

September 21, 2023

FINAL NARRATIVE REPORT

*Washington, DC Regional Planning
Commission on Health and HIV,
District of Columbia Eligible
Metropolitan Area Consumer Status
Neutral Needs Assessment, 2022-2023*

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**District of Columbia Eligible Metropolitan Area
Consumer Status Neutral Needs Assessment,
2022-2023**

DC Department of Health (DC Health)
HIV/AIDS, Hepatitis, STD and TB Administration (HAHSTA)

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INTRODUCTION

The Washington, DC Regional Planning Commission on Health and HIV (COHAH), the HIV/AIDS, Hepatitis, STD and TB Administration (HAHSTA), and the George Washington University (GW) Milken Institute School of Public Health conducted a consumer status neutral needs assessment study to inform the comprehensive planning process for the Washington, DC Eligible Metropolitan Area (DC EMA). The study aims to understand the current care service needs and gaps of people living with HIV (PLWH) and those not living with HIV but may benefit from prevention services. Incorporating consumer viewpoints is an essential component of COHAH's annual priority-setting and resource allocation process.

Background

Over the past four decades, there has been a great deal of progress in science, policy, and programming to end the HIV/AIDS (human Immunodeficiency virus; acquired immunodeficiency syndrome) epidemic. From an epidemiological perspective, researchers and public health professionals have set a goal of reducing the number of new infections per year in the United States (U.S.) to less than 3,000 cases by 2030.¹ Accordingly, efforts to “end” the HIV/AIDS epidemic seek to make new HIV/AIDS infections so rare HIV will be eventually eradicated.²

HIV is a virus and acquired AIDS is the syndrome that results from long-term untreated infection with the virus. HIV transmission can occur through sexual contact; sharing of needles, syringes, or other drug injection equipment; or from mother to baby. There is still no vaccine or cure for HIV; however, the disease can be managed with antiretroviral therapy (ART) to achieve sustained HIV viral load suppression (VLS). Additionally, individuals who have a sexually transmitted disease (STD) are more likely to get HIV or transmit it to others. These STDs include chlamydia trachomatis, gonorrhea, syphilis, and herpes.

In recent years, the U.S. and the DC EMA have adopted a status neutral HIV prevention and care approach for engagement to accelerate progress toward ending the epidemic. The multidirectional continuum begins with an HIV test and proposes two pathways depending on the test results: 1) a prevention pathway for those testing negative and 2) a treatment pathway for those testing positive. Both pathways lead to a common final position where people are engaged in clinical care, either taking daily pre-exposure prophylaxis (PrEP) for those behaviorally vulnerable to HIV or achieving sustained VLS for PLWH. The status neutral continuum has the following implications: 1) emphasizes HIV testing as the gateway to prevention and care, 2) supports integrated prevention and care programs by recognizing the same approach used for achieving VLS treatment is necessary for HIV prevention, 3) highlights that approaches to serving people for prevention and treatment are indistinguishable, and 4) eliminates the stigma of HIV by placing consumer needs above their HIV status.³

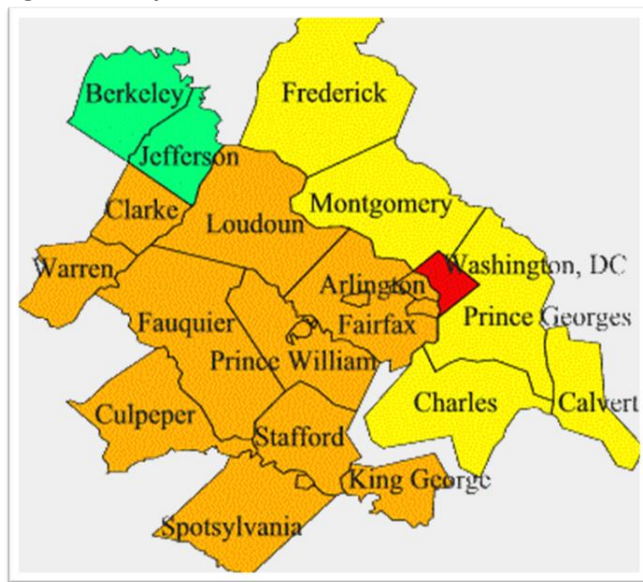
The DC EMA includes the District of Columbia (DC), five counties in suburban Maryland, 11 counties and six independent cities in Northern Virginia, and two counties in West Virginia. While these jurisdictions share borders, they may prioritize HIV-related services based on their unique needs. Figure 1 is a visual depiction of the DC EMA.

