, 5, 6] The data from MDPH and NH DHHS is not exclusively Part A clients and should be considered as a proxy measurement for the EMA. 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.

As of December 31, 2021, there are 20,582 PLWH reported in the Boston EMA across all counties (Figure 2). In 2021, there were 391 people newly diagnosed with HIV, a 1.3 percent increase in HIV diagnoses since 2020. In 2021, there were 181 people newly diagnosed with AIDS, a 15.3 percent increase in AIDS diagnoses since 2020. These trends can be seen more clearly in figures 3 and 4 on the following page.

FIGURE 2 | Prevalence of HIV Cases by EMA County, 2021

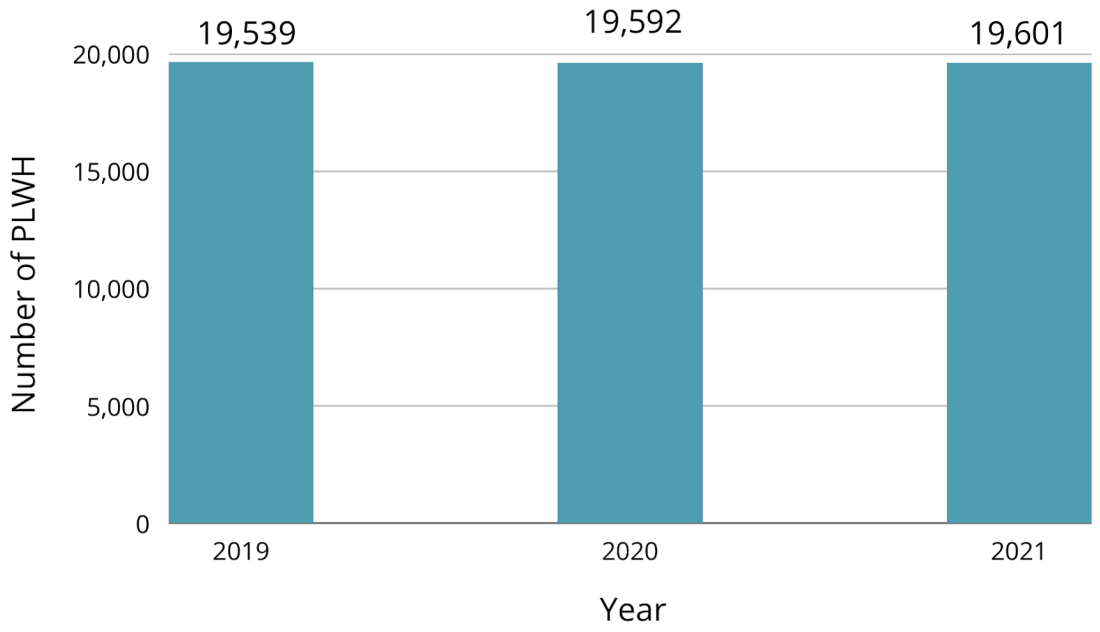


Data collected from MDPH and NH DHHS, includes all individuals reported as residing in the county of interest as of 12/31/2021, regardless of where they were first diagnosed.

*Suffolk County
**Norfolk County

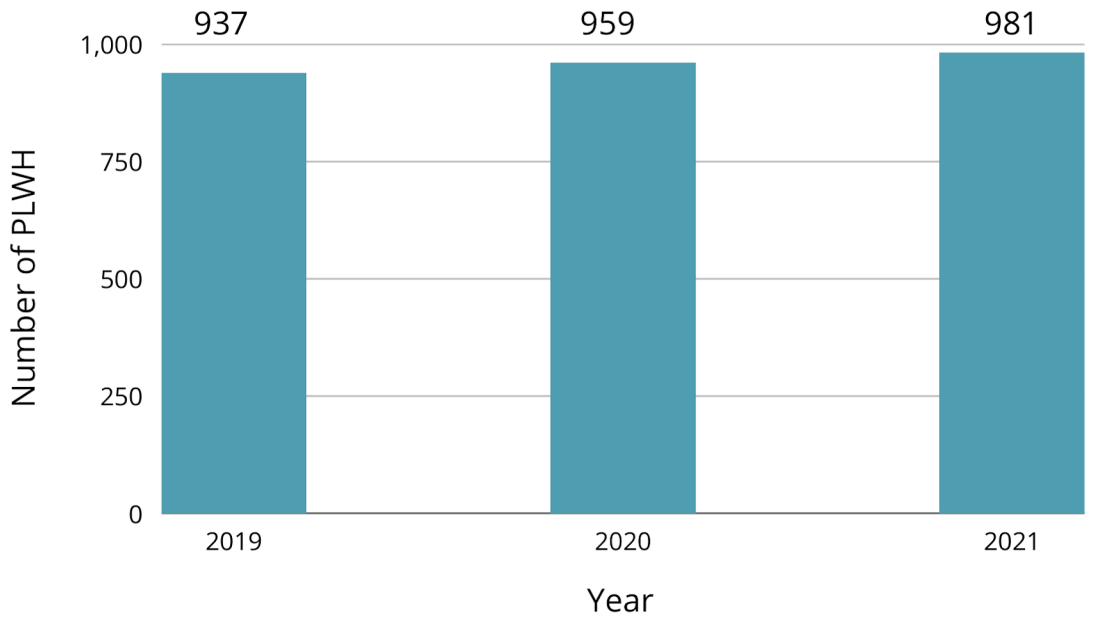
4 Boston EMA Epidemiologic Overview 2019-2021. Massachusetts Department of Public Health (MDPH), January 2023.
5 NH Epidemiologic Overview - Hillsborough, Rockingham, and Strafford Counties 2019-2021, New Hampshire Department of Health and Human Services (NH DHHS), January 2023.
6 HIV/AIDS Bureau Measures Report, e2Boston, Boston Public Health Commission (BPHC), February 28, 2023.

FIGURE 3 | Prevalence of HIV Cases in MA Counties of the Boston EMA, 2019-2021



Boston EMA Epidemiologic Overview 2019-2021. Massachusetts Department of Public Health (MDPH), January 2023.

FIGURE 4 | Prevalence of HIV Cases in NH Counties of the Boston EMA, 2019-2021



NH Epidemiologic Overview - Hillsborough, Rockingham, and Strafford Counties 2019-2021, New Hampshire Department of Health and Human Services (NH DHHS), January 2023.

DEMOGRAPHICS OF PLWH IN THE BOSTON EMA

The following data is from MDPH, current as of January 2023 or NH DHHS, current as of October 2022. All PLWH that are engaged in care and live in any of the 10 EMA counties are included below. Since the EMA spans two states and is very diverse in terms of availability of services and data, the states differ slightly in how they measure the demographics of their HIV populations. We combine the data where possible to reflect the full EMA and specify when there are differences.

FIGURE 9 | Sex at Birth of People Living with HIV in the Boston EMA, All Counties, 2019-2021

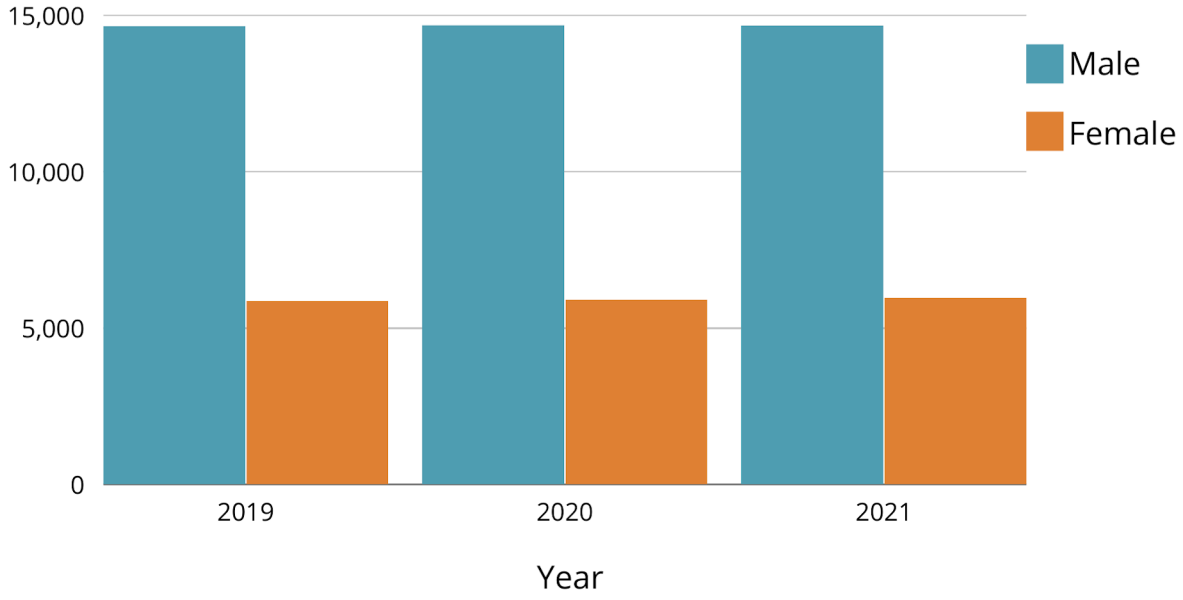


TABLE 4 | Current Gender of People Living with HIV in the Boston EMA, Massachusetts, 2019-2021

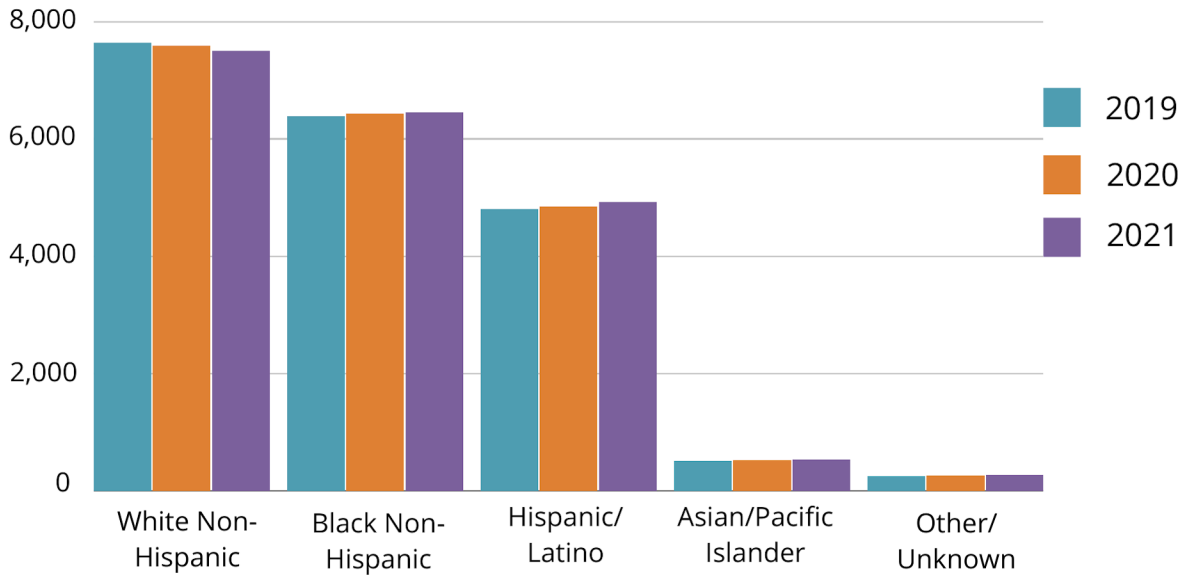
Year	**2019**		**2020**		**2021**	
MA	Incidence	Prevalence	Incidence	Prevalence	Incidence	Prevalence
Cisgender	<5	19,430	380	19,477	<5	19486
Transgender	<5	109	6	115	<5	115

*Values <5 are suppressed to protect privacy, and additional values may be suppressed to avoid back-calculation.

Boston EMA Epidemiologic Overview 2019-2021. Massachusetts Department of Public Health (MDPH), January 2023.
NH Epidemiologic Overview - Hillsborough, Rockingham, and Strafford Counties 2019-2021, New Hampshire Department of Health and Human Services (NH DHHS), January 2023.

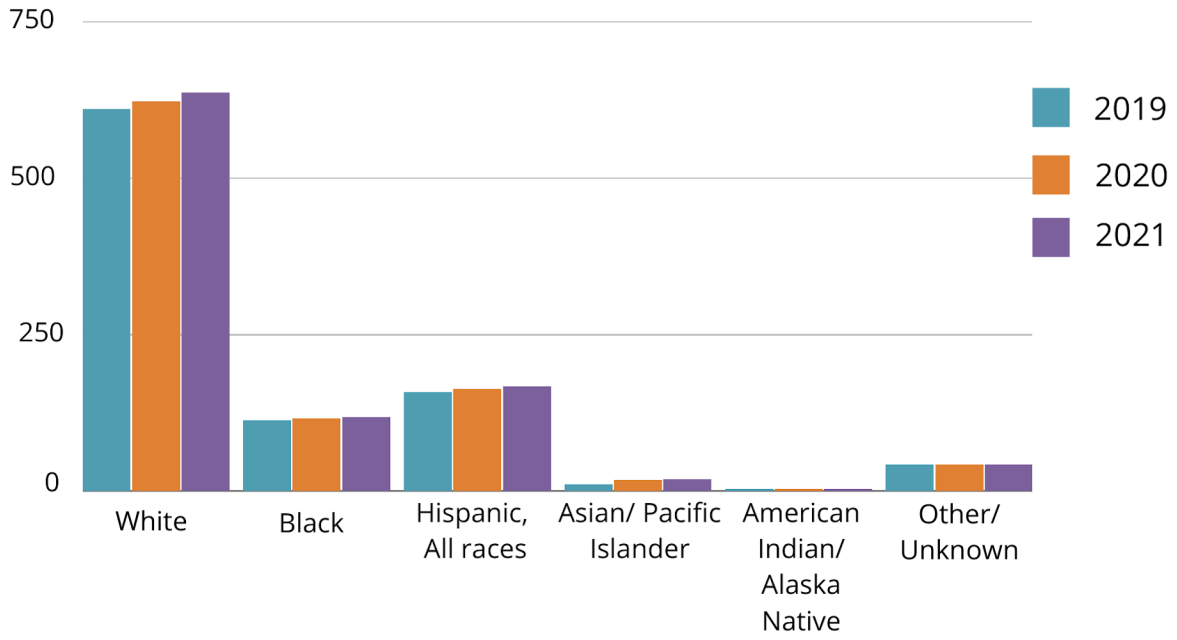
Race categories differed slightly between the two states, with Massachusetts separating out White and Non-Hispanic and Black and Non-Hispanic from those that are Hispanic/Latino, as seen in Figure 10.

FIGURE 10 | Race of People Living with HIV in the Boston EMA, Massachusetts, 2019-2021



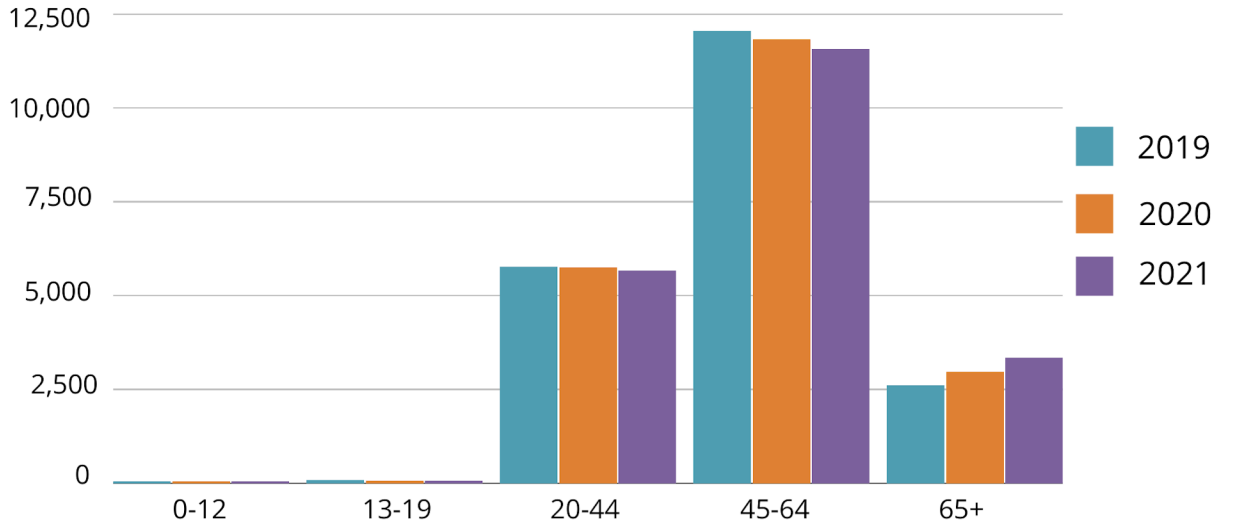
Boston EMA Epidemiologic Overview 2019-2021. Massachusetts Department of Public Health (MDPH), January 2023.

FIGURE 11 | Race of People living with HIV in the Boston EMA, New Hampshire, 2019-2021



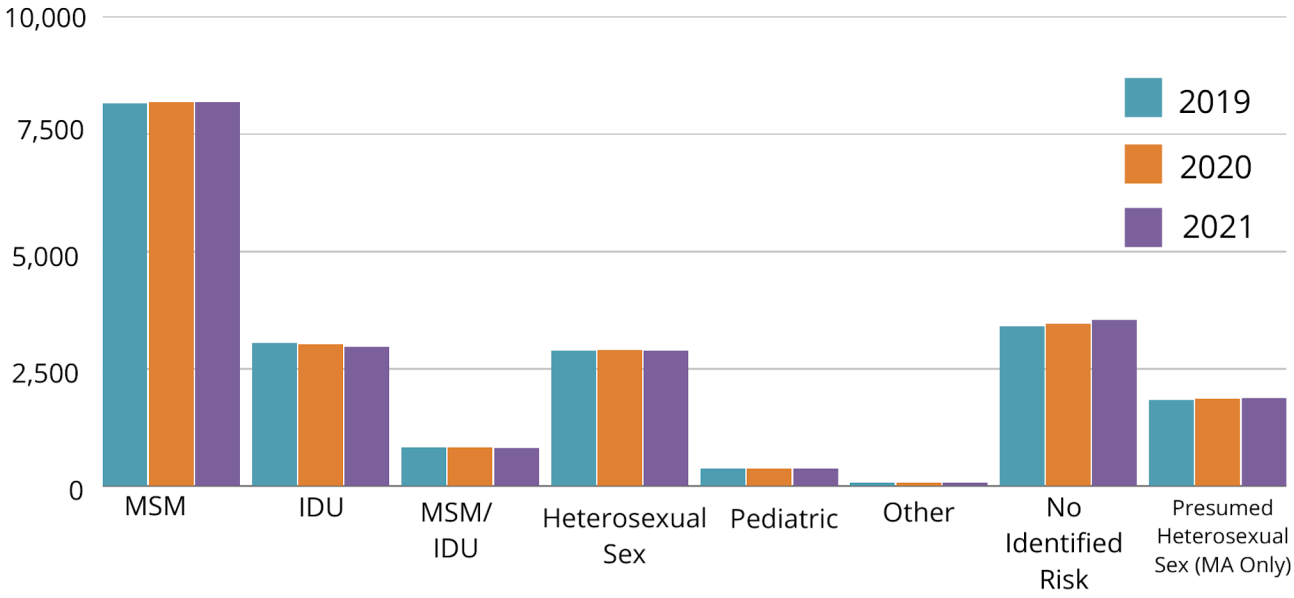
NH Epidemiologic Overview - Hillsborough, Rockingham, and Strafford Counties 2019-2021, New Hampshire Department of Health and Human Services (NH DHHS), January 2023.