¹ Guilamo-Ramos V, Thimm-Kaiser M, Benzekri A. Is the USA on track to end the HIV epidemic?. *Lancet HIV*. 2023;10(8):e552-e556. doi:10.1016/S2352-3018(23)00142-X

² Eisinger RW, Fauci AS. Ending the HIV/AIDS Pandemic. *Emerg Infect Dis*. 2018;24(3):413-416. doi:10.3201/eid2403.171797

³ Myers JE, Braunstein SL, Xia Q, et al. Redefining Prevention and Care: A Status-Neutral Approach to HIV. *Open Forum Infect Dis*. 2018;5(6):ofy097. Published 2018 May 2. doi:10.1093/ofid/ofy097

Figure 1. Map of the DC EMA, 2023



There are a total of 39,725 individuals living with HIV in the DC EMA. The District of Columbia is the epicenter of diagnosed HIV cases despite accounting for 10.8% of the DC EMA general population. In 2022, 17,829 (44.8%) diagnosed HIV cases were from DC; 13,536 (34.1%) from Maryland; 8,360 (21.0%) from Virginia; and 265 (<1%) from West Virginia.⁴ Across the region, the HIV epidemic disproportionately impacts people of color (78%), men (70.4%), and those over 40 years of age (77.0%) with the most common mode of transmission being sexual contact (78%). There are jurisdictional variations to these trends, Maryland had the highest proportion of transmission from heterosexual contact (46%).

The DC EMA is a unique region that spans multiple jurisdictions, each with its own specific HIV-related needs. The prevalence of HIV varies among these jurisdictions, with DC having the highest rates. Understanding the demographic breakdown and transmission patterns within the DC EMA is crucial for implementing targeted prevention and support initiatives to combat the spread of HIV and address the unique challenges faced by each jurisdiction.

The aim of this study is to 1) understand the current service utilization and barriers to receiving and remaining engaged in comprehensive care; and 2) assess the demographic, economic, and social characteristics that may affect access to medical care and support services for PLWH and people behaviorally vulnerable to HIV. This approach aligns with the status neutral continuum and the integration of prevention and care strategic planning of the COHAH. The analysis will inform the COHAH's priority setting and resource allocation process to improve the health and well-being of people and communities in the DC EMA.

METHODS

This cross-sectional survey study was administered in two phases from July 6, 2022 to June 30, 2023, in Spanish and English. A convenience sample of DC EMA consumers was invited to participate using a

⁴ The number of individuals diagnosed with HIV residing in West Virginia is only available through 2019 due to limited staffing availability.

mixed-mode approach. The DC Department of Health (DC Health) Institutional Review Board for the Public Health approved the study on April 22, 2022, IRBPH# 2022-4.

Survey Development

Between March 2021 and June 2022, the COHAH's Research and Evaluation Committee (REC) and researchers from GW developed a 68-question consumer status neutral needs assessment survey (hereafter referred to as *survey*)—the first status neutral survey for the DC EMA. The survey was informed by existing surveys from across the nation, including status neutral consumer needs assessments from Maryland, Virginia, and San Francisco, California; the 2019 DC EMA Survey; and the Community Needs Assessment Survey available on LinkU (linkudmv.org) to build an organizing framework that defines the current and past topics and questions to be addressed.