FIGURE 12 | Ages of People Living with HIV in the Boston EMA, All Counties, 2019-2021



In Figure 12, age was categorized differently across New Hampshire and Massachusetts. We consolidated the New Hampshire data according to the Massachusetts age groups.

FIGURE 13 | Exposure Mode/Risk Category in the Boston EMA, All Counties, 2019-2021



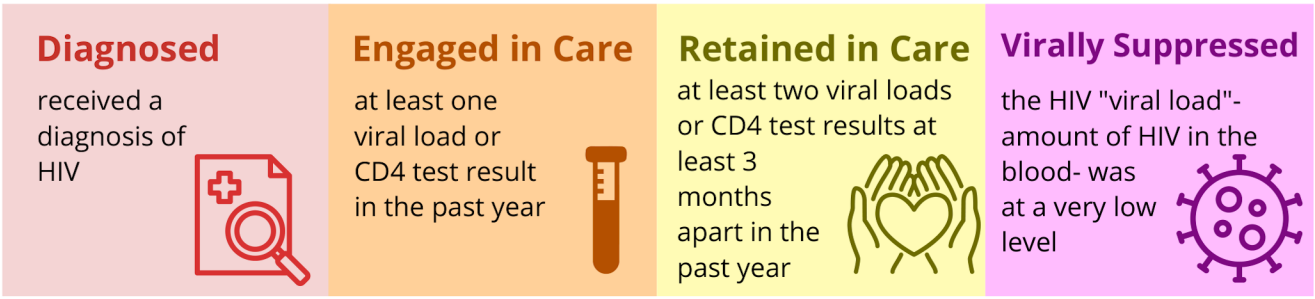
There were a few differences in how Massachusetts and New Hampshire reported exposure mode/risk category in Figure 13. Massachusetts uses presumed heterosexual sex to include people that identify as women with a negative history of injection drug use who report having sex with a person who identifies as a man of unknown HIV status or risk. Pediatric cases are those exposed under the age of 13, typically through perinatal transmission.

Boston EMA Epidemiologic Overview 2019-2021. Massachusetts Department of Public Health (MDPH), January 2023.
NH Epidemiologic Overview - Hillsborough, Rockingham, and Strafford Counties 2019-2021, New Hampshire Department of Health and Human Services (NH DHHS), January 2023.

HIV CARE CONTINUUM MEASURES

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. 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. The HIV Care Continuum is outlined in Figure 6 for Massachusetts counties, inspired by the CDC's HIV Care Continuum.

FIGURE 5 | Understanding the HIV Care Continuum



In the HCC, someone is **diagnosed** if they have received a diagnosis of HIV within the Boston EMA.

A person is **engaged in care** if they have had at least one viral load (VL) or CD4 test result in the past year (In this case, 2021).

Retained in care means that person has had at least two VL or CD4 test results at least 3 months apart in the past year (In this case, 2021).

Virally suppressed means a person's HIV viral load, or the amount of HIV in the blood, was at a very low level, defined as less than 200 copies/mL for the most recent viral load drawn in 2021. Figure 6 on the following page represents the HCC in the Massachusetts counties of the Boston EMA in calendar year (CY) 2021. Table 1 then explains how each stage is defined.

7 Understanding the HIV Care Continuum. Centers for Disease Control and Prevention, July 2019, www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf.

FIGURE 6 | HIV Care Continuum in the MA Counties of the Boston EMA, 2021*

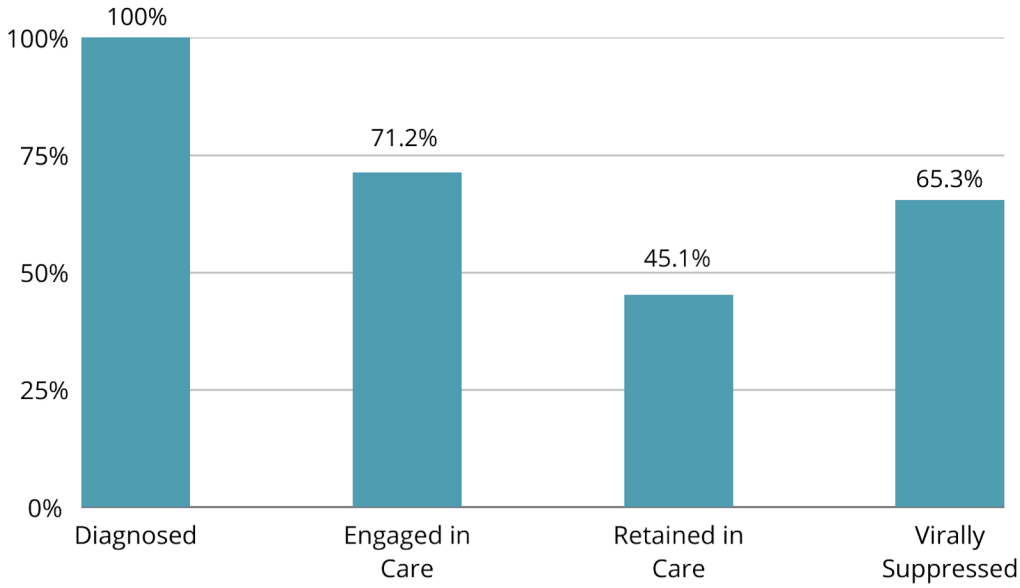


TABLE 1 | HIV Care Continuum Narrative and Definitions in the MA Counties of the Boston EMA, 2021*

Diagnosed	**(18,634/18,634) 100%** **Numerator:** Total number of people diagnosed with HIV in the Boston EMA, Individuals diagnosed through 12/31/2020, alive through 12/31/2021, and living in MA counties of the Boston EMA at the end of 2021 based on last known address **Denominator:** Total number of people diagnosed with HIV in the Boston EMA
Engaged in Care	**(13,268/18,634) 71.2%** **Numerator:** At least one viral load (VL) or CD4 test result in 2021 **Denominator:** Total number of people diagnosed with HIV in the MA counties of the Boston EMA
Retained in Care	**(8,404/18,634) 45.1%** **Numerator:** At least two VL or CD4 test results at least 3 months apart in 2021 **Denominator:** Total number of people diagnosed with HIV in the MA counties of the Boston EMA
Virally Suppressed	**(12,170/18,634) 65.3%** **Numerator**: 4 Viral Load <200 copies/mL for the most recent VL drawn in 2021 **Denominator**: Total number of people diagnosed with HIV in the MA counties of the Boston EMA

*This data is from MA and does not include PLWH living in the EMA counties of NH. This data also includes PLWH who are receiving services other than just Part A funded services. This report is used as a proxy measure for the EMA.

Boston EMA Epidemiologic Overview 2019-2021. Massachusetts Department of Public Health (MDPH), January 2023.

Figures 7 and 8 and Tables 2 and 3 reflect data from BPHC's Part A electronic client-level data tracking system, e2Boston. These data reflect Part A clients across all counties of the EMA, including Massachusetts and New Hampshire. All clients included here reported a care engagement within the measurement period, March 2022-February 2023. A care engagement is defined as an HIV medical visit, serologic test or a viral load test.

e2Boston tracks HIV Core Performance Measures for all Part A service consumers across all EMA counties (Figure 7). Table 2 defines each measure further.

FIGURE 7 | HIV Core Performance Measures, Part A Services, All Counties, Boston EMA, 2022

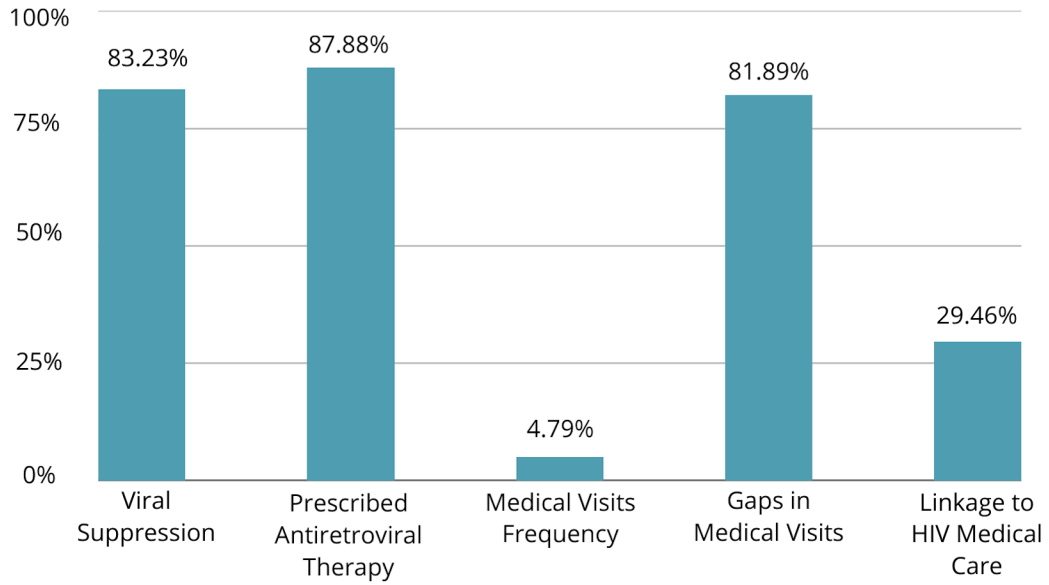


TABLE 2 | Core Performance Measures Narrative and Definitions, Part A Services, All Counties, Boston EMA, 2022

Viral Suppression	**(2,363/2,839) 83.23%** **Numerator:** Number of clients in the denominator with a HIV viral load less than 200 copies at last viral load test during the 12-month measurement year or the measurement period **Denominator:** Number of clients who were Care Engaged and have at least one medical visit during the 12-month measurement year or the measurement period
Prescribed HIV/AIDS Antiretroviral Therapy (ART)	**(2,495/2,839) 87.88%** **Numerator:** Number of clients, in the denominator, prescribed HIV antiretroviral therapy during the 12-month measurement year or the measurement period **Denominator:** Number of clients who were Care Engaged and have at least one medical visit in the 12-month measurement year or the measurement period

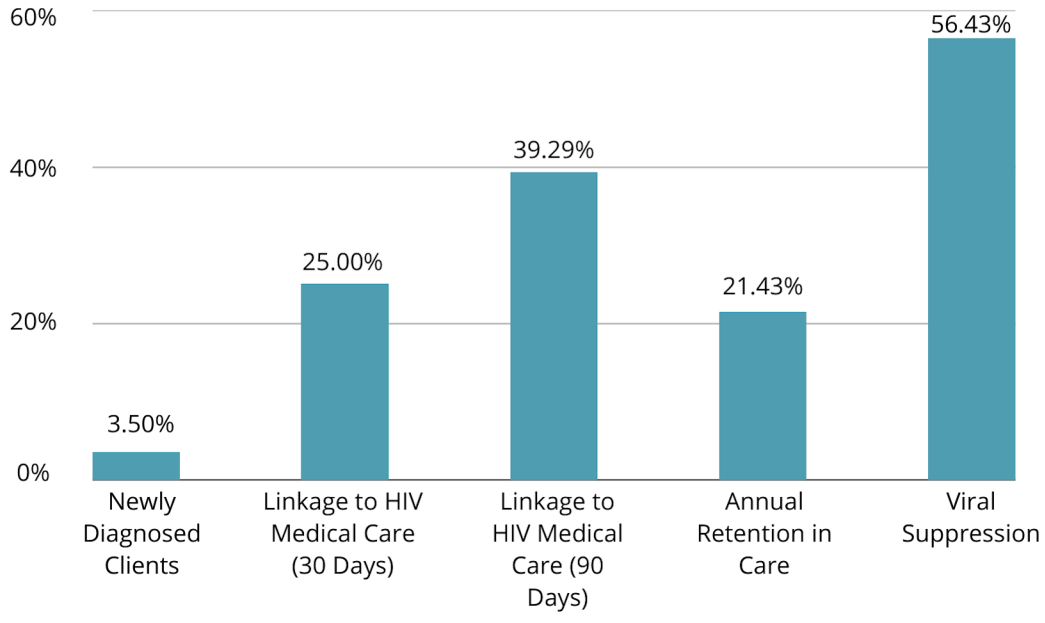
HIV/AIDS Bureau Measures Report, e2Boston, Boston Public Health Commission (BPHC), February 28, 2023.

TABLE 2 CONTINUED

Medical Visits Frequency	**(77/1,609) 4.79%** **Numerator:** Number of clients with at least one medical visit in each 6-month period of the 24-month measurement period with a minimum of 60 days between medical visits **Denominator:** Number of clients who were Care Engaged and have at least one medical visit in the first 6 months of the 24-month measurement period
Gaps in Medical Visits	**(1,207/1,474) 81.89%** **Numerator:** Number of client in denominator who did not have a medical visit in the last 6 months of the 12-month measurement period **Denominator:** Number of clients who were Care Engaged and have at least one medical visit in the first six months of the 12-month measurement period
Linkage to HIV Medical Care	**(33/112) 29.46%** **Numerator:** Number of Care Engaged clients in the denominator who attended a routine HIV medical care visit within 1 month of HIV or AIDS diagnosis **Denominator:** Number of clients who have been HIV or AIDS diagnosed during the 12-month measurement year

e2Boston collects additional information specifically for newly diagnosed PLWH who receive Part A services across all EMA counties (Figure 8). Table 3 on the following page defines each measure further.

FIGURE 8 | Newly Diagnosed HIV Care Continuum, Part A Services, All Counties, Boston EMA, 2022



HIV/AIDS Bureau Measures Report, e2Boston, Boston Public Health Commission (BPHC), February 28, 2023.

TABLE 3 | Newly Diagnosed HIV Care Continuum Narrative and Definitions, Part A Services, All Counties, Boston EMA, 2022	
Newly Diagnosed Clients	**(140/3,999) 3.50%** **Numerator:** Number of clients from the denominator with the diagnostic date falls in 12-month measured period **Denominator:** Total number of diagnosed clients who have been served during 12-month period, prior to the "End Date"
Linkage to HIV Medical Care (30 days)	**(35/140) 25.00%** **Numerator:** Number of newly diagnosed clients from the denominator who have been linked to care within 30-day period **Denominator:** Number of Part A clients who have been identified as a Newly Diagnosed Clients
Linkage to HIV Medical Care (90 days)	**(55/140) 39.29%** **Numerator:** Number of newly diagnosed clients from the denominator who have been linked to care within 90-day period **Denominator:** Number of Part A clients who have been identified as a Newly Diagnosed Clients
Annual Retention in Care	**(30/140) 21.43%** **Numerator:** Number of newly diagnosed clients who had at least two VL test, CD4 test, or Medical Care Dates at least 3 months apart during 12 months after diagnosis **Denominator:** Number of Part A clients who have been identified as Newly Diagnosed Clients
Viral Suppression	**(79/140) 56.43%** **Numerator:** Clients from the denominator who had most recent viral load test result <200 copies/mL or "Undetectable" **Denominator:** Number of Part A clients who have been identified as Newly Diagnosed Clients

HIV/AIDS Bureau Measures Report, e2Boston, Boston Public Health Commission (BPHC), February 28, 2023.

E2BOSTON: PART A SERVICES CLIENT DEMOGRAPHICS

BPHC collects all Part A client service data through e2Boston, an electronic system that agencies utilize to report their clients receiving Part A services. The following demographic data in Table 4 includes clients that utilized Part A services at least once between March 1, 2022 and February 28, 2023 as reported on by the agency where they received services. All data are categorized by gender and each section includes the proportion of each category out of total reported clients.

TABLE 4 | Demographics of Part A Clients by Gender, All Counties, Boston EMA, FY 2022

Age	Male	Female	Transgender	%
0 - 12 Years	1	1	1	0.10%
13-19 Years	3	1	0	0.10%
20-44 Years	1046	423	44	30.30%
45-64 Years	1645	938	24	52.10%
65+ Years	573	298	2	17.50%
Total	3268	1661	71	100.00%

Race	**Hispanic or Latino/a**			**Not Hispanic or Latino/a**			**Unknown / unreported**			**Total**	%
	Male	Female	Transgender	Male	Female	Transgender	Male	Female	Transgender		
White	605	260	8	1120	313	13	1	1	0	2321	46.40%
Black or African American	183	90	10	853	737	22	0	2	0	1897	37.90%
Asian	2	0	0	59	13	0	0	0	0	74	1.50%
Native Hawaiian	3	1	1	1	0	0	0	0	0	6	0.10%
American Indian	3	0	0	3	3	0	0	0	0	9	0.20%
More than one race selected	38	21	1	31	27	2	0	0	0	120	2.40%
Unknown / unreported	307	147	10	39	27	4	20	19	0	573	11.50%
Total	1141 (22.8%)	519 (10.4%)	30 (0.6%)	2106 (42.1%)	1120 (22.4%)	41 (0.8%)	21 (0.4%)	22 (0.4%)	0 (0%)	5000	100%

HIV/AIDS Bureau Measures Report, e2Boston, Boston Public Health Commission (BPHC), February 28, 2023.

E2BOSTON: PART A SERVICES CLIENT PROFILE

Table 4 Continued					
Exposure Category	Male	Female	Transgender	# of Clients	%
Men who have sex with men (MSM)	1811	22	54	1887	37.70%
Injection drug users (IDU)	450	191	6	647	12.90%
MSM & IDU	58	1	5	64	1.30%
Heterosexual contact	906	1278	9	2193	43.90%
Perinatal transmission	46	47	3	96	1.90%
Hemophilia/Coagulation disorder	15	9	1	25	0.50%
Through blood, blood products, tissue	46	38	0	84	1.70%
Other risk	19	16	0	35	0.70%
Risk factor not reported or identified	264	168	7	439	8.80%
Total unique clients	3269	1661	71	5001	100%

HIV/AIDS Bureau Measures Report, e2Boston, Boston Public Health Commission (BPHC), February 28, 2023.