These questions (and the consumer response options) were categorized by topic and cross-walked. The REC selected the survey topics and questions for inclusion, and, where applicable, modified or wrote new questions to collect data of interest to the REC. REC members reviewed the questions, question order, and skip logic of the survey in late spring through early summer of 2021. GW built the REC-approved survey in the DC Health REDCap (Research Electronic Data Capture), a secure online survey application. REC members tested the survey length, usability, and comprehensibility. The anonymous survey was composed of questions across 11 domains:

- Demographic information
- HIV status
- Service utilization (Ryan White)
- Living environment
- Work and finances
- Insurance and care
- HIV treatment or prevention
- Other health conditions
- Substance use
- Transgender services
- Healthcare access and interactions

The survey included a combination of Likert scale, multiple choice (both mutually exclusive and not mutually exclusive), dichotomous, and short open-ended questions. The survey also included questions on how the COVID-19 pandemic impacted many of these domains.

Survey Administration

The study team administered the survey in two phases through multiple modes, inviting responses to a paper survey or an online survey. During summer 2021, REDCap experienced a system failure after the creation of the online survey that could not be recovered, and an alternative survey platform was not immediately accessible. The paper version of the survey was therefore fielded at two DC Ryan White (RW) HIV/AIDS Program provider clinics from July 6, 2022 to November 9, 2022 by four student investigators to facilitate data quality and survey completion.

In tandem, researchers rebuilt the survey in DC Health Salesforce, a customer relationship management software, in July 2022 as the platform was the only alternative available. The team encountered technical challenges with Salesforce for several months; the platform was actively working by

September 2022. All RW providers were encouraged to promote the survey to their consumers using a flyer with a quick response (QR) code for self-administration as well.

In February 2023, all RW providers were encouraged to continue promoting the survey to increase the survey response rate and to achieve a representative sample of the DC EMA. A secondary group of four student investigators facilitated survey administration using the paper and online Salesforce survey at RW provider clinics in Maryland (two clinic locations) and Virginia (one clinic location), from April 26, 2023 to June 30, 2023. Researchers also recruited consumer participants at the Pride in the Plaza festival in Silver Spring, Maryland on June 25, 2023. The primary aim of the secondary phase was to gather a representative sample across the DC EMA.

Across both phases, the student investigators entered the paper responses into Salesforce. The survey took 15-20 minutes to complete, depending on skip logic used for the survey response (e.g., consumers who were HIV-positive answered questions related to HIV treatment and HIV-negative consumers answered questions related to HIV prevention). Verbal and written informed consent were obtained from the participants and no personal identifying information (e.g., name, email, address, or phone number) was collected; consumers remained entirely anonymous. All respondents were 18 years of age or older, HIV status neutral (both negative and positive), and residing in the DC EMA. A modest financial incentive (\$15 Walmart gift card) was provided for participation.

Data Analysis

We defined survey completion as returned surveys with respondent consent and HIV status. One of us (J.O.) conducted the analysis using χ^2 and Fisher exact tests to compare the characteristics of survey respondents and DC EMA jurisdictions, assess the association between survey responses and respondents' characteristics, and survey responses and jurisdictions. Statistical significance was set at a threshold of $P=0.05$. The survey respondents' characteristics analyzed included age, racial and ethnic minority group, country of birth, gender, educational attainment, sexual orientation, and place of residence. Descriptive analysis was conducted using IBM SPSS Statistics, version 25 (IBM Corp).

RESULTS⁵

Survey Response and Characteristics

A total of 429 surveys were submitted with varying levels of completion from the District of Columbia (246 of 425 [57.9%]); Maryland (99 of 425 [23.3%]); Virginia (67 of 425 [15.8%]); West Virginia (3 of 425 [0.7%]); (10 of 425 [2.3%]) Other; and 4 respondents did not identify their place of residence. A priori estimates of the number of surveys needed were 212 (51.5%) for the District of Columbia, 131 (31.7%) for Maryland, 64 (15.6%) for Virginia, and 5 (1.2%) for West Virginia. The survey targets were reached and/or exceeded for the District of Columbia and Virginia.

The majority of those who participated were 25-34 years of age (126 of 407 [31.0%]), male (216 of 425 [50.8%]), Black not Hispanic (246 of 417 [59.0%]), heterosexual (214 of 422 [50.7%]), US-born (314 of 417 [75.3%]), and high school graduates (119 of 420 [28.3%]). Table 1 shows the representation of the demographic characteristics of the survey respondents across the different jurisdictions of the DC EMA.

⁵ Statistically significant results with $p < .05$ are indicated with a single dagger (†); $p < .001$ are indicated with a double dagger (§). In cases where the small number of responses (referred to statistically as "small cells") prevented analysis from measuring the level of statistical significance in jurisdictional differences, results are marked with a section symbol (§)

Table 1. Characteristics of Consumer Respondents in the Needs Assessment, 2022-2023^a

Characteristics	District of Columbia	Maryland	Virginia	West Virginia
Age^d	No. (%)	No. (%)	No. (%)	No. (%)
18-24	33 (13.7)	10 (10.6)	12 (20.7)	0 (0)
25-34	71 (29.5)	26 (27.7)	26 (44.8)	0 (0)
35-44	51 (21.2)	27 (28.7)	4 (6.9)	3 (100.0)
45-54	28 (11.6)	7 (7.4)	5 (8.6)	0 (0)
55-64	39 (16.2)	19 (20.2)	10 (17.2)	0 (0)
65+	19 (7.9)	5 (5.3)	1 (1.7)	0 (0)
Race and ethnicity^e				
Asian, not Hispanic	6 (2.5)	0 (0)	1 (1.5)	0 (0)
Black, not Hispanic	159 (66.0)	63 (65.6)	16 (24.6)	1 (33.3)
Latino/a or Hispanic	14 (5.8)	17 (17.7)	31 (47.7)	0 (0)
White, not Hispanic	28 (11.6)	6 (6.3)	5 (7.7)	1 (33.3)
Middle Eastern/North African, not Hispanic	0 (0)	0 (0)	1 (1.5)	0 (0)
Two or more races	27 (11.2)	9 (9.4)	6 (9.2)	1 (33.3)
Other	3 (1.2)	0 (0)	2 (3.1)	0 (0)
Prefer not to answer	4 (1.7)	1 (1.0)	3 (4.6)	0 (0)
Gender^e				
Female	109 (44.3)	47 (48.0)	17 (25.8)	2 (66.7)
Male	121 (49.2)	47 (48.0)	41 (62.1)	1 (33.3)
Transgender	9 (3.7)	1 (1.0)	6 (9.1)	0 (0)
Non-Binary	6 (2.4)	2 (2.0)	0 (0)	0 (0)
Prefer not to answer	1 (0.4)	1 (1.0)	2 (3.0)	0 (0)
Education^e				
8 th grade	1 (0.4)	1 (1.0)	2 (3.2)	0 (0)
Some high school	16 (6.5)	3 (3.1)	10 (15.9)	0 (0)
High school graduate/GED	79 (32.2)	22 (22.4)	13 (20.6)	1 (50.0)
Technical/vocational school	15 (6.1)	4 (4.1)	1 (1.6)	0 (0)
Some college	50 (20.4)	22 (22.4)	9 (14.3)	0 (0)
Associate's degree	12 (4.9)	9 (9.2)	5 (7.9)	0 (0)
Bachelor's degree	35 (14.3)	16 (16.3)	9 (14.3)	1 (50.0)
Some graduate school	2 (0.8)	5 (5.1)	1 (1.6)	0 (0)
Graduate degree	32 (13.1)	9 (9.2)	9 (14.3)	0 (0)
Other	0 (0)	4 (4.1)	1 (1.6)	0 (0)
Prefer not to answer	3 (1.8)	3 (3.1)	3 (4.8)	0 (0)
Sexual orientation^e				
Heterosexual	130 (53.3)	46 (46.9)	32 (48.5)	1 (50.0)
Gay/Lesbian/Same Gender Lover	75 (30.7)	31 (31.6)	23 (34.8)	0 (0)
Bisexual	23 (9.4)	14 (14.3)	8 (12.1)	0 (0)
Queer	7 (2.9)	0 (0)	0 (0)	1 (50.0)