Part A Funded Services

(see Appendix A for service categories by agency)

Part A funded services include core medical care and support services, including:

- AIDS Drug Assistance Program (ADAP/HDAP)
- Medical Case Management, *including Training and Capacity Building Services*
- Housing
- Non-Medical Case Management
- Emergency Financial Assistance
- Oral Health Care
- Food Bank/Home-delivered Meals
- Psychosocial Support
- Medical Transportation
- Health Education and Risk Reduction
- Medical Nutrition Therapy
- Other Professional Services - Legal

The Minority AIDS Initiative also funds the following services in addition to Part A:

- MAI Case Management, Medical
- MAI Case Management, Non-Medical
- MAI Emergency Financial Assistance
- MAI Psychosocial Support
- MAI Linguistic Services
- MAI Other Professional Services - Legal

Boston EMA Planning Council Members 2022-2023

Alves, Justin
Amato, Daniel
Barrett, Adam
Batchelder, Stephen
Baum, Patrick
Brown-Noguera, Lamar
Cabrera, Henry
Callis, Barry
Carlesimo, Joey
Corbett, Stephen
Custodio, Sandra
Day, Larry
Gaines, Damon
Gavin, Beth
Giannasca, Robert
Hart, Amanda
Hazen, Jerome
Hector, Melissa
Hendricks, Darian
Holliday, Brian
Jones, Lorraine
Kirchgasser, Allison
LeBlanc, Wendy
Lefebvre, Jordan
Lituri, Kathy
Lombe, Margaret
McClendon, Allan
Nolen, Keith
Olivera, Ericka
Ouimet, Ethan
Perron, Yvette
Pierre, Arielle
Pinheiro, Mahara
Pires, Manuel
Rajabiun, Serena
Rosa, Luis
Ross, Nate
Sack, Darren
Skehan Gillis, Mairead
Swaney, Michael
Thomas, Bryan
Weerts, Catherine
White, Karen
Williams, Naika
Wilson, Kim
Young, Tim

Needs Assessment of PLWH and their Providers

INTRODUCTION

Grantees of Ryan White funding are required to conduct a needs assessment of the population of PLWH in the service area. The assessment must consists of:

1) Epidemiologic profile describing trends in the service area;
2) Assessment of needs of PLWH specifically related to HIV care;
3) Resource inventory, highlighting the availability of services;
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.

Based on a HRSA recommendation, the Needs, Resources and Allocations Committee (NRAC) of the Planning Council developed a 3-Year Needs Assessment model (Table 5) in order to collect data that can be used to inform allocation decisions and sufficiently assess the need within the EMA. Many components of the assessment are updated annually, such as the epidemiological profile and resource inventory. Data were collected from both consumers and providers from 2022-2023.[8,9]

TABLE 5 | 3-Year Needs Assessment Model, Updated as needed

Component	**2020-2021**	**2021-2022**	**2022-2023**
Epidemiologic Profile	Update current information based on State Surveillance data		
Assessment of Service Needs • PLWH in care • PLWH out of care • Resource Inventory	1) Develop methodology for consumer study within the EMA	Design and implement consumer study	Present final results
	2) Develop quantitative surveys and qualitative data collection tools	Begin data analysis	
	3) Analyze current reports and E2Boston data for available resources within the EMA	Present results as they are collected	
Profile of Provider Capacity and Capability	Develop methodology and implement	Analyze results	Present results
Assessment of unmet needs and service gaps across the study years	Summarize data from all other components	Analyze results	***Create final Needs Assessment Report (May 2023)***

8 Ryan White HIV/AIDS Program, Part A Manual, HRSA, https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/resources/manual-part.pdf, Last Updated: March 2023
9 Ryan White HIV/AIDS Program Planning Council/Planning Body Training Guide, Module 4: Needs Assessment, prepared by JSI Research & Training Institute, Inc. and EGM Consulting, LLC, HRSA, https://targethiv.org/planning-chatt/training-guide-module4, Last Updated: February 2019

This cycle may be updated as needed by NRAC in order to accommodate for various changes in the service area and funding environment. NRAC works together with Planning Council Support (PCS) staff in order to determine the best methods for conducting this assessment every three years. Lessons and recommendations are carried over each year and thoroughly reviewed in order to emphasize continuous evaluation of the process.

METHODS

To assess service needs of and barriers to care for PLWH in the Boston EMA, NRAC used a mixed-method research approach that included collecting quantitative data from both a consumer survey and a provider survey, and exploring qualitative data from a series of semi-structured focus group discussions with consumers of HIV services at some of our agencies. It sought to incorporate the perspectives of PLWH and their care providers across the ten counties in the Boston EMA.

Consumer Survey

NRAC along with PCS staff developed a 23-question survey for consumers of HIV services throughout the Boston EMA. The survey was adapted from previous needs assessment surveys developed from past student groups. All data was collected from March 2022 to March 2023.

The consumer survey (Appendix A) collected data using a series of predominantly closed-ended questions, with the opportunity for respondents to provide additional context to their responses. Consumer surveys were initially available online via SurveyMonkey in English and in paper format in both English and Spanish. In early 2023, NRAC decided to add two additional language translations in order to encourage more diverse participation. For all data collection that happened in 2023, the survey was available in paper format in English, Spanish, Portuguese and Haitian Creole to reflect the dominant languages spoken by clients accessing services from Part A funded agencies. The online format was still available only in English. No incentives were offered for completing the survey. NRAC members and PCS staff distributed the surveys using a convenience sampling method. Surveys were sent to all Part A funded agencies and additional listservs recommended to the committee by various members. The participating agencies assisted in the distribution of the surveys to their clients. Respondents created a unique ID at the time of taking the survey and all responses were anonymous. The survey asks for information on respondents' demographic data, service needs, access to services, perceived barriers, and access to virtual services during the COVID-19 pandemic.

Provider Survey

NRAC also developed a 26-question survey to be distributed to providers of HIV services in the Boston EMA. This survey was adapted from previous surveys designed by the committee and previous interns from Boston University School of Public Health (see Appendix B). Surveys were distributed online via Survey Monkey in English. No incentives were offered for completing the surveys. Surveys were sent to all Part A funded agencies and additional listservs recommended to the committee by various members. We asked providers to fill out the provider survey themselves and distribute the consumer survey to their clients. The survey asked for the agency name where the respondent works, but was otherwise anonymous. The provider survey asks about agencies' service needs, perceived barriers to services reported by clients, barriers to providing services, and factors impacting access to services during the COVID-19 pandemic.

Focus Group Discussions

The focus group discussions were facilitated by PCS staff and NRAC members using a semi-structured guide (Appendix C). Four focus groups took place in collaboration with partner agencies in the Boston EMA. We selected participants for the focus group using convenience sampling from the respondents to the consumer survey and specifically recruited individuals apart of specific high-risk groups. Gift cards were offered to participants for their time and input. Facilitators reviewed confidentiality and informed consent with participants. Responses were anonymized and included responses to questions about perceived service needs, barriers to access, the impact of the pandemic, and the benefits of virtual services.

ANALYSIS

PCS staff and interns conducted quantitative and qualitative data analysis from October 2022 to May 2023 in a multistep process, collaborating with various NRAC members to determine the best analysis methods as data were collected. Descriptive statistics were generated for the consumer surveys and general agency information was compiled from the provider surveys. All analyses were completed in Microsoft Excel (2019). Transcripts from the focus group discussions were reviewed by multiple people to identify themes across conversations. Codes were developed from these themes and responses were grouped according to theme. We compared consumer survey data and focus group discussion data to create a broad picture of service needs and barriers to care for PLWH in the Boston EMA. General themes from the provider survey data were also compared to consumer survey data, but no further quantitative analysis was done between provider and consumer surveys.

RESULTS

Consumer Survey Data

DEMOGRAPHICS

We received 186 responses to our consumer survey, 11 of which were incomplete and therefore not included in data analysis. The total number of complete responses is 175. Participants in the survey represented the majority of counties in the EMA, as seen in Figure 14 below. Table 6 displays the demographics of our survey respondents. Most respondents were white (56%), with 33% identifying as White/Non-Latino and 23% identifying as White/Latino. The majority of respondents were male (68%). About half of participants identified as heterosexual (51%), with 40% identifying as gay. 56% of respondents identified as gay and male. Majority of respondents were between 50-59 years old (28%) and 60-69 years old (27%).

62% of people prefer to speak English, with 6 additional respondents listing English and another language (6%), 21% of people prefer to speak Spanish, and 13% prefer Portuguese. 69% of respondents are US citizens, 10% are Legal Permanent Residents and 10% are Undocumented. 9% either did not respond to this question or chose 'prefer not to answer'. Throughout Table 6, if a participant did not respond, it is listed as 'NR'.

FIGURE 14 | Map of Respondents by Current Zip Code

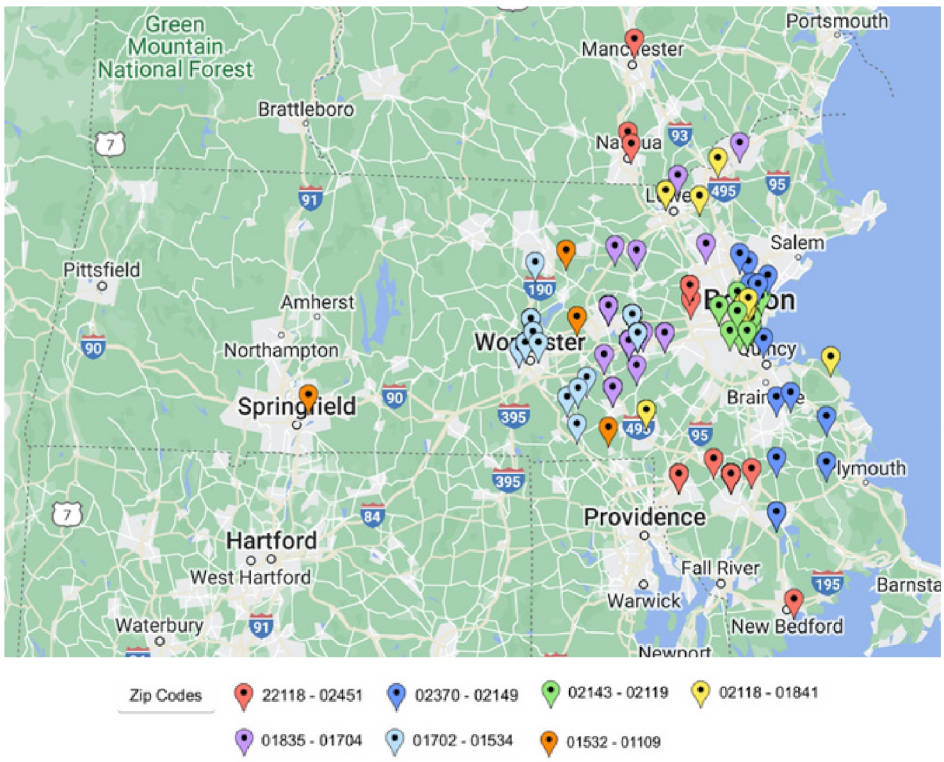


TABLE 6 | Demographic Characteristics of the Consumer Survey Respondents in the Boston EMA

Gender		
Female	52	30%
Male	119	68%
Non-Binary	1	1%
NR	3	2%
Sexual Orientation		
Heterosexual	88	50%
Gay	70	40%
Lesbian	1	1%
Bisexual	9	5%
Unsure	1	1%
Other	1	1%
NR	3	2%
Age		
20-29	6	3%
30-39	21	12%
40-49	36	21%
50-59	49	28%
60-69	48	27%
70+	13	7%
NR	2	1%

Preferred Spoken Language		
English	108	62%
English, Spanish	4	2%
English, Spanish, Portuguese, French	2	1%
Portuguese	22	13%
Spanish	37	21%
NR	1	1%
Other	1	1%
Immigration Status		
Legal Permanent Resident	18	10%
Refugee/Asylee (legal/approved)	1	1%
Undocumented	18	10%
US Citizen	121	69%
VISA: Student, Work, Business or Tourist	1	1%
NR	12	7%
Prefer not to answer	4	2%

Race	**Latino/Yes**	**Latino/NR**	**Latino/No**	
American Indian/Alaskan Native	1		1	1%
Asian	1		1	1%
Black/African American	19	1	32	30%
Native Hawaiian/Pacific Islander	1			1%
White/Caucasian	40	1	57	56%
No Response (NR)	6	1		4%
Other	11		2	7%
	45%	2%	53%	

167 respondents provided the year they first tested positive for HIV and 35% are long term survivors of HIV (diagnosed in 1995 or earlier). The average year of first diagnosis was 2001 and the average year of initiating treatment is 2003. The most recent year any respondent tested positive was 2022, with medication starting the same year. 79% of respondents had engaged in care within one year of their diagnosis and 78% of respondents had an undetectable viral load at their last doctor's appointment.

FIGURE 15 | Year Respondents First Tested Positive for HIV, N = 175

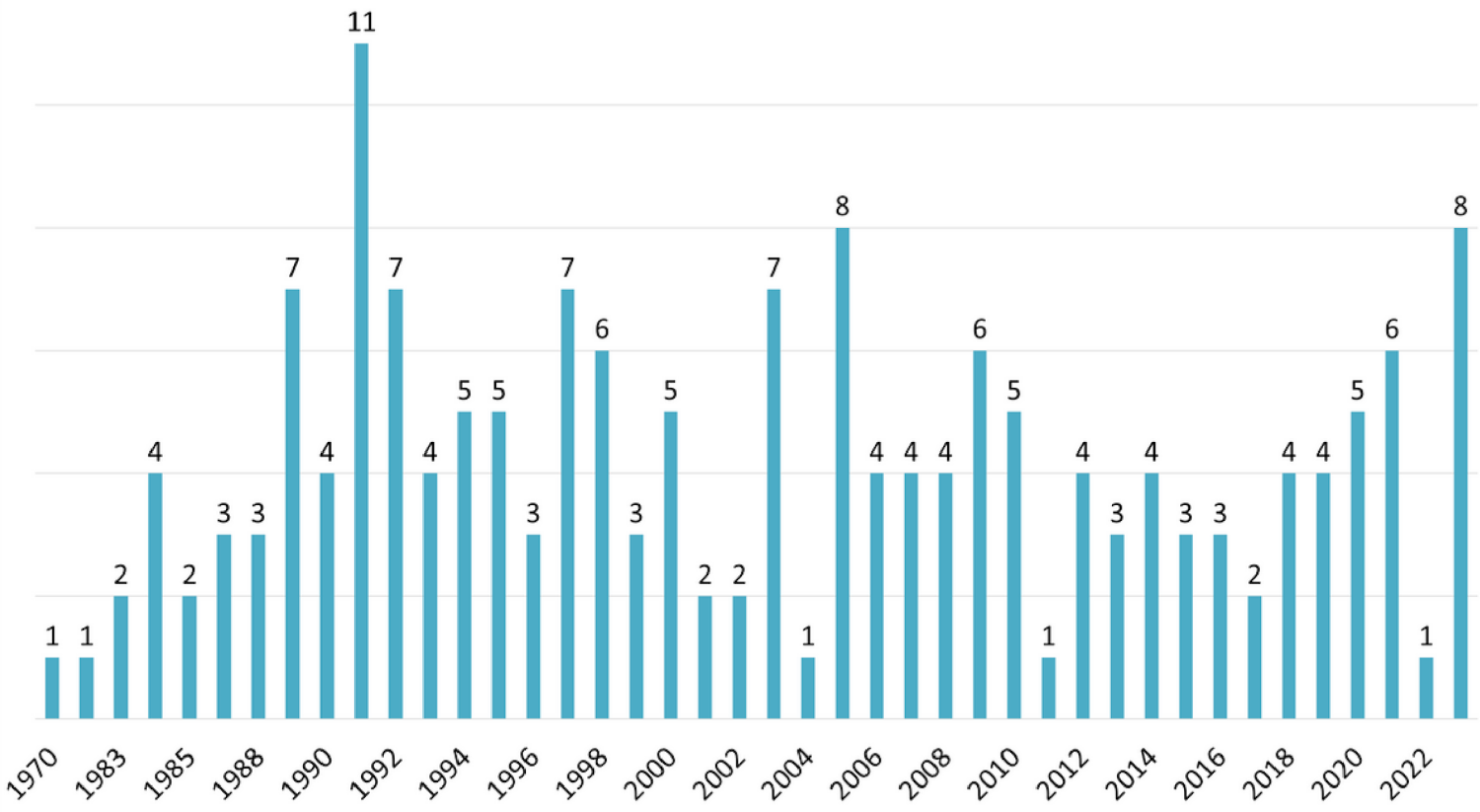


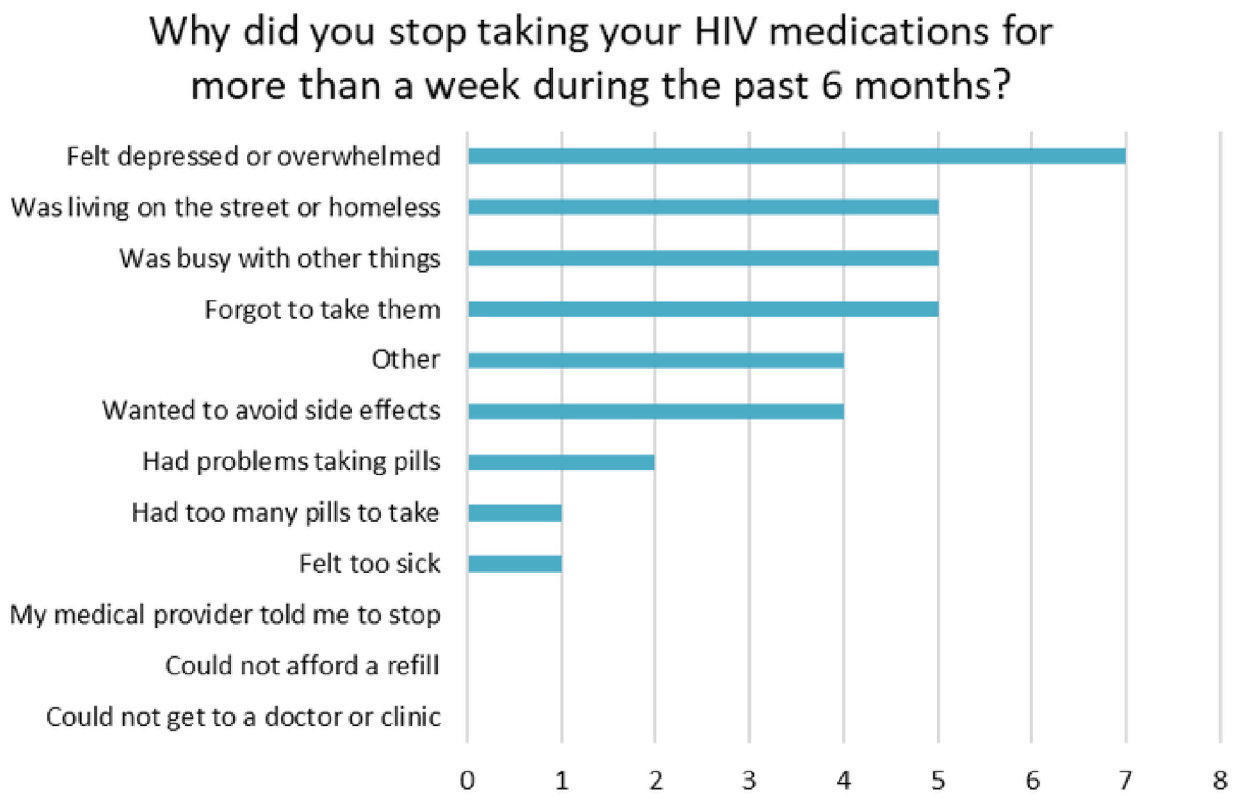
TABLE 7 | Time to Engagement in Care, N = 159, 16 No Responses

Years Between Diagnosis and Engaging in Care	**Number of Respondents**
0-1 year	126 (79%)
2-5 years	16 (10%)
6-10 years	8 (5%)
Over 10 years	9 (5.6%)

Respondents were asked, *If you are currently taking HIV medications, during the past 6 months, have you ever stopped taking any of them for more than a week (i.e. 7 days in a row or longer)?*. 20 respondents (11%) had stopped taking their medication at some point for more than 7 days in the past 6 months. The most common reasons for stopping medication were housing insecurity, depression or other mental health issues, forgetting to take them or having other things to do.