Pansexual ^b	0 (0)	3 (3.1)	0 (0)	0 (0)
Not sure/Questioning	3 (1.2)	2 (2.0)	0 (0)	0 (0)
Other	1 (0.4)	1 (1.0)	0 (0)	0 (0)
Prefer not to answer	5 (2.0)	1 (1.0)	3 (4.5)	0 (0)
Income^e				
\$499 or less	33 (14.9)	13 (14.1)	19 (31.1)	0 (0)
\$500-\$999	33 (14.9)	7 (7.6)	5 (8.2)	1 (33.3)
\$1,000-\$1,999	39 (17.6)	13 (14.1)	8 (13.1)	1 (33.3)
\$2,000-\$2,999	23 (10.4)	11 (12.0)	4 (6.6)	0 (0)
\$3,000-\$3,999	19 (8.6)	14 (15.2)	7 (11.5)	1 (33.3)
\$4,000 or more	44 (19.8)	18 (19.6)	8 (13.1)	0 (0)
Don't know	11 (5.0)	7 (7.6)	7 (11.5)	0 (0.0)
Prefer not to answer	20 (9.0)	9 (9.8)	3 (4.9)	0 (0)

^aExcludes "Other" as place of resident selection due to low cell responses and specificity.

^bIncludes "Pansexual" extracted from the "Other" category.

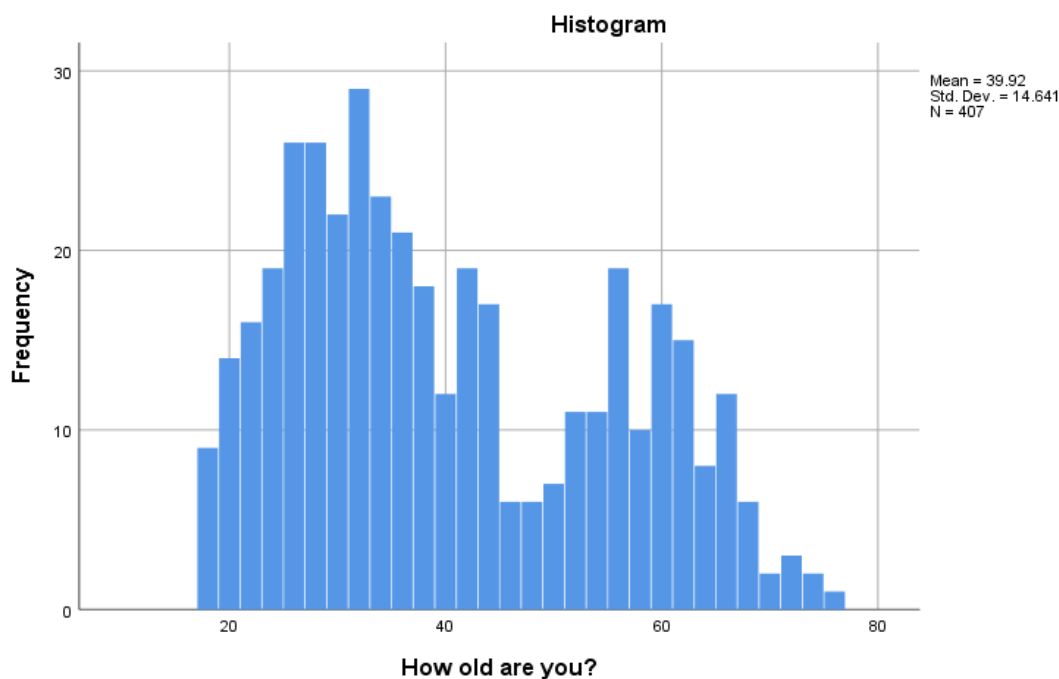
^c $p < .05$

^d $p < .001$

^e Small cell responses precluded statistical analysis by jurisdiction.

The survey respondents ranged from 18-75 years of age, with a median age of 36 years. The age distribution is bimodal with two peaks—a major mode (value that occurs more frequently) between 20-40 years and a minor mode between 50-70 years. Figure 1. shows the bimodal distribution of respondents by age.

Figure 1. Distribution of Consumer Respondents in the Needs Assessment by Age, 2022-2023^a



^aExcludes "Prefer not to answer" responses.