35% of those that had stopped taking their medication at some point cited that they stopped because they felt depressed or overwhelmed.

FIGURE 16 | Reasons for Stopping HIV Medication, N = 20



ACCESS TO SERVICES

Most participants traveled to appointments with a personal vehicle (59%) and 37% used public transportation. 61 participants, or 37% of participants selected multiple transportation options (Figure 17). Other responses not listed included "electric scooter" and "medical transportation".

Majority of respondents (138, or 79%) are currently accessing Case Management. 56%, or 98 respondents, utilize Medical Care and 33%, or 57 respondents, are accessing housing services. 69% of people listed more than one service that they are currently accessing (Figure 18).

FIGURE 17 | Transportation to Appointments, N = 166

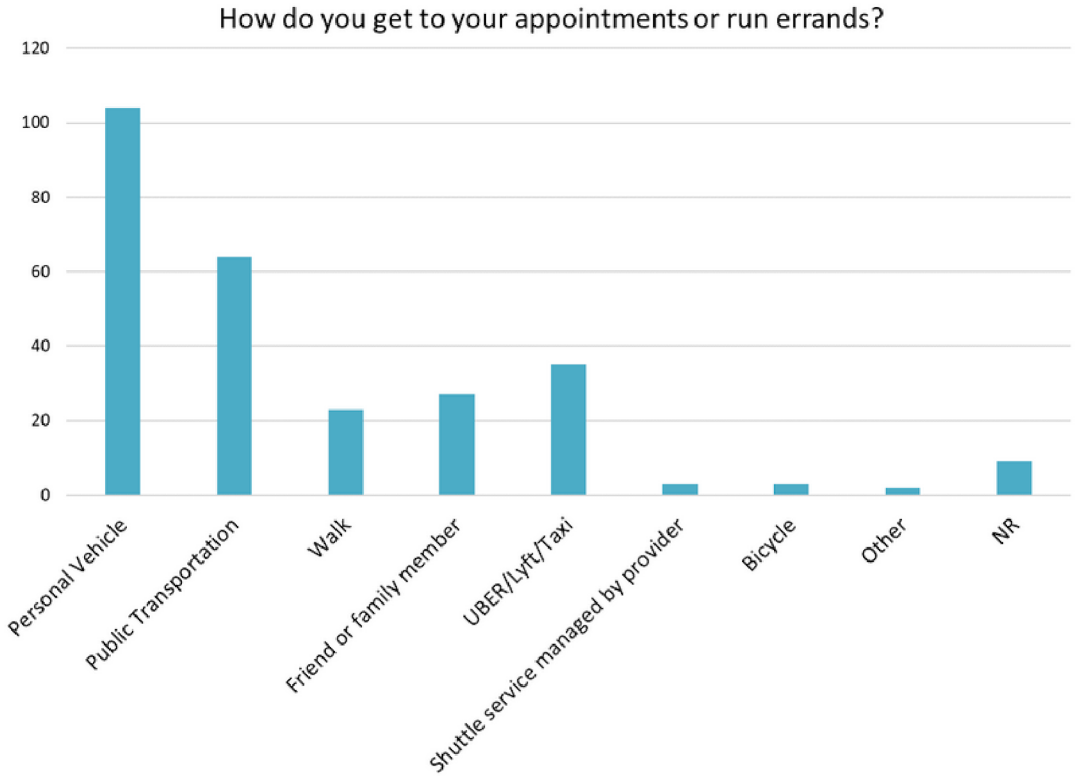
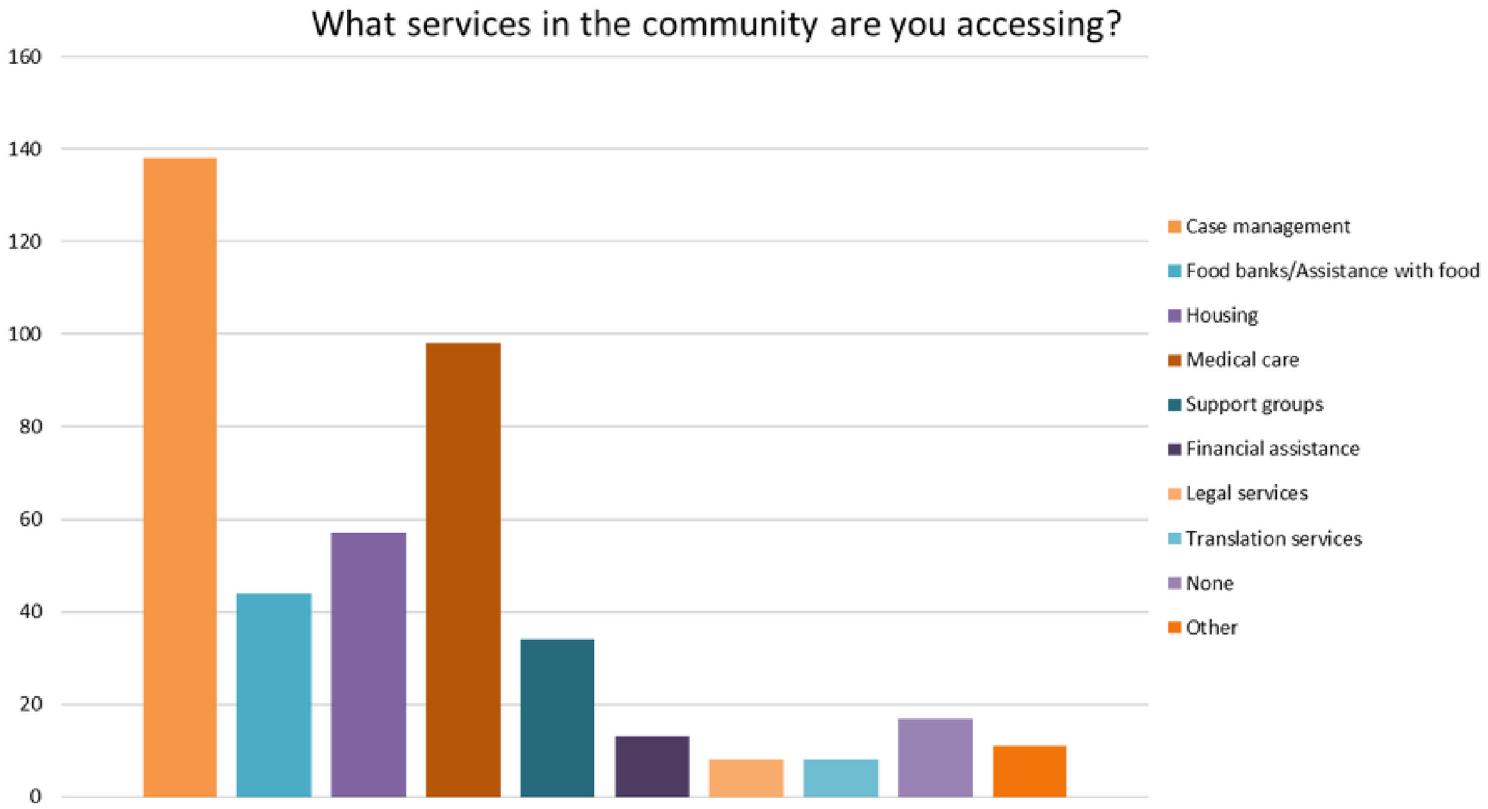


FIGURE 18 | Services Accessed in the Community, N = 175

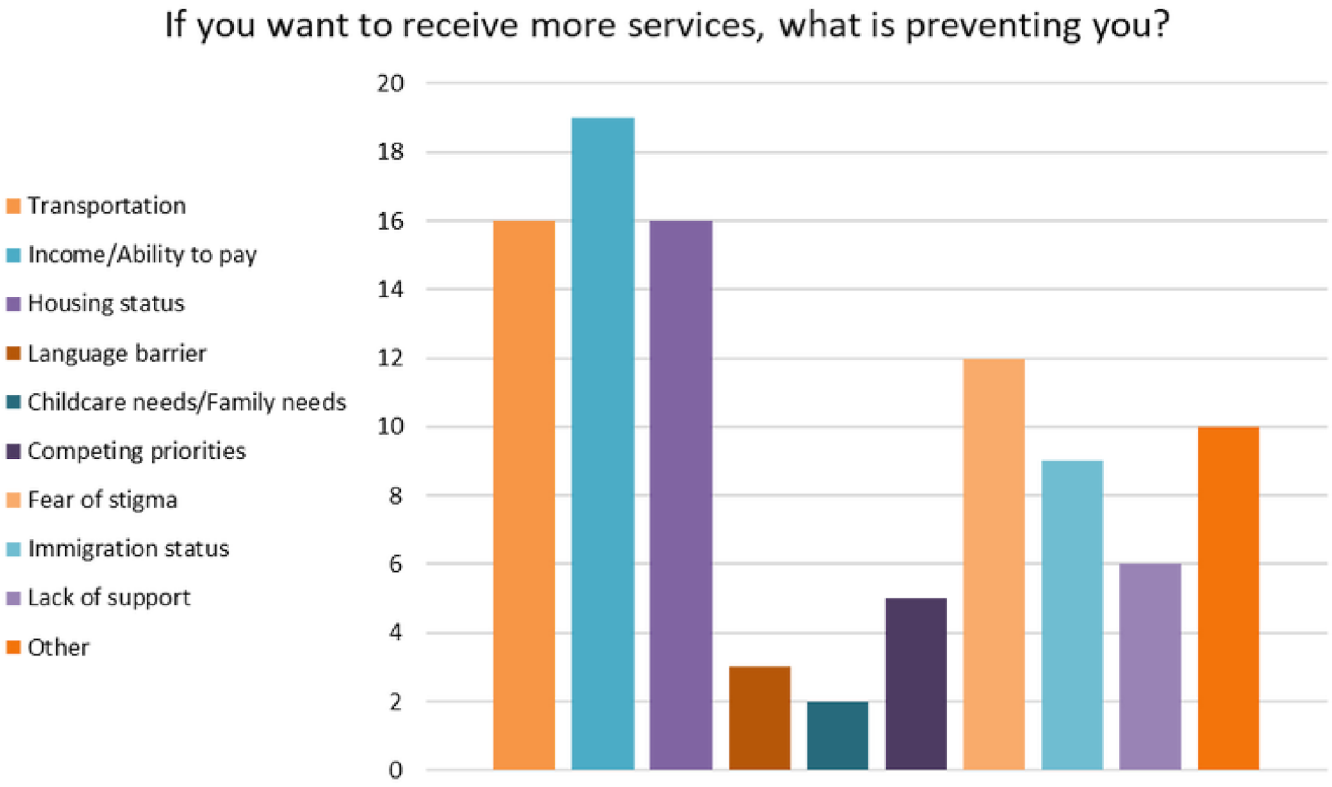


26 people, 15% of respondents, listed an additional service that they would like to access that are not available to them. Many of the suggestions of additional services included things like peer support and mental health services or help with basic needs such as food and housing.

CONSUMER NEEDS

59 people listed reasons that are preventing them from receiving more services. 32% indicated that income/ability to pay was preventing them from receiving more services, 27% indicated transportation as a prevention, 27% noted housing status was preventing them, and 20% noted fear of stigma as a prevention from receiving services (Figure 19). 24 or 41% of respondents to this question listed more than one reason that is preventing them from receiving more services.

FIGURE 19 | Barriers to Receiving Services, N = 59

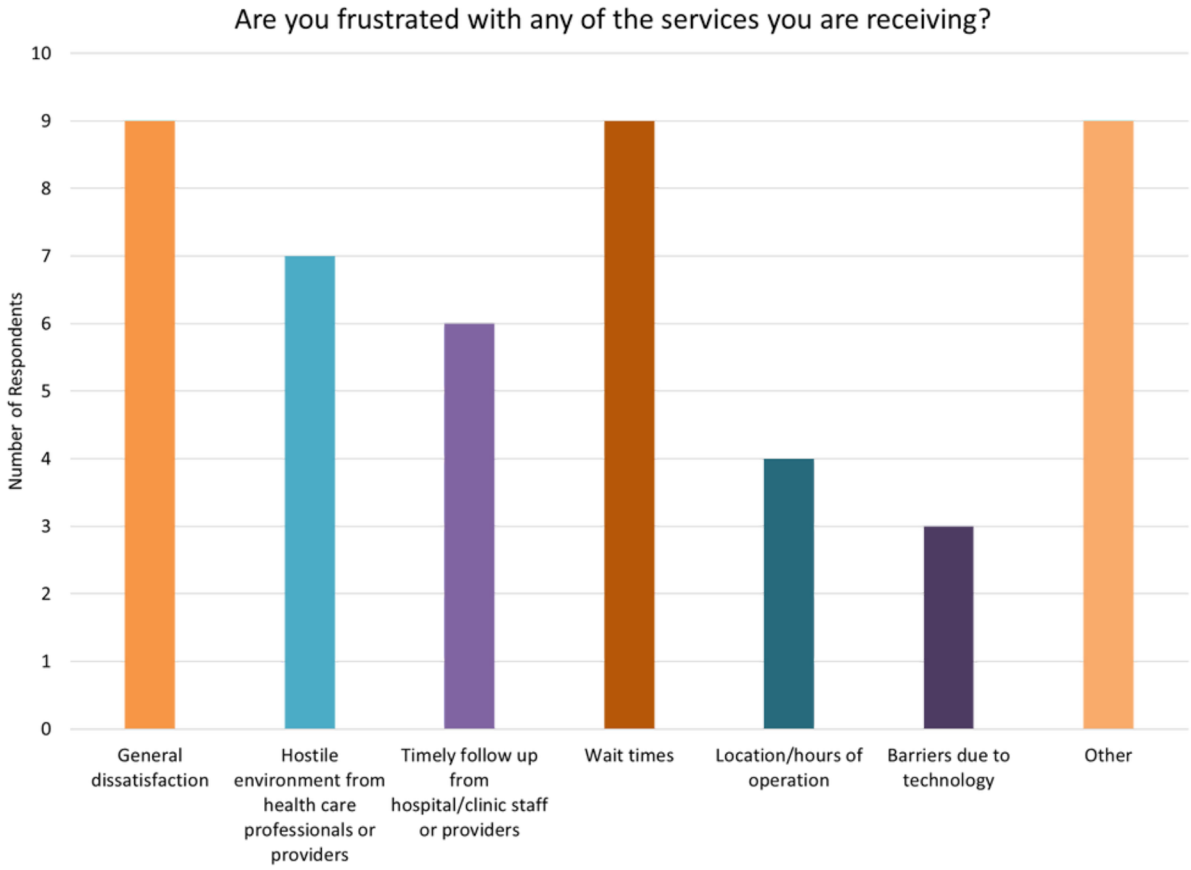


20 people (11%) responded when asked, *If you have accessed services in the past that you are no longer, what made you stop?.* Responses included COVID-related concerns, unemployment or a change in employment, lack of consistency with employees and services, transportation issues, and negative experiences with staff at various agencies.

When asked if they were frustrated with any of the services they are receiving, 24 respondents (14%) said yes. 129 people said no and 22 people did not respond to this question.

Of the 24 people who indicated a frustration with services, 37.5% listed general dissatisfaction, 37.5% listed wait times, and 37.5% listed other. 46% of respondents to this question listed multiple reasons. Other reasons listed included limitations with dental providers, lack of treatment for additional health concerns, housing issues and unsafe environments at service provider spaces.

FIGURE 20 | Frustration with Services, N = 24



STIGMA

20% of respondents indicated stigma associated with HIV has a lot of impact on their ability or comfort accessing services, 18% indicated stigma has a little impact on accessing services, and 53% said stigma does not have an impact. 54% of respondents identifying as women and 32% of respondents identifying as men responded that stigma has a little or a lot of an impact on their ability or comfort accessing services.

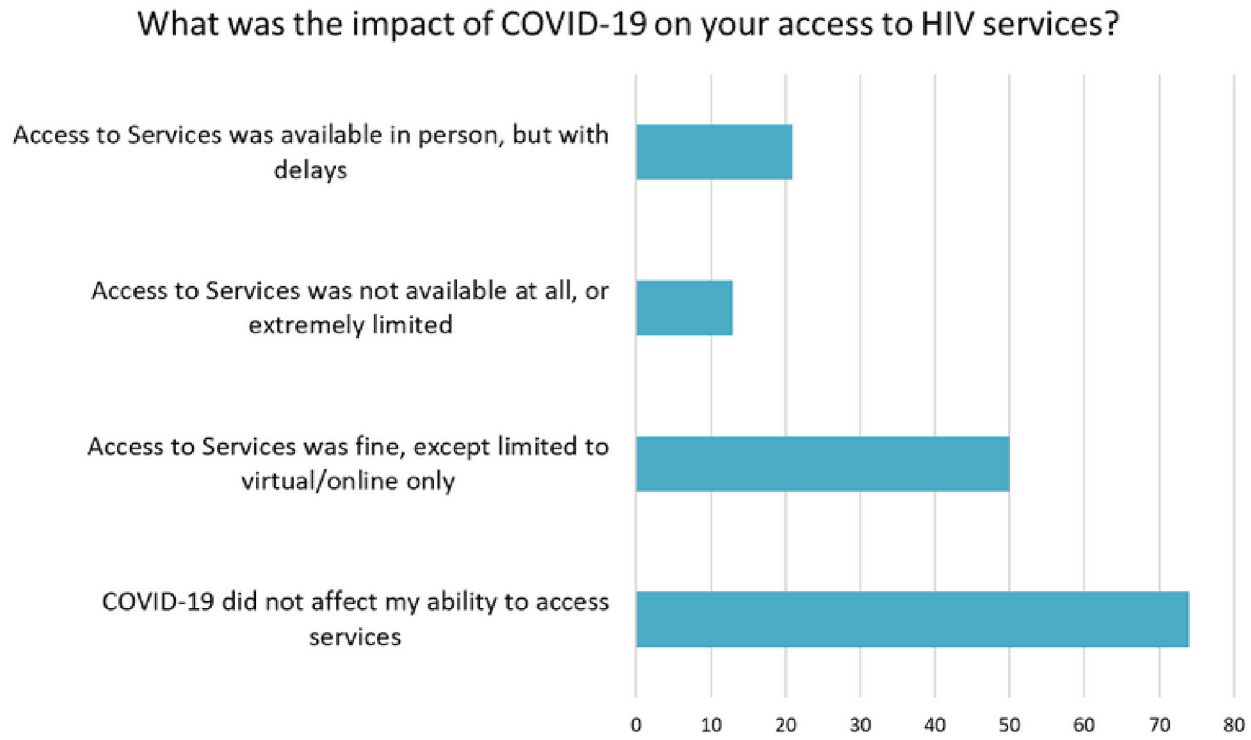
TABLE 8| Impact of Stigma on Ability/Comfort in Accessing Services

Yes, a lot	35	20%
Yes, a little	32	18%
No	93	53%
NR	14	8%

IMPACT OF COVID-19

Most respondents indicated that HIV did not impact their ability to receive HIV services (42%), while 29% indicated that access to services was fine, except limited to virtual/online only. 14 people did not respond to this question.