Of the 415 responses, the District of Columbia (159 of 241 [66%]) and Maryland (63 of 96 [65.6%]) had a higher proportion of Black, not Hispanic respondents, while Virginia (31 of 65 [47.7%]) had the highest proportion of Latino/a or Hispanic respondents.[§] The District of Columbia had the most respondents who identified as two or more races (27 of 45 [60%]) than the other jurisdictions.[§] The gender distribution is consistent across jurisdictions with a higher proportion of respondents who identified as transgender (9 of 16 [56.3%]) and non-binary (6 of 8 [75%]) in the District of Columbia compared with responses from other jurisdictions.[§] Educational attainment was reported at varying levels among the 420 responses, with 28.3% (119) of respondents being high school graduates, 19.8% (83) having some college, and 14.8% (62) obtaining a bachelor's degree.[§] While most respondents reported being US-born in the District of Columbia (214 of 243 [88.1%]) and Maryland (65 of 95 [68.4%]), Virginia (40 of 64 [62.5%]) had the highest proportion of respondents who were not US-born.[‡]

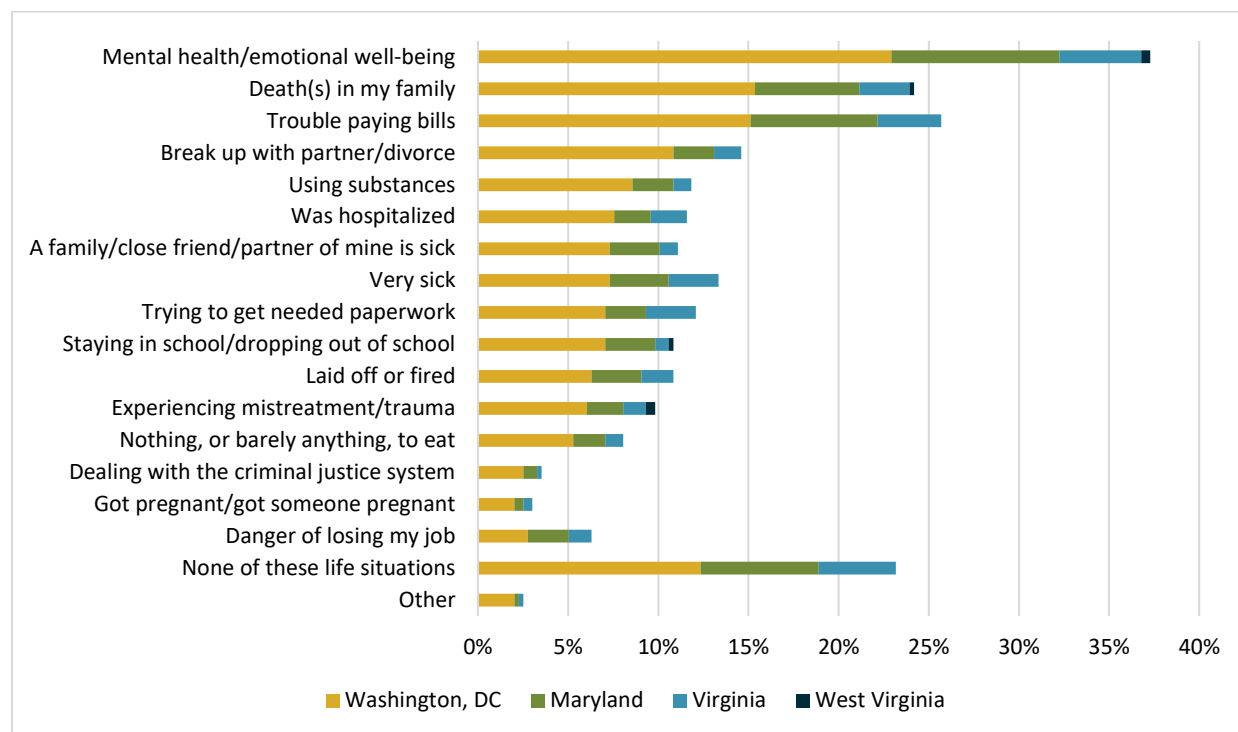
Living Environment and Social Support

Most respondents (241 of 404 [59.8%]) reported living in a house, apartment, or condo which they rented and approximately 1 out of every 5 respondents (79 of 404 [19.6%]) owned their homes. Nearly 8% (31 of 404) reported living in a house, apartment, or condo they got through federal housing assistance. Housing instability was reported to be a challenge, with 11.1% (45 of 404) of respondents living temporarily with friends or family, in a homeless shelter, anywhere outside, and in a motel/hotel. While responses were consistent across jurisdictions, respondents from the District of Columbia were less likely to live in a house, apartment, or condo that they owned (35 of 231 [15.2%]) compared with other jurisdictions.[§] Nearly all respondents (347 of 401 [86.5%]) have been in the living situation for more than three months.

Most respondents (328 of 403 [81.4%]) reported they had never been incarcerated. Of the 63 respondents who identified that they had been incarcerated, over half (42 [66.7%]) had been incarcerated more than five years ago.