FIGURE 21 | Impact of COVID on Accessing HIV Services, N = 161

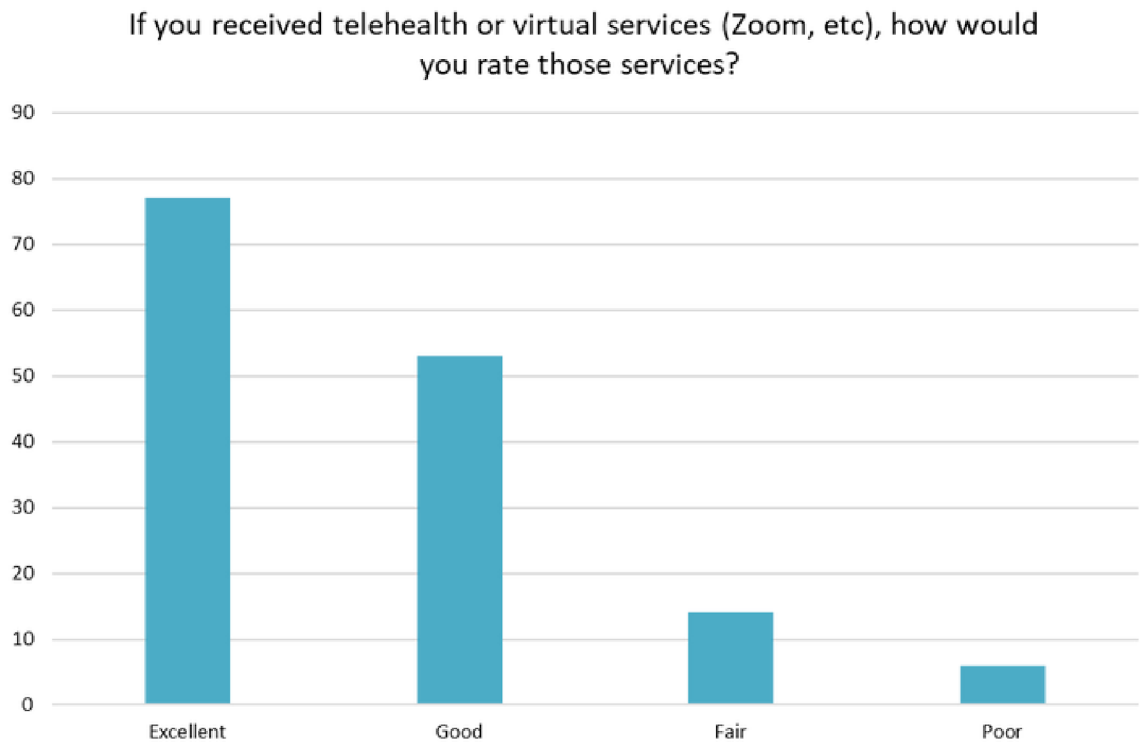


17 people (10%) responded to the question, *If access to services was limited, which services were hard to obtain?* Responses included challenges making appointments, inability to meet with case managers, general difficulty accessing public services due to the pandemic and challenges completing recertifications and applications.

Most respondents rated their telehealth services as excellent (44%), 30% rated it as good, 8% as fair and 3% rated it as poor (Figure 22). Those that rated services as excellent or good said that they were satisfied with their services and appreciated that telehealth is convenient. Other respondents cited technology issues, virtual options not being the same as in person, and other reasons for rating services fair or poor. 66% of respondents said they would continue using telehealth if it were being offered. 25 did not respond to this question.

Of the 26 responses, the most common information people wanted to share was the feeling of isolation and lack of support they experienced from the COVID-19 pandemic. Other responses included people worrying about their exposure to COVID, the wait time being longer for services, or that they experienced no impact on services.

FIGURE 22 | Telehealth or Virtual Services, N = 150



Provider Survey Data

RESPONDENT DEMOGRAPHICS AND AGENCY INFORMATION

35 providers of HIV services or care responded to this survey. 15 (43%) of the providers are either Program Managers or Supervisors. The majority of respondents either spend more than 50% of their time with clients (n=8) or 0 to 10% of their time with clients (n=15). 28.6% of respondents have been with their agencies for more than 15 years, with 20% being there for 0-2 years and another 20% being there for 3-5 years (Table 9).

Each respondent also provided information about their agency (Table 10). 14 (40%) agencies provide multiple services. Majority of agencies are medical providers (20%), mental health providers (14%) or housing/homeless service providers (14%). 49% of agencies have more than 50 employees and 46% of agencies serve between 100 and 1000 clients. The main agency's funding streams included the state government (16%), Ryan White Part A (16%), and the federal government (13%). Respondents represented agencies from all over the Boston EMA, however, 89% of respondents work at agencies in Massachusetts.

TABLE 9 | Demographic Characteristics of the Provider Survey Respondents in the Boston EMA

Respondent's Position (n, %)		
Case Manager/Social Worker	6	17%
Executive Director or Deputy Director	6	17%
Physician/Nurse Practitioner/Physician Assistant	1	3%
Program Manager/Supervisor	16	46%
Registered Dietician	2	6%
Other	4	11%
Percent of Time Spent with Clients (n, %)		
0 – 10%	15	43%
11 – 20%	3	9%
21 – 30%	3	9%
31 – 40%	4	11%
41 – 50%	2	6%
More than 50%	8	22%

Time at Current Agency ("How long have you been at your agency?") (n, %)		
0 - 2 years	7	20%
3 – 5 years	7	20%
6 – 10 years	6	17%
11 – 15 years	5	14%
More than 15 years	10	29%

FIGURE 23 | Location of Agencies of Respondents

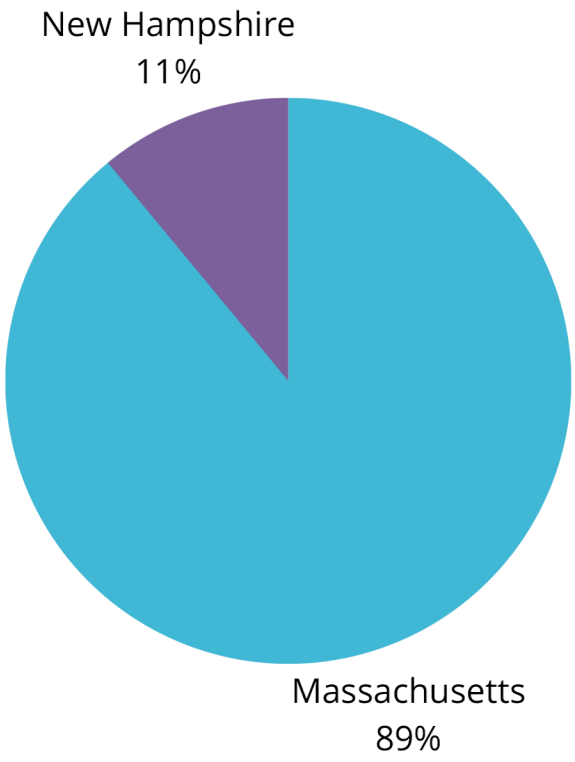


TABLE 10 | Agency Information of Provider Survey Respondents in the Boston EMA		
Type of Agency (Respondents could select more than one)		
Medical Provider	17	46%
Substance Use Services Provider	11	31%
Mental Health Provider	12	34%
Housing/Homeless Services Provider	12	34%
AIDS Service Organization	11	31%
Public Health Clinic Provider	8	23%
Financial Assistance Provider	5	14%
Legal Assistance Provider	5	14%
Food Organization	2	6%
Faith Based Organization	3	9%
Other	0	0%
Number of Employees		
0 - 10	7	20%
11 - 20	1	3%
21 – 30	4	11%
31 – 40	2	6%
41-50	4	11%
More than 50	17	49%
Number of Clients Served		
Less than 100	9	26%
100-1000	16	46%
1000-5000	1	3%
More than 5000	9	26%
Funding Streams (Respondents could select more than one)		
Foundation	10	29%
Federal Government (CDC, HOPWA, SAMHSA, etcetera, other than Ryan White)	24	69%
State Government	24	69%
Contributions/Private Donations	14	40%
Revenue (Fees)	6	17%
Ryan White Part A Part B Part C Part D Part F	 24 9 6 4 0	 69% 26% 17% 11% 0%
Medicaid	10	29%
HIV Prevention Funding	14	40%
Other	3	9%

AGENCY ACCESSIBILITY

86% of agencies listed Spanish as a language most requested by clients (Table 11). 89% of respondents said that their agency offers language translation services either via current multilingual staff (n=27, 29%), they use a language line (n=23, 25%), they ensure translators are provided from an outside organization or company (n=17, 18%) or they translate patient materials into languages other than English (n=26, 28%), as seen in Table 12. 80% of agencies utilize multiple services to assist with language translation, and 9 agencies use all four options provided in this survey.

TABLE 11 | Language Most Requested by Clients

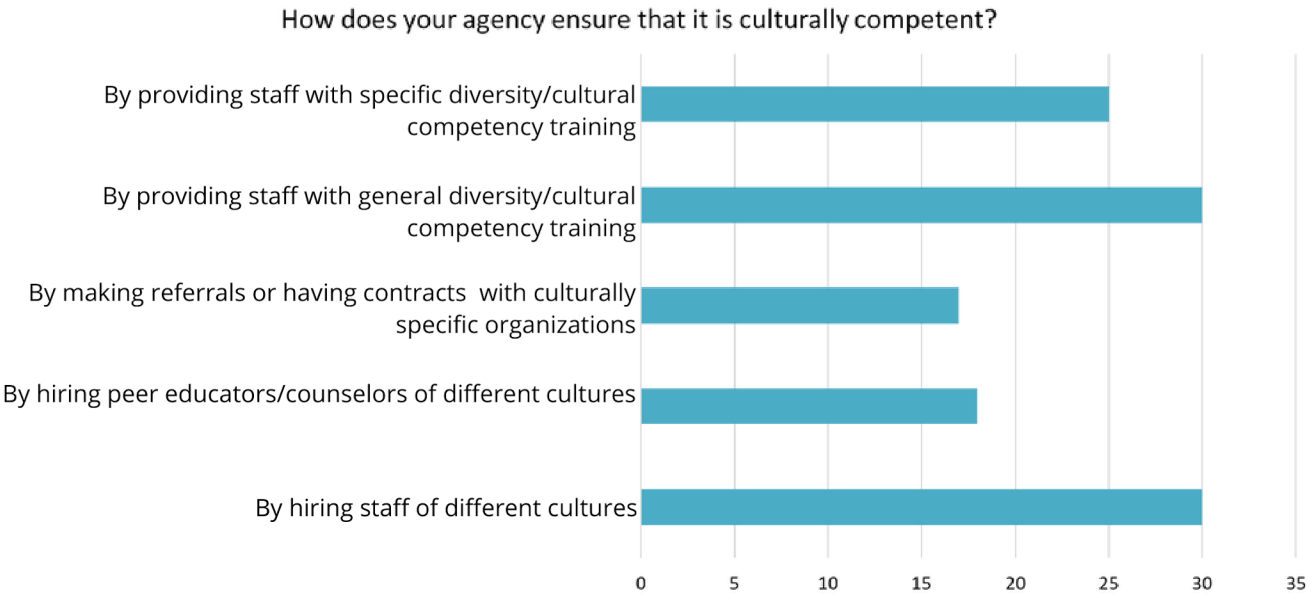
Spanish	30	38%
Portuguese Creole	15	19%
Haitian Creole	12	15%
French	5	6%
Cape Verdean	10	13%
Other	6	8%

TABLE 12 | How Providers Serve Clients who Don't Speak English

Currently have bilingual staff on staff	27	29%
Language line	23	25%
Ensuring translators are provided by an outside organization/company	17	18%
Translating patient materials into languages other than English	26	28%

91% of respondents selected multiple ways in which their agencies ensure they are culturally competent. 86% of respondents chose that their agency ensures culturally competency by hiring staff of different cultures. 86% also selected that their agency provides staff with general diversity/cultural competency training, and 71% of respondents selected their agency provides staff with specific diversity/cultural competency training.

FIGURE 24 | Cultural Competency in Agencies



89% of agencies are public transportation accessible. 3 agencies in Massachusetts and 1 in New Hampshire are not readily accessible by public transportation.

TABLE 13 | Public Transportation Accessibility		
Yes	31	89%
No	4	11%

TABLE 14 | Agency's Hours of Operation		
Weekday hours (8am to 5pm)	31	89%
Weekday evenings (after 5pm)	13	37%
Weekend hours	9	26%

Majority of agencies (89%) are open at least weekday hours, either 8 to 5 or 9 to 5. 23% of respondents listed that their agencies are open weekday hours, weekday evenings and weekend hours. Respondents could select multiple responses.

AGENCY NEEDS

63% of agencies have seen an increase in the number of clients seeking services as well as an increase in the general demand for services. 26% of respondents stated that their agency has had a decrease in private donations and 20% stating a decrease in funding from any funding stream. 20 respondents or 57% selected multiple options.

TABLE 15 | Have any of the following occurrences taken place within your agency in the past year?		
An increase in the number of clients seeking services	22	63%
An increase in the demand for services from clients	22	63%
A decrease in the amount of funding provided from private donations	9	26%
A decrease in funding your agency receives from any funding streams	7	20%

20 respondents listed more than one of the above situations as happening in their agency within the past year, with most seeing an increase in both clients and service demand.

66% of respondents selected funding to expand current capacity and 51% of respondents selecting funding to develop new capacity as one of their needs (Figure 25). 13 respondents selected both options.

FIGURE 25 | Current Agency Needs, N = 35

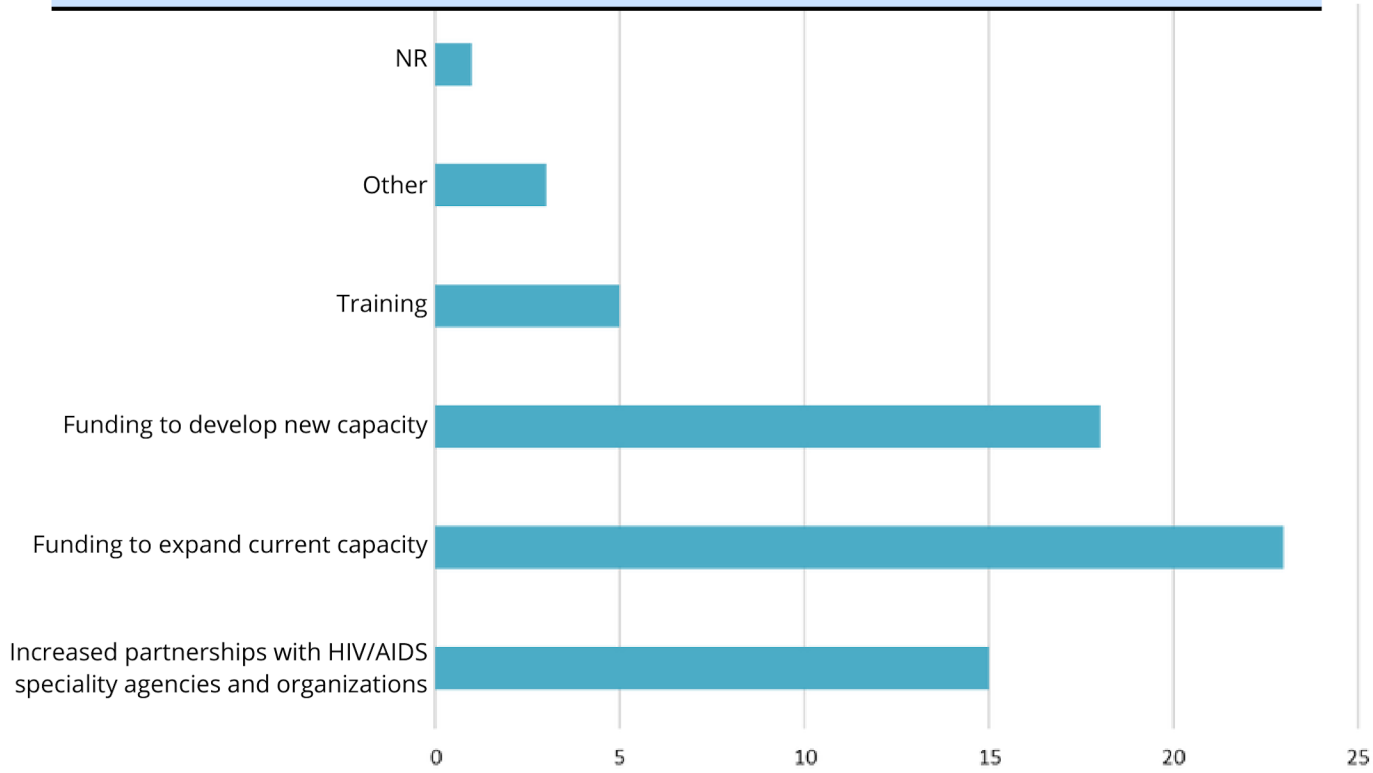


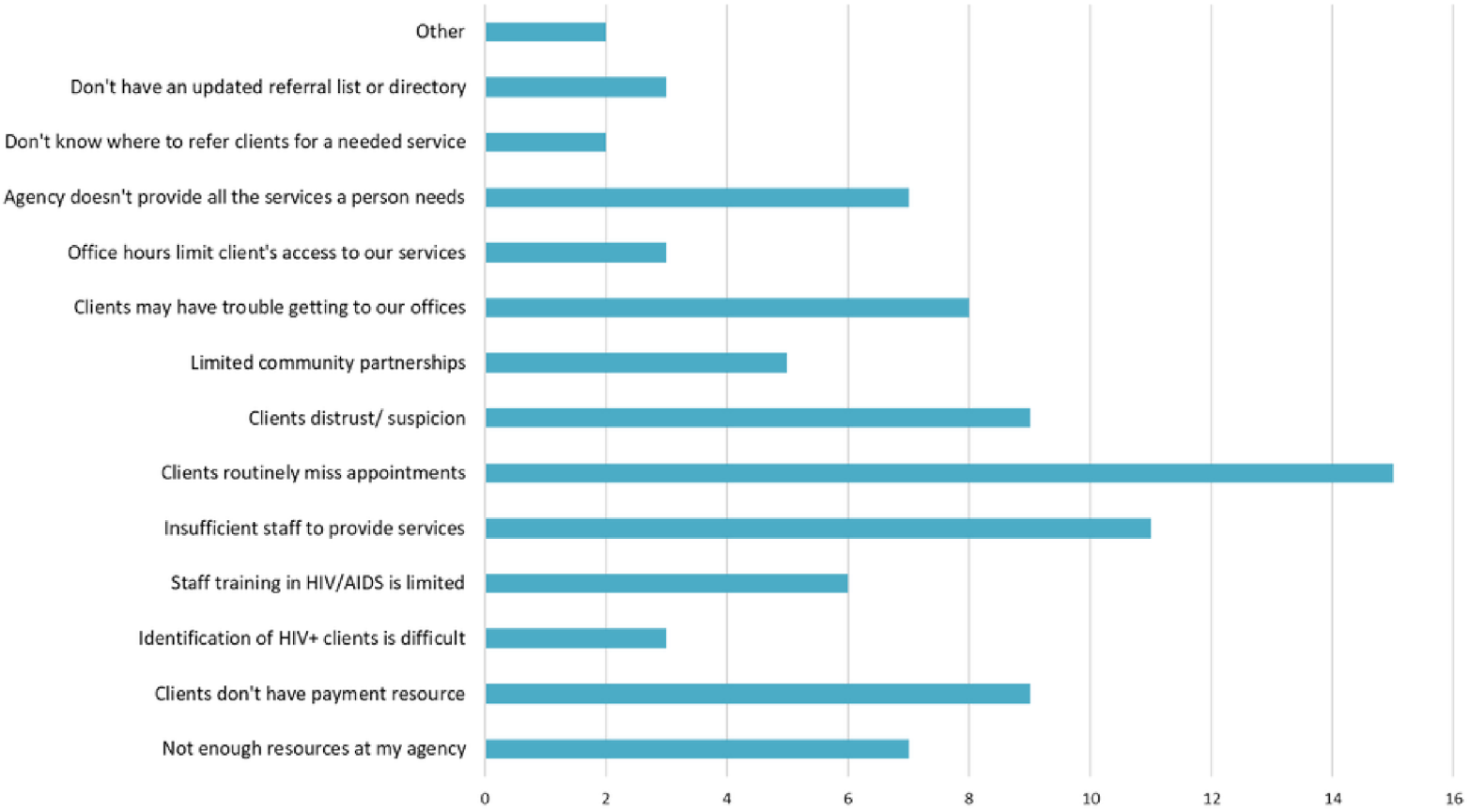
TABLE 16 | Agency Needs by Number of Employees

	Agency Needs (Respondents could select more than one need)					
Number of Employees	Increased partnerships with HIV/AIDS specialty agencies/organizations	Funding to expand current capacity	Funding to develop new capacity	Training	Other	NR
0 - 10	3	4	3	0	1	0
11 - 20	1	1	0	0	0	0
21 - 30	1	4	1	0	0	0
31 - 40	1	2	2	1	1	0
41 - 50	0	3	2	1	0	0
More than 50	9	9	10	3	1	1
Total	15	23	18	5	3	1

As seen in Table 16, all agencies with 0 to 10 employees responded that they need additional funding, either to expand current capacity or to develop new capacity. Majority of agencies with over 50 employees selected multiple options, with 59% of them selecting funding to develop new capacity.

The four most common barriers to providing services include clients routinely missing appointments (43%), insufficient staff to provide services (29%), client distrust or suspicion and lack of payment resources (both 26%) (Figure 26). In addition to those listed in Figure 26, other barriers listed included insufficient funding to hire and retain staff, challenges with accessing services among people who are unhoused, and general funding issues. 25 respondents or 71% listed more than one barrier to providing services.

FIGURE 26 | Barriers to Providing Services



46% of respondents said their agency has a wait list for services. The most common service that there is a wait list for is behavioral health/mental health services followed by housing, dental services and food assistance services. Many people listed that their wait lists for these services are often months or even years long.

TABLE 17 | Wait List for Services	
Yes	11
No	24

When asked what two changes in the Ryan White care system would make it easier for clients to access services, 24 people provided at least one open ended response (69%) (Table 18). Responses are categorized below and include comments about staffing related issues, reducing the administrative burden of the program, reducing restrictions on both funding as well as eligibility for the program and increasing resources for specific services and emerging needs.

TABLE 18 | In your opinion, what two changes in the Ryan White care system would make it easier for clients to access services?

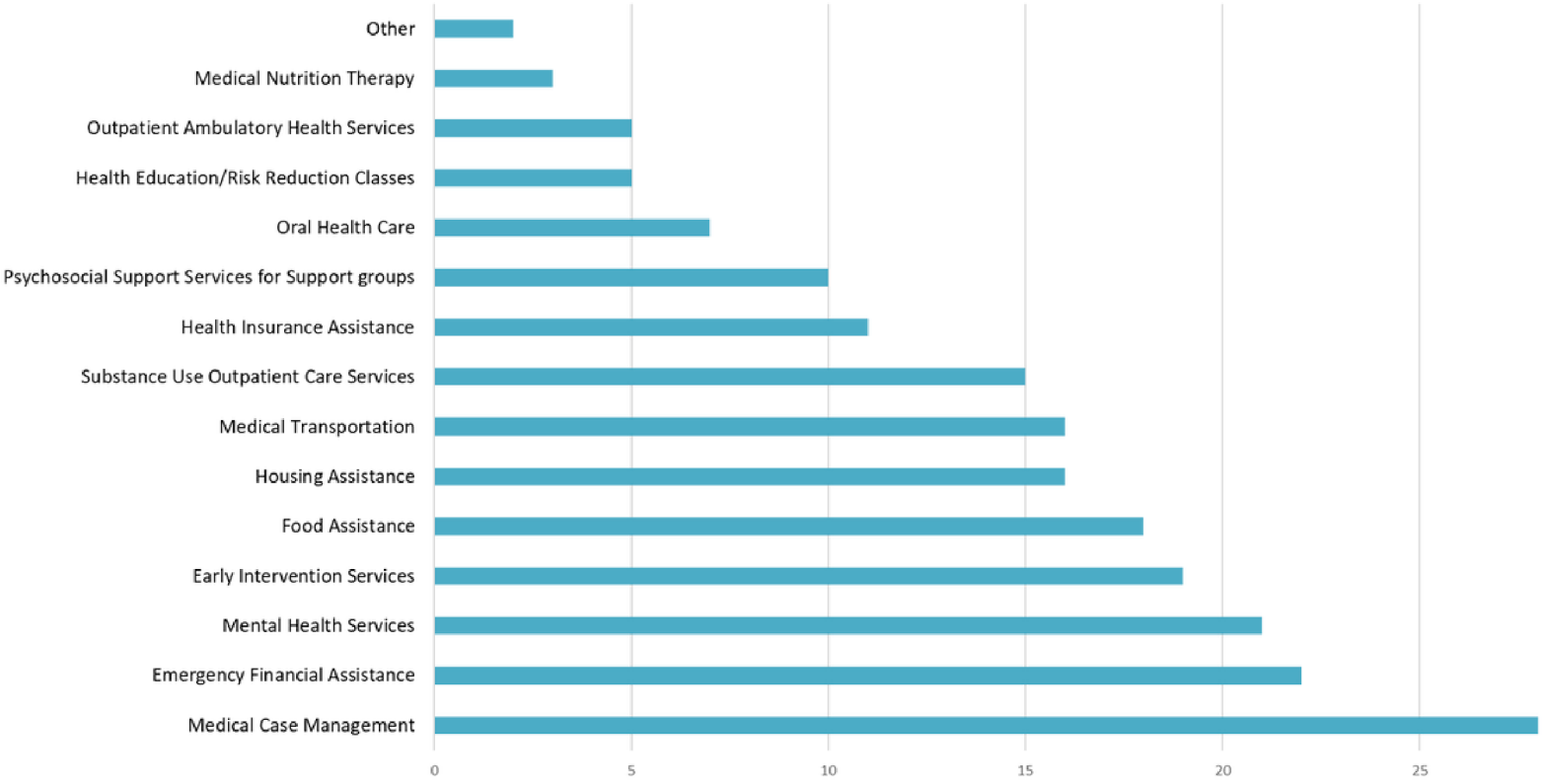
Staffing Related Issues	Reduction in Administrative Burden	Less Restrictions	Increased Resources for Services
"Additional funding to hire more staff"	"Streamlining ALL RW grants, reports, etc. to be on the same timelines."	"Less restrictions on eligibility and how money can be spent..."	"Provide more funding for psychosocial support"
"Staff retention and training support (funding to keep up with cost-of-living...)"	"Reducing the reporting requirements which takes away from patient care."	"Increase the financial eligibility income limit"	"More funding for food security"
"Increase in pay to help onboard and retain staff"	"Removing the need to do an income review. This can be a challenge for a lot of patients."	"Allow federal dollars to be spent on drugs for prevention"	"More contracted dental providers in NH"
"More funding for staff"	"Annual recertification and reassessments instead of every 6 months"	"Make the funding less restrictive (not last emergency resource)"	"More access to affordable housing"

CLIENT NEEDS

The survey asked providers to list up to three of the most critical needs of PLWH seen at their agency. The most listed need was housing or housing-related services, such as rental assistance, utility assistance and lack of affordable or subsidized housing. 94% of respondents listed a housing-related service as one of their top 3 client needs. 46% of respondents listed food assistance and 29% listed mental health services. Other commonly mentioned needs include substance use and addiction treatment services, transportation and insurance or medical systems navigation services.

Providers were then asked to select the five most important Ryan White services, in no particular order. Figure 27 demonstrates that 80% of respondents chose Medical Case Management as one of the most important services, followed by Emergency Financial Assistance (63%), Mental Health Services (60%), Early Intervention Services (54%), Food Assistance (51%) and Housing Assistance and Medical Transportation (both at 46%).

FIGURE 27 | 5 Most Important Ryan White Care Program Services



IMPACT OF COVID-19

The COVID-19 pandemic affected about half of the agency's abilities to offer services. They were then asked to state three ways the pandemic impacted their agency. These responses included both negative and positive impacts. The negative impacts included staffing shortages and high turnover, loss of in-person connection, and increasing strain on resources for patients, specifically with food assistance and housing services.

The positive impacts included innovation of service delivery, increased accessibility with telehealth, elimination of transportation barriers, and increased benefit eligibilities.

TABLE 19 | Did the COVID-19 pandemic impact your agency's ability to offer services?

Yes	17	49%
No	18	51%

FOCUS GROUP DISCUSSIONS

PCS staff and NRAC members conducted four focus group discussions (FGDs) at various funded agencies throughout the Boston EMA. Each FGD had five to nine participants, all of whom were consumers.

IMPORTANT SERVICES

When asked about the most important HIV related services, many supportive services were discussed. Participants talked about how transportation enables them to see multiple doctors in one day. Multilingual doctors allow patients to feel like they can communicate and understand their care plan more effectively. Participants also talked about the importance of mental health services.

“The Mass Health cabs (transportation), as well. If it weren’t for the cabs we have here, I would really be in trouble. I have multiple doctors and on any given day they could call me and tell me they need to see more tomorrow." - AIDS Project Worcester

"I have a doctor there who speaks Spanish, and that has helped me a lot because I can communicate better and understand better like this. Because I don’t speak any English at all.” - Casa Esperanza

"I needed counseling because my mental health wasn’t there. I suffered from being told that I was HIV+. Mental health was critical to me." - Harbor Care

Along with mental health services, participants expressed the importance of having peer support and a positive support team who understand PLWH and give them the support that they need to stay in care.

“We need to bring back peers, rather than a psychosocial support person who doesn’t have to be HIV+ or have any knowledge of what an HIV+ person goes through. Need to bring back the peer specialist title.” - AIDS Project Worcester

“Something that is very important to me as a person receiving treatment – having a community of people who understand is very important. I was in prison when I got diagnosed, and I was so scared. I thought it was a death sentence. This place has provided a lot of support for me." - Boston Living Center

"Support groups for me were also very critical to see other people who have survived longer than me, it helped me stop whining about my condition when I saw other people who have been living with HIV for many years. Support groups are important to share information and meeting each other." - Harbor Care

Participants also talked about the importance of medical services such as the Ryan White Dental Program and HDAP. These services help participants to remain engaged in care and live healthily with HIV.

"I have RW for dental and they're helping me to get implants, and I'm really grateful for that." - AIDS Project Worcester

"I appreciate HDAP, and the fact that they've made it even more low-barrier to renew, the one-pager, is really, really helpful." - AIDS Project Worcester

BARRIERS TO CARE

Participants mentioned the inability to meet basic needs such as shelter and access to food and how these insecurities make it difficult to access health care and other HIV-related services, creating barriers to care.

"The food pantry is also very important to me, we have a lot of hard times making ends meet especially while paying for medical care." - Harbor Care

"...if you're separated from someone and need to find a place to live, it's a grueling long process to get your own proper housing, to have shelter, somewhere to eat proper meals." – AIDS Project Worcester

"[Housing services]... that is what I'm struggling with with her. It will be 9 months, and I'm waiting and waiting, so I had to get in here meanwhile, because there is nothing else." - Casa Esperanza

"Housing is expensive – it's $1,100 for a one-bedroom. Section 8 is limited, it's almost impossible to get on there. Or get to a point where you can see the light, progress and move forward." - AIDS Project Worcester

Participants also listed other barriers to care that included a lack of services for mental health. Many mental health services have long waiting lists or inconsistent providers.

"...They want you to be on a waiting list for therapy for 6 months. What if a person is in a real crucial state of mind and you're going to make them wait 6 months for a therapist? It shouldn't be that way." - AIDS Project Worcester

"I've had problems accessing mental health services, like a therapist or psychiatrist... I haven't had a steady therapist since I've been out of prison and that's been 11 years." - AIDS Project Worcester

Whether it was the cost, or not being able to get transportation in general, participants also faced difficulties with transportation.

“Sometimes transportation is a bit hard for me. I always try to get to my appointments.” - Casa Esperanza

“I was trying to get medical rides to go to the doctor and I had a hard time.” - Boston Living Center

'People in rural areas often times don’t have transportation to get to a provider. The most knowledgeable providers are in urban areas." - Harbor Care

Participants described barriers to care related to negative or nonexistent relationships between a PLWH and their doctors/nurses, etc., many times attributed to staff turnover, retention and hiring issues.

“A lot of providers are in and out in a couple of years. I’ve been at the health center for a long time, but I still haven’t had a long-term provider.” - AIDS Project Worcester

“Staff retention in nonprofits and medical facilities. Usually what causes people to fall out of care is the inconsistency of these services being available, especially when you have such a big rotation of staff. Ultimately, what it has to come down to, is staff are overworked and underpaid.” - AIDS Project Worcester

“I don’t like when they give me a new doctor. I have to explain everything over again.” - Boston Living Center

“We don’t have many advocates anymore. We only have one advocate, and they are overwhelmed with case work. I’ve had the same one since I’ve been diagnosed, and she does everything.” - Boston Living Center

“With HIV care, I haven’t had the same doctor the whole time. That can be a barrier.” - Boston Living Center

Finally, participants described HIV stigma as a barrier to accessing medical services. Stigma against PLWH creates unsafe environments and a barrier to accessing health care and social services. Many participants emphasized stigma perpetuated by their doctors and other medical professionals as well.

"I think that’s the biggest issue... [PLWH] are embarrassed of having HIV. It is looked upon as a disease that makes you untouchable." - Harbor Care

"[The doctor] washed his hands, and he didn't put on one pair of gloves, he put on two. It made me feel like I was an insect. If anyone should know more about HIV, it should be them, but they're the first ones to make us feel uncomfortable." - AIDS Project Worcester

"The thing is many people don't understand the condition. As they don't understand the condition, they think you get the condition like this, you get the condition here, you get the condition there. They get, you know, afraid, you know? They don't know how to explain it, so they don't know how to talk to people. So instead of just asking questions, they get apart. Even the same doctors..." - Casa Esperanza

"My dental hygienist, when she realized that I am HIV+, she was not comfortable touching me. Her actions spoke louder than words. I asked her if she was scared of touching me, she was very truthful and I told my case manager and she told the head of the dental department." - Harbor Care

"There are people that still have a lot of stigma and they don't look at us the same as everyone else. I see myself as the same as everyone else, we aren't different." – AIDS Project Worcester

"There are people who really are not well aware of what is the disease. And, well, having more talks about this in hospitals or places. Because sometimes there are people who have the virus, and they don't say it out of fear of society." - Casa Esperanza

IMPACT OF COVID-19

COVID-19 had both positive and negative impacts on the participants' abilities to receive services and interact with their care providers. Focus group participants discussed that they prefer in person doctor's appointments and meetings with their case managers, stating that Zoom or phone calls for medical-related appointments is impersonal. Participants talked about varying skill and comfort with technology.

"Everyone wants to do everything over the phone, it's very impersonal. Instead of a physical check-up, they just want to see you on Zoom. Zoom is not bad all the time, but it's not good all the time, either. There are times when you would feel better seeing someone in person. It's not the same as being face-to-face." – AIDS Project Worcester

"Right before COVID, in 2019, I had a cancerous lesion removed and I haven't been able to go for a follow up, the dermatologist closed. It's been hard to go and make appointments. There are less time slots available and sometimes I let appointments go. I know a lot of doctors cut back their hours..." - Harbor Care

“Having to be at social distance has made it difficult to get services." - Boston Living Center

“I’m not good with technology, so I come to APW when I need to learn something, like with Zoom, and they help.” – AIDS Project Worcester

COVID-19 also led to a lot of loneliness and isolation for some participants, exacerbating mental health issues that many were already dealing with.

"During COVID, being retired, living alone, I got very depressed. I started feeling like a lot of it was because of COVID and it was affecting my mental health pretty badly." - Harbor Care

"All day long. And the whole pandemic, I couldn’t go out. I did not go out and then, well, I got very depressed, but I feel better now." - Casa Esperanza

“At the beginning of the pandemic, I had my bike. It was very lonely during the pandemic. No one wanted to be around anyone.” - Boston Living Center

"I wish the support groups hadn’t stopped. That was a huge barrier for me, not getting the support I needed during the pandemic when I actually needed a lot of peer support." - AIDS Project Worcester

Some participants talked about COVID-19 in a positive way. Positive impacts of the pandemic included more accessibility to providers and innovation by service organizations to use technology for increased productivity and service delivery.