While over half of respondents (265 of 406 [65.3%]) did not receive any late notices for unpaid utility in the past three months, over a quarter (104 of 400 [26%]) reported having trouble paying their bills. Respondents frequently cited life situations including having a death in the family (96 of 400 [24%]) and mental health issues (151 of 400 [37.8%]) as challenges they faced over the last 12 months. Figure 2. Displays the challenges respondents experienced over the past 12 months by the percentage of the total number of observations.

Figure 2. Life Situations of Respondents in the Past 12 Months, 2022-2023



While responses were consistent across jurisdictions, Virginia respondents (11 of 63 [17.5%]) were less likely to have had a death in the family, and West Virginia respondents (2 of 3 [66.7%]) were more likely to have suffered from mental health issues over the last 12 months.⁵ There were no major changes to the challenges of the respondents' life experiences during the COVID-19 pandemic. Respondents from the District of Columbia (48 of 201 [23.9%]) were more likely to have trouble paying their bills during the COVID-19 pandemic than the other jurisdictions.⁵

Of the 394 survey responses, most respondents (354 [90.1%]) reported having a social support system in place. These included the ability to rely on family (282 [71.6%]), friends (242 [61.4%]), service providers (84 [21.3%]), support groups (58 [14.7%]), and spiritual advisors (57 [14.5%]). However, nearly 10% (39) of respondents disclosed they lacked a support system. Respondents from the District of Columbia (55 of 224 [24.6%]) were more likely to rely on service providers for support compared to the other jurisdictions; there were no responses from West Virginia for service providers.⁵

Work and Finance

Over half of respondents reported being employed full-time (190 of 391 [48.6%]) or part-time (49 of 391 [12.5%]), with most respondents being employed in the District of Columbia (162 of 352 [46%]).⁵ Nearly 13% (49 of 391) of respondents reported being disabled and 19.6% (69 of 352) of respondents reported being unemployed.⁶ A large proportion of respondents who live in the District of Columbia also work in DC (126 of 199 [63.3%]).⁵

⁶ Categories for current work status were not mutually exclusive. For instance, a respondent could respond they were both employed full-time and employed part-time.