“I had a different experience. Early on in the pandemic, I felt like I was getting more wellness calls from my provider. I really appreciated hearing from them every few weeks instead of every six months.” - AIDS Project Worcester

"Medical appointments were over the phone, I loved technology.” - Casa Esperanza

" I think it’s here to stay. The technological advancements are something we’ll have to live with. This is part of living and advancing into the future." - Harbor Care

Some participants felt that COVID-19 did not have a significant impact on their services.

"I didn’t have a problem during COVID. I was able to go to my doctor, we had a small support group that was going, everything HIV-wise was fine for me. Nothing changed for me." - Boston Living Center

ADDITIONAL THEMES & EMERGING NEEDS

Throughout the focus group discussions, there were many recurring themes outside of the realm of the discussion questions. Many participants offered many suggestions for improving the HIV care continuum, many of which were related to systemic issues or social support service delivery. Other participants suggested additional services related to emerging needs.

Participants in one group acknowledged the issues of instability among staff, creating complicated situations for patients seeking care. These issues included staff management issues or lack of communication between providers

"More accountability "at the top" and less micromanagement of staff at the "bottom." There's so much micromanagement of the case managers, but at the top there's no management at all. More accountability for administrative staff within a health care agency." - AIDS Project Worcester

"One will give you a pill and the other will ask why. All they would have to do is look on the computer, and they would see the info from the doctor I just saw, why don't they just call that doctor. It's confusing and aggravating, and I don't want to go to the doctor for that." - AIDS Project Worcester

Participants in another group talked about the emerging need of people aging with HIV, having not expected to live as long as they are able to now and needing additional support services.

"We need something set up for people diagnosed over 20 years. I never expected to live this long. We need something to help with housing, etc. I gave up everything I had because I didn't think I was going to live this long." - Boston Living Center

Participants in multiple groups expressed the need for more targeted services for people who inject drugs or use substances.

"There should be a specific Ryan White service that specifically targets people who are sharing needles, etc. There are people who are undiagnosed. There should be an Request for Proposal (RFP) to get direct funding, like we did with MSM." - Boston Living Center

"Expansion of harm reduction services... More harm reduction recovery services not aimed at abstinence-only or sobriety. Services for specific substance users. Recovery isn't one-size-fits-all." - AIDS Project Worcester

Conclusion

This mixed method needs assessment with perspectives from both PLWH and providers highlights common themes regarding the needs of and barriers to care of PLWH in the Boston EMA. Respondents were generally engaged in care, but still described significant barriers to their health and experience living with HIV, demonstrating the systemic issues faced by PLWH. Barriers predominantly fell among support services. Our findings from both the surveys and the focus group discussions emphasize that the lack of access to basic needs such as shelter and food is a significant and primary barrier to engaging in care. Providers corroborated these needs from their own perspectives, also acknowledging that high staff turnover, general inflation, and lack of financial resources have exacerbated these barriers and have made it difficult to provide adequate services. Providers also attributed the increasing strain on resources for food assistance and housing services to the COVID-19 pandemic. Mental health services and peer support continue to be critical to adherence and retainment in care, so that PLWH feel supported by a community of people who understand their experience. Consumers also emphasized the need for consistency in many of these services as staff relationships with patients are important for building up trust and ensuring patients continue with their services. Mental health was further explored in the focus group discussions as an integral part of maintenance in care and was severely impacted by the COVID-19 pandemic as well. Providers acknowledged that mental health services are one of the most important for their clients, yet it is also the most common service there is a waitlist for.

Our data demonstrates that COVID-19 impacted PLWH and the HIV care continuum in many ways, both positively and negatively. COVID-19 created a lack of in-person social support mechanisms and PLWH and agencies alike had trouble accessing and providing services due to both barriers in staff retention, funding, and restriction to virtual appointments. Some PLWH expressed that they felt no change in their care throughout the pandemic and enjoyed the virtual accessibility to their providers, emphasizing that this pandemic truly had a different effect on everyone depending on an individual's tolerance for change and technology and the extent of their health and social service needs. This needs assessment provides important information that will guide the Ryan White HIV Services Planning Council in our prioritization of services and allocation of Part A funding. It also provides additional insight into the experience of PLWH in the Boston EMA that can be used to ensure a comprehensive, coordinated continuum of care and support services. This needs assessment provides information in the context of a major global pandemic, which elevated many existing barriers in the care continuum, allowing us to continue to plan programs and services in an adaptable and flexible way. It will also inform future data collection activities by the Planning Council that may explore specific barriers and unmet needs.

Limitations

We acknowledge the limitations present in this needs assessment. Survey respondents and focus group participants were recruited through a convenient sampling methodology at a number of organizations across the EMA. While the organizations were geographically distributed, they do not reflect the full population of PLWH in the Boston EMA who are currently in care. Further, due to our small sample size, our results are not necessarily reflective of the demographics of PLWH in the Boston EMA as a whole. The survey questions on demographic questions, such as ethnicity and race, do not match the data measures from MDPH or NH DHHS. This also makes it difficult to understand whether the survey data is representative of the larger population.

There were a few limitations to our data collection in both the surveys and the focus group discussions. Self-reported bias or error is possible. To ensure anonymity of the survey, no information is referenced with records and therefore we rely on self-reported data which may have been incorrect due to mistakes in recall. Additionally, the data collection time period was long and respondents could have answered the survey more than once due to the anonymous nature of the survey. Our survey was only available in other languages in paper format, likely making it more difficult to reach additional populations and gather more reflective responses. Additionally, there is no method to control how the survey is facilitated in the organizations that it was sent to. As HIV is a highly stigmatized condition, respondents to the consumer survey and participants in the focus group discussions may have responded in a way to not expose them to further stigma or judgement.

Often times, focus group discussions have the potential for multiple forms of bias. Participants may have wanted to appear socially desirable or acceptable to other participants and therefore did not always respond with complete transparency. Additionally, selection bias may have been present since those who do not feel positive about the care they receive may have been more likely to decline participation than those who have had more positive experiences with the organization and its staff.

COVID-19 also presented challenges to data collection, and we had a significantly smaller response rate compared to needs assessments conducted prior to the pandemic. Our focus on online survey distribution may have also presented accessibility issues to some respondents and narrowed the type of participant who was able to respond. Additionally, the ability to conduct focus groups was impacted by COVID-19 as people were harder to reach due to differences in availability of in person programming at organizations.

Organizations were limited in their capacity to assist in survey distribution and focus group discussion recruitment while they focused on pandemic response and ensuring continuity of care through the emergency. Providers were likely also limited in their individual capacity to respond to the provider survey throughout the pandemic and staffing shortages.

Recommendations

We recommend that future needs assessments use the same variables for demographic data as MDPH and NHDHHS so that data comparisons can be made between respondents and the EMA as a whole. This will ensure that we are capturing a representative population through our assessment and strengthen our results and conclusions for use throughout the service area.

Another recommendation is to alter the way codes are created for each respondent. Since the goal of this unique code is to prevent more than one response per person, the current method could have resulted in more than one response per person. While we did go through and ensure that each response that had the same code had different responses, it is possible for respondents to have submitted more than one survey.

Further, both online and paper surveys should be available in all major languages in the Boston EMA to improve accessibility of the surveys. It may also be beneficial to provide agencies with postage for them to mail in paper copies.

There need to be significant updates to the language on some survey questions and survey design in general to reflect language that is de-stigmatizing. NRAC members also offered recommendations for future survey design including adding on more space for free response comments, making the provider survey more specific to Part A services and Part A capacity and asking questions of both providers and consumers about awareness of services.

Lastly, outreach for the needs assessment survey should be strengthened to collect a respondent pool representative of the PLWH in Boston EMA. Outreach should include an increased effort from current members of the Planning Council to distribute paper copies within their geographical regions. Further, we recommend that there are more focus group discussions in the future. For preparation purposes, the committee members that would like to be apart of a working group to facilitate this assessment should be identified at or before the first meeting and additional time commitments must be specified.

Appendix A. Agencies by Service Category

Part A Service Categories and Agencies

AIDS Drug Assistance Program (ADAP/HDAP)

- AccessHealth MA
- New Hampshire Department of Health and Human Services

Emergency Financial Assistance

- AIDS Project Worcester
- Catholic Charitable Bureau of the Archdiocese of Boston
- Codman Square Health Center/Dorchester House Health/Mattapan Community Health Center
- Fenway Community Health Center
- Greater Lawrence Family Health Center
- Massachusetts Alliance of Portuguese Speakers
- Making Opportunity Count
- Multicultural AIDS Coalition, Inc.
- Upham's Corner Health Center
- Whittier Street Health Center

Food Bank/Home-Delivered Meals

- AIDS Project Worcester
- Making Opportunity Count
- Victory Programs, Inc.

Health Education/Risk Reduction

- AIDS Project Worcester
- Boston Children's Hospital
- Casa Esperanza, Inc.
- Massachusetts Alliance of Portuguese Speakers
- Making Opportunity Count
- Multicultural AIDS Coalition, Inc.
- Victory Programs, Inc.

Housing

- Father Bill's & MainSpring
- Fenway Community Health Center
- Harbor Health Services, Inc.
- Justice Resource Institute, Inc.
- Victory Programs, Inc.

Appendix A. Agencies by Service Category

Medical Case Management

- AIDS Response Seacoast
- Beth Israel Deaconess Hospital - Plymouth
- Boston Health Care for the Homeless Program
- Cambridge Health Alliance
- Codman Square Health Center/Dorchester House Health/Mattapan Community Health Center
- Dimock Community Health Center
- Edward M. Kennedy Community Health Center
- Fenway Community Health Center
- Greater Lawrence Family Health Center
- Harbor Care
- Harbor Health Services, Inc.
- Lynn Community Health Center
- Massachusetts General Hospital – Boston
- Massachusetts General Hospital – Chelsea

Medical Nutrition Therapy

- Boston Children's Hospital
- Community Servings, Inc

Medical Transportation

- AIDS Project Worcester
- Beth Israel Deaconess Hospital - Plymouth
- Boston Health Care for the Homeless Program
- Casa Esperanza, Inc.
- Codman Square Health Center
- Dimock Community Health Center
- Edward M. Kennedy Community Health Center
- Fenway Community Health Center
- Greater Lawrence Family Health Center
- Justice Resource Institute, Inc.
- Lynn Community Health Center
- Massachusetts General Hospital -Boston
- Massachusetts General Hospital - Chelsea
- Making Opportunity Count
- Multicultural AIDS Coalition, Inc.
- Victory Programs, Inc.
- Whittier Street Health Center

Appendix A. Agencies by Service Category

Non-Medical Case Management

- AIDS Project Worcester
- Casa Esperanza, Inc.
- Catholic Charitable Bureau of the Archdiocese of Boston
- Merrimack Valley Assistance Program
- Making Opportunity Count
- Multicultural AIDS Coalition, Inc.
- Victory Programs, Inc.

Oral Health Care

- BPHC Ryan White Dental Program

Other Professional Services—Legal

- Justice Resource Institute, Inc.

Psychosocial Support

- AIDS Project Worcester
- Dimock Community Health Center
- Fenway Community Health Center
- Harbor Care
- Justice Resource Institute, Inc.
- Making Opportunity Count
- Victory Programs, Inc.
- Whittier Street Health Center

Appendix A. Agencies by Service Category

Minority AIDS Initiative (MAI) Services and Agencies

Medical Case Management - MAI

- East Boston Neighborhood Health Center
- Upham's Corner Health Center
- Whittier Street Health Center

Psychosocial Support - MAI

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

Emergency Financial Assistance - MAI

- Harbor Health Services, Inc.

Other Professional Services—Legal - MAI

- Fenway Community Health Center

Non-Medical Case Management - MAI

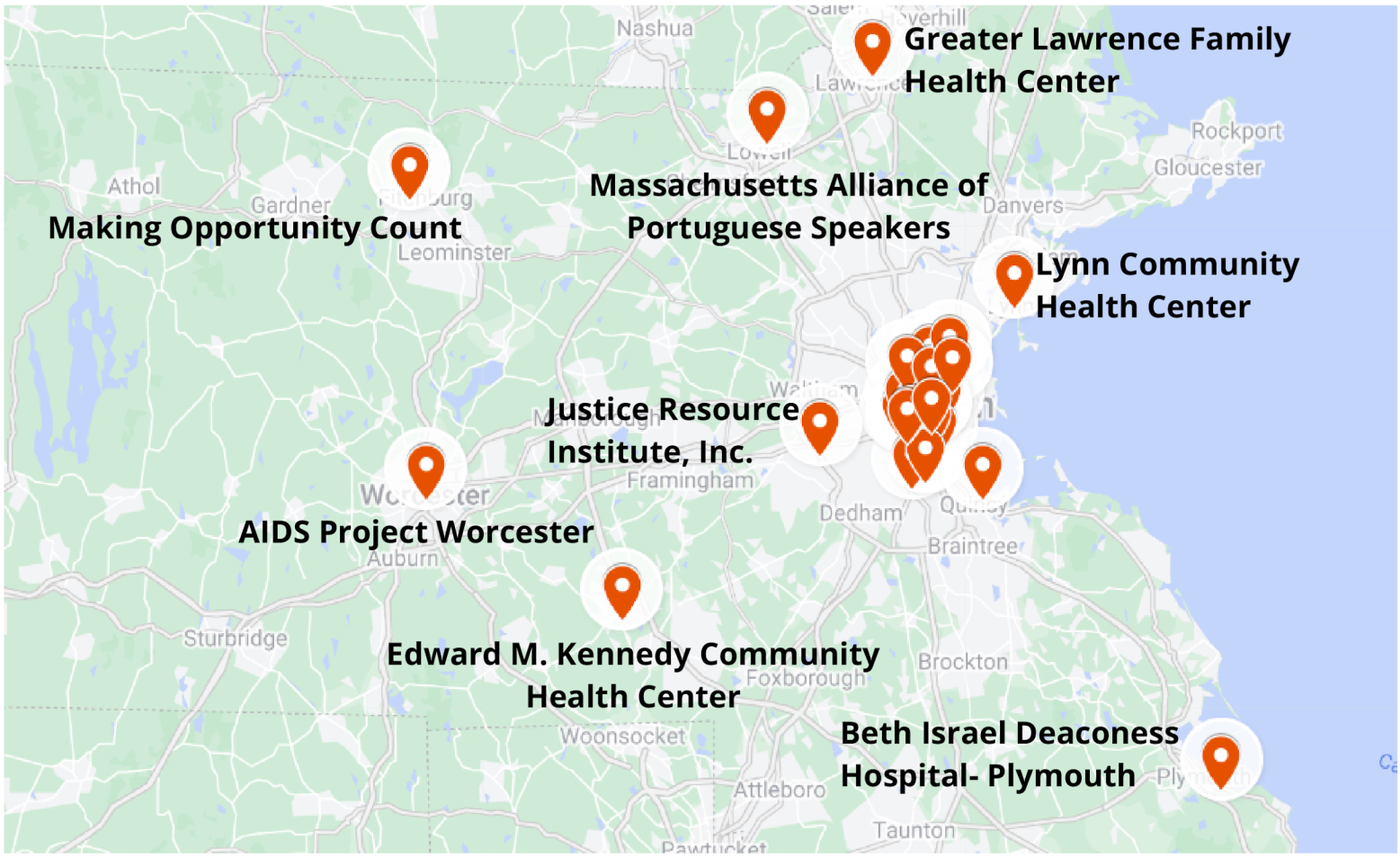
- Massachusetts Alliance of Portuguese Speakers

Linguistic Services - MAI

- Catholic Charitable Bureau of the Archdiocese of Boston

Appendix B. Part A/MAI Agency Maps

MASSACHUSETTS



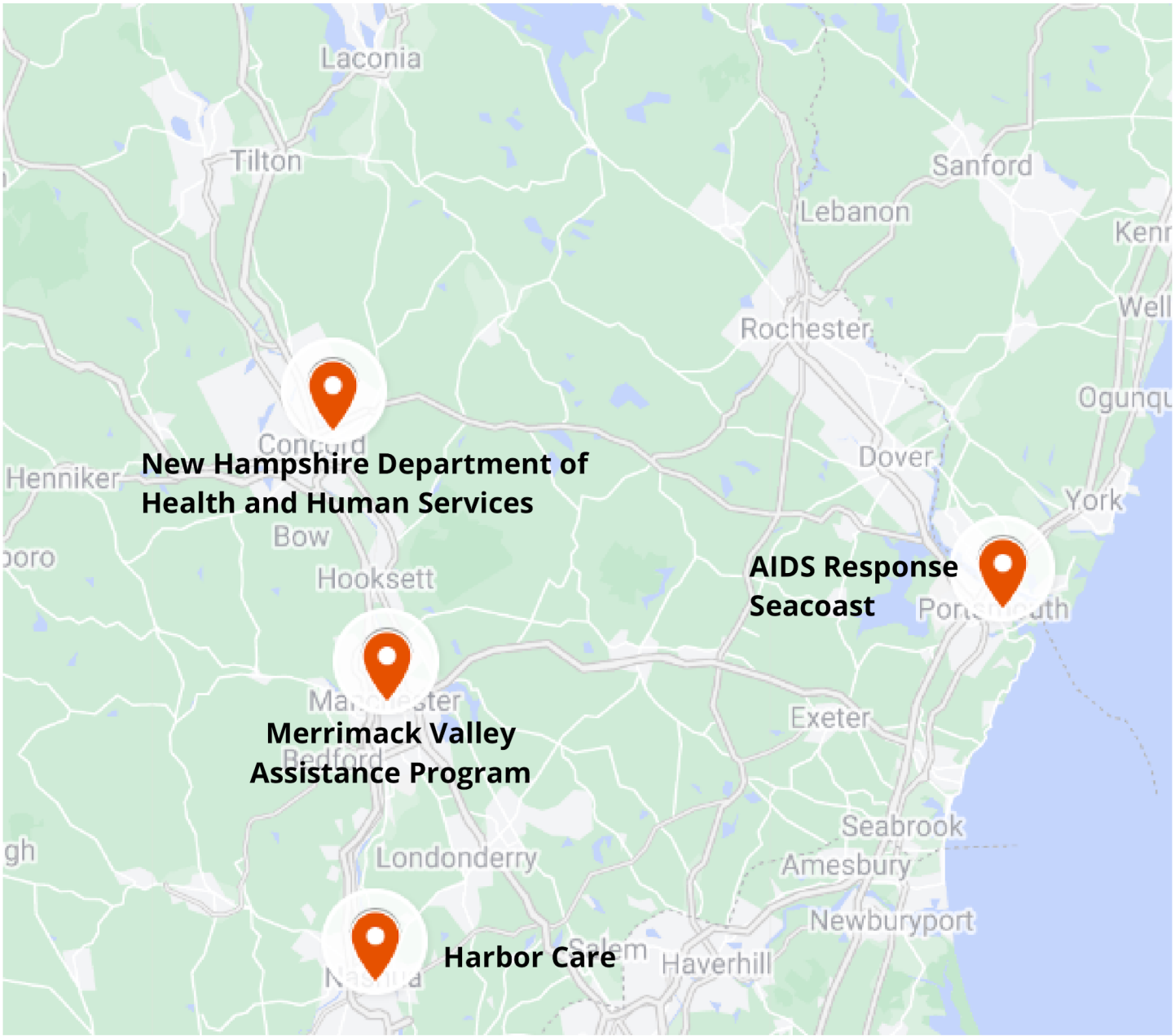
Appendix B. Part A/MAI Agency Maps

GREATER BOSTON NEIGHBORHOODS

1- Fenway Community Health Center
2- Boston Children's Hospital
3- Whittier Street Health Center
4- Multicultural AIDS Coalition
5- Boston Health Care for the Homeless Program
6- Dimock Health Center

Appendix B. Part A/MAI Agency Maps

NEW HAMPSHIRE

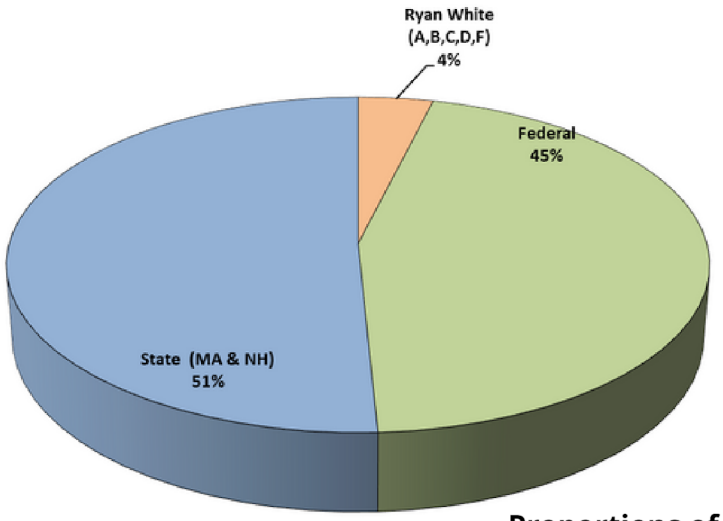


Appendix C. Boston EMA Resource Inventory

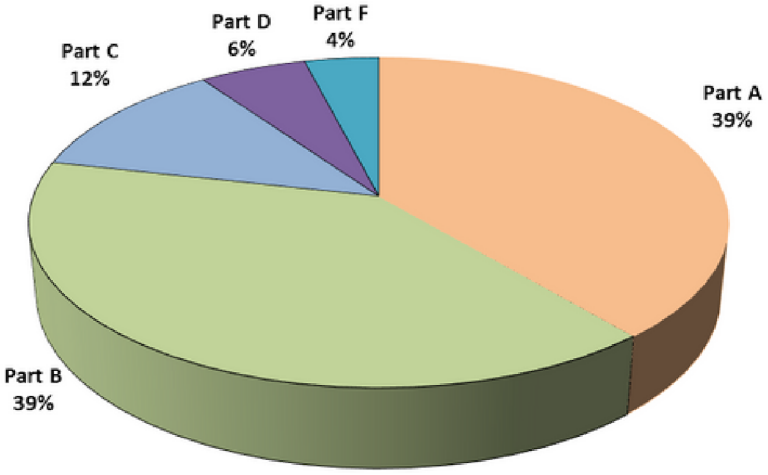
The Ryan White HIV/AIDS program (RWHAP) has several core medical and support services that are required by legislation and funded by the Department of Health and Human Services under appropriation from the federal government. This resource inventory will provide a brief overview on our funding streams available to HIV services within the Boston EMA. Data for this appendix is collected by PCS staff throughout the Council year and is used to help inform priority setting and allocations decisions for the EMA. Agencies could report either FY22 expenditure or FY23 allocation. We had a 70.2% response rate and therefore this inventory is not 100% comprehensive of all funding within the EMA, but it is used as an estimate.[1]

The RWHAP is made up of 5 component parts; A, B, C, D, and F. Funding from Part A is administered by HRSA/HAB using the Part A formula and MAI fund and supplemental components of the grant. Additional resources within the Boston EMA include other federal funding from sources such as the Center for Disease Control (CDC) and Housing Opportunities for Persons With AIDS (HOPWA), State funding from both Massachusetts and New Hampshire and any reported private foundation funding to agencies.

Proportions of public funding to the Boston EMA[1]



Proportions of RWHAP funding to the Boston EMA[1]



1 Funding Streams Summary Report, Planning Council Support Staff, 02/01/23 - 04/30/23.

Appendix C. Boston EMA Resource Inventory

Appendix C. Table 1. Current Funding Stream Breakdown in the Boston EMA[1]

Funding Stream	Total Allocation	Percentage
Part A	$15,968,930	1.6%
Part B	$15,492,554	1.5%
Part C	$4,596,539	0.5%
Part D	$2,254,020	0.2%
Part F	$1,561,712	0.2%
HOPWA	$7,205,250	0.7%
CDC	$6,247,050	0.6%
Federal Medicaid (MassHealth & NH)	$436,895,740	43.5%
EHE Funding	$1,144,974	0.1%
SAMHSA	$3,274,826	0.3%
Other Federal	$336,917	0.0%
MassHealth	$436,895,740	43.5%
MA General Funds	$32,868,619	3.3%
MDPH - BSAS	$35,420,942	3.5%
MA Other	$4,978,225	0.5%
NH State General Funds	N/A or Not Reported	0.0%
Private Funding (if reported)	$361,041	0.0%
TOTAL	$1,004,694,494	100.0%

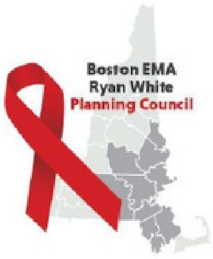
This table includes funding for all Core Medical, Support Services and administrative and program support such as capacity building and technical assistance, clinical quality management and other indirect program costs.

Appendix C. Table 2. FY 2022 (3/1/22-2/28/23) Boston EMA Part A/MAI Resources[2]

	Part A	MAI	Total
Award Amount ($)	$14,855,281	$1,113,649	$15,968,930
# of Subrecipients	32	10	32
# of Service Categories	12	6	12
# of Clients Served	3,698	423	4,121

1 Funding Streams Summary Report, Planning Council Support Staff, 02/01/23 - 04/30/23.
2 Visual Analytics (Demographics) report in e2Boston ran on 05/08/23. Columns are separated by clients served by Part A funds ONLY and MAI funds ONLY.

Appendix D. Consumer Survey



2022-2023 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.

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 Planning Council Support at 617-947-4299 or email: pcs@bphc.org.

Please create a unique code using this information: A parent or guardian'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: ____ ____ ____ ____

Appendix D. Consumer Survey

BE SURE TO SUBMIT THIS PAGE WITH YOUR SURVEY

PART 1: DEMOGRAPHIC AND BACKGROUND INFORMATION

1. **What is your age?**
   - ☐ 13-19
   - ☐ 20-29
   - ☐ 30-39
   - ☐ 40-44
   - ☐ 45-49
   - ☐ 50-59
   - ☐ 60-64
   - ☐ 65-69
   - ☐ 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 Latin, 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
   - ☐ 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

Appendix D. Consumer Survey

- ☐ Cape Verdean Creole
- ☐ 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)**

Appendix D. Consumer Survey

PART 2: MEDICAL CARE AND SERVICE GAPS

12. If you are 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.
- ☐ Yes

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 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
- ☐ Housing
- ☐ Medical care
- ☐ Support groups
- ☐ Financial assistance
- ☐ Legal services
- ☐ Translation services
- ☐ None
- ☐ Other: _____

Appendix D. Consumer Survey

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
- ☐ Childcare 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
- ☐ Barriers due to technology
- ☐ Other: _____

Appendix D. Consumer Survey

PART 3: IMPACT OF COVID-19

20. What was the impact of COVID-19 on your ability to access HIV services?

- ☐ Access to services was not available at all, or extremely limited
- ☐ Access to services was fine, except limited to virtual/online only
- ☐ Access to services was available in person, but with delays
- ☐ COVID-19 did not affect my ability to access HIV services

If access to services was limited, which services were hard to obtain?

21. If you received services via Tele-health or Virtual (Zoom, etc), how would you rate those services?

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Excellent

Why did you give these services this rating?

22. If you used telehealth or virtual access to services, would you like it to continue to be offered in the future (regardless of if COVID is an impact or not)?

- ☐ Yes
- ☐ No

23. Does the stigma associated with HIV have an impact on your ability/comfort accessing services?

- ☐ Yes, a little
- ☐ Yes, a lot
- ☐ No

24. What other information would you like to share with us on the impact of COVID-19 on your ability to receive services and manage life with HIV?

END OF SURVEY

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
Email: pcs@bphc.org
Fax: 617-419-1629

Appendix E. Provider Survey

2022-2023 Boston EMA Provider Capacity and Capability Survey

Thank you for taking the time to complete this survey. The purpose of this assessment is to identify the extent to which HIV-related services in the area are accessible, available, and appropriate for people living with HIV (PLWH) in the Boston EMA (Massachusetts Counties: Bristol, Essex, Middlesex, Norfolk, Plymouth, Suffolk, and Worcester; New Hampshire Counties: Hillsborough, Rockingham, and Strafford). Your input will assist the Ryan White Planning Council and the Boston Public Health Commission in making informed decisions about improving the system of care for PLWH in the Boston EMA.

Please answer all questions to the best of your ability and submit your response by February 24th, 2023. If you have any questions about this survey, please contact Planning Council Support at 617-947-4299 or email: pcs@bphc.org.

1. What is your agency name?

2. Are there other offsite locations?

- [ ] Yes
- [ ] No

If yes, how many?

Appendix E. Provider Survey

3. How many employees does your agency have?

- ◯ 0 - 10
- ◯ 11 - 20
- ◯ 21 - 30
- ◯ 31 - 40
- ◯ 41 - 50
- ◯ More than 50

4. How many clients is your agency currently serving? (Give your closest estimate)

5. What best describes your position at your agency?

- ◯ Case Manager/ Social Worker
- ◯ Nurse
- ◯ Physician/ Nurse Practitioner/ Physician Assistant
- ◯ Program Manager/ Supervisor
- ◯ Administrative Support Personnel/ Front Desk Staff
- ◯ Executive Director or Deputy Director
- ◯ Grant Coordinator
- ◯ Finance/ Accounting Personnel
- ◯ Client Educator/ or Prevention
- ◯ Registered Dietician
- ◯ Mental Health/ Substance Abuse Counselor or Therapist
- ◯ Other (please specify)

6. What percentage of your time do you spend with clients?

- ◯ 0 - 10%
- ◯ 11 - 20%
- ◯ 21 - 30%
- ◯ 31 - 40%
- ◯ 41 - 50%
- ◯ More than 50%

Appendix E. Provider Survey

7. Does your agency target a particular population? For example, are your services oriented towards people of a particular race/ ethnicity, gender, age, sexual orientation, or towards people with substance abuse/ mental health issues or people who are homeless etc. ?

- ◯ No
- ◯ Yes

If Yes (Please Specify)

8. How long have you worked with people living with HIV/AIDS?

- ◯ 0 - 5 years
- ◯ 6 - 10 years
- ◯ 11 - 15 years
- ◯ More than 15 years

9. How long have you been at your agency?

- ◯ 0 - 2 years
- ◯ 3 - 5 years
- ◯ 6 - 10 years
- ◯ 11 - 15 years
- ◯ More than 15 years

Appendix E. Provider Survey

10. Which of the following best describes your agency (SELECT ALL THAT APPLY)

- ☐ AIDS Service Organization
- ☐ Medical Provider
- ☐ Housing/ Homeless Service Provider
- ☐ Faith Based Organization
- ☐ Food Organization
- ☐ Substance Use Services Provider
- ☐ Mental Health Provider
- ☐ Legal Assistance Provider
- ☐ Public Health Clinic Provider
- ☐ Financial Assistance Provider
- ☐ Other

Other (please specify)

11. Which of the following best describes the funding streams currently supporting your organization? (SELECT ALL THAT APPLY)

- ☐ Foundation
- ☐ Federal Government
- ☐ State Government
- ☐ CDC
- ☐ SAMHSA
- ☐ Contributions/ Private Donations
- ☐ Revenues (Fees)
- ☐ Ryan White Part A Funding
- ☐ Ryan White Part B Funding
- ☐ Ryan White Part C Funding
- ☐ Ryan White Part D Funding
- ☐ Ryan White Part F Funding
- ☐ HOPWA
- ☐ Medicaid
- ☐ HIV Prevention Funding
- ☐ Other

Other (please specify)

12. Do you have language translation services available?

- ◯ Yes
- ◯ No

Appendix E. Provider Survey

13. How do you serve clients who do not speak English? (SELECT ALL THAT APPLY)

- ☐ Currently have multilingual staff on hand
- ☐ Language line
- ☐ Ensuring translators are provided by an outside organization/ company
- ☐ Translating patient materials into languages other than English

14. Which languages are most often requested by your consumers, besides English?

- ☐ Spanish
- ☐ French
- ☐ Portuguese Creole
- ☐ Cape Verdean
- ☐ Haitian Creole
- ☐ Other

Other (please specify)

15. Is public transportation readily accessible near your agency?

- ◯ Yes
- ◯ No

16. Please indicate your agency's hours of operation by selecting all the relevant categories below. (SELECT ALL THAT APPLY)

- ☐ Weekday hours (8am to 5pm)
- ☐ Weekday evenings (after 5pm)
- ☐ Weekend hours
- ☐ Other
- ☐ Other (please specify)

Appendix E. Provider Survey

17. Have any of the following occurrences taken place within your agency in the past year?

- [ ] An increase in the number of clients seeking services?
- [ ] An increase in the demand for services from clients?
- [ ] A decrease in the amount of funding provided from private donations?
- [ ] A decrease in funding your agency receives from any funding streams?

18. What does your agency need to increase its capacity to serve persons living with HIV/AIDS (SELECT ALL THAT APPLY)

- [ ] Increased partnerships with HIV/AIDS specialty agencies and organizations
- [ ] Training (Please specify in the box below what type of training)
- [ ] Funding to expand current capacity
- [ ] Other
- [ ] Funding to develop new capacity

Other (please specify)

19. What do you think are the most pressing needs of persons living with HIV/AIDS seen at your agency in the past year? (LIST UP TO THREE)

1.
2.
3.

Appendix E. Provider Survey

20. Please check the five (5) services that you feel are the most important for clients in managing their HIV status

- ☐ Early Intervention Services for persons newly diagnosed or not currently in HIV care
- ☐ Emergency Financial Assistance for emergency rental assistance or emergency utility assistance
- ☐ Food assistance for grocery store gift cards or food pantries
- ☐ Health Education/ Risk reduction classes
- ☐ Health Insurance Assistance for lab and medical visit co-pays
- ☐ Housing Assistance for short-term, limited rental payments
- ☐ Medical Case Management for care coordination and service referrals
- ☐ Medical Nutrition Therapy to meet with a registered dietician
- ☐ Medical transportation for bus passes, gas vouchers, or van rides
- ☐ Mental Health services to meet with a counselor, therapist, or psychiatrist
- ☐ Oral Health Care for dental services
- ☐ Outpatient Ambulatory Health Services for HIV primary medical care
- ☐ Psychosocial Support Services for Support groups
- ☐ Substance Use Outpatient Care services to meet with a drug and alcohol counselor
- ☐ Other

Other (please specify)

Appendix E. Provider Survey

21. What barriers does your agency typically encounter while providing client services, if any? (SELECT ALL THAT APPLY)

- ☐ N/A
- ☐ Not enough resources at my agency
- ☐ Clients don't have payment resource
- ☐ Identification of HIV+ clients is difficult
- ☐ Staff training in HIV/AIDS is limited
- ☐ Insufficient staff to provide services
- ☐ Clients routinely miss appointments
- ☐ Clients distrust/ suspicion
- ☐ Limited community partnerships
- ☐ Clients may have trouble getting to our offices
- ☐ Office hours limit client's access to our services
- ☐ Agency doesn't provide all the services a person needs
- ☐ Don't know where to refer clients for a needed service
- ☐ Don't have an updated referral list or directory
- ☐ Other

Other (please specify)

22. Is there currently a waiting period or a wait list for any services in your agency?

- ◯ Yes
- ◯ No

23. What services currently have a wait time and how long is the wait time (days, weeks, months)?

1.
2.
3.
4.
5.

Appendix E. Provider Survey

24. In your opinion, what two changes in the Ryan White care system would make it easier for clients to access services?

1.
2.

25. Has the COVID-19 pandemic affected your agency's ability to offer services?

- ◯ Yes
- ◯ No

26. If yes, please state three ways the COVID-19 pandemic has impacted the ability of your agency to deliver services.

1.
2.
3.

27. How does your agency ensure that it is culturally competent?

- ☐ By hiring staff of different cultures
- ☐ By hiring peer educators/ counselors of different cultures
- ☐ By making referrals or having contracts with culturally specific organizations
- ☐ By providing staff with general diversity/ cultural competency training
- ☐ By providing staff with specific diversity/ cultural competency training
- ☐ My agency does not do anything to ensure that it is culturally competence
- ☐ Other (please specify)

This is the end of the survey! Thank you so much for your input. Please email Planning Council Support Staff at pcs@bphc.org with any further questions.

Appendix F. Focus Group Discussion Guide

Introduction and Guiding Script
Boston EMA Ryan White Planning Council
Consumer 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 your opinions to be collected in order to improve the service system. 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 _____ county.

A little about the 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 and support services such as peer groups, 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 for any reason. We would like to ask for your permission to record this session. The recording only be used to review this conversation in case we miss anything. The recording will not be shared with anyone and will be destroyed after we have completed our analysis. You do not have to share any personal information that you do not feel comfortable disclosing and please participate in a way that feels safe 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.

Appendix C. Focus Group Discussion Guide

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 in instant changes, rather it will help inform change over time. Each person will receive a $10 Target gift card after the completion of this discussion.

Focus Group Questions

What are the most important HIV related services that help PLWH stay in care?
- Prompt/probe: What do PLWH need in order to maintain good health?

What do you feel are issues that stop PLWH from going to the doctor or other healthcare provider?
- Prompt/probe: Why do you think people don't get medical care for HIV?
- Prompt/probe: What are some of the barriers to accessing HIV services?

Over the past year, what HIV-related services did you need and was able to get?
- Prompt/probe: What HIV services do you currently receive?

Over the past year, were there services that you needed but were not able to get?
- This could be any service for your overall health and wellness.

What suggestions do you have for making it easier for PLWH to get the services they need to stay in care?
- Prompt/probe: How can the quality of HIV-related services be improved?
- Prompt/probe: What services would be helpful, but aren't available?

How has Covid-19 impacted your ability to receive services?

How has technology impacted your ability to receive services?
- Prompt/probe: How has technology impacted the quality of the services you receive?

Anything else you would like to share?
- Prompt/probe: Maybe something that is important for me to know that I didn't ask about already? Or something that you wanted to say earlier but didn't get the chance to say?

That concludes our session today. If you do have any questions or comments (or would like more information on the Boston EMA Ryan White Planning Council), please feel free to message Planning Council Support staff at pcs@bphc.org