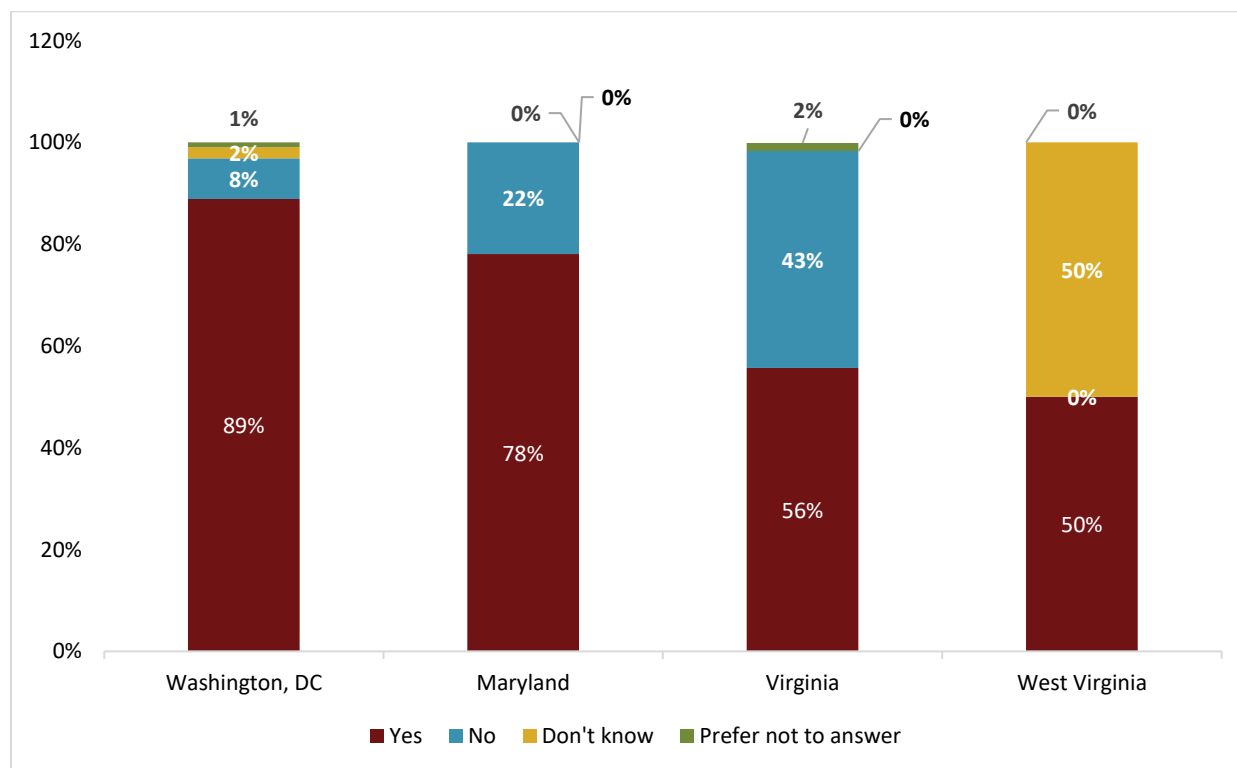
When questioned about finances, most respondents reported their primary source of income being work (243 of 399 [60.9%]). In contrast, 12.3% (49 of 399) of respondents reported having no income source, with more respondents from Virginia reporting no income source (12 of 61 [19.7%]) compared with other jurisdictions.[§] Two of three respondents (66.7%) from West Virginia relied on Supplemental Security Income (SSI) as their primary source of income.

Respondents also reported varying levels of income, with 18% (70 of 389) of respondents earning \$4,000 or more, 16.7% (65 of 389) earning \$499 or less, and 16.5% (64 of 389) earning \$1,000 to \$1,999 in the last 30 days. Virginia had a higher proportion (19 of 61 [31.1%]) of respondents who reported earning \$499 or less and a lower proportion (8 of 61 [13.1%]) earning \$4,000 or more.[§] There were mixed responses on the impact of COVID-19 and income, with 42.6% (166 of 390) reporting their income had not been impacted and 31.3% (122 of 390) reporting an income decrease due to the pandemic. Virginia respondents were more likely (27 of 59 [45.8%]) to report an income decrease due to COVID-19.[§] When questioned about how their income had been impacted, most respondents reported a decrease in income due to job loss or decreased working hours, while some cited a decrease in food stamps.

Insurance and Care

The majority of respondents reported having health insurance coverage (321 of 396 [81.1%]), with 88.9% (201 of 226) from the District of Columbia, 78.1% (75 of 96) from Maryland, and 55.7% (34 of 61) from Virginia.[§] Virginia had a higher proportion (26 of 61 [42.6%]) of respondents who did not have insurance.[§] Figure 3. shows respondents' health insurance coverage by jurisdiction.

Figure 3. Health Insurance Coverage by Jurisdiction, 2022-2023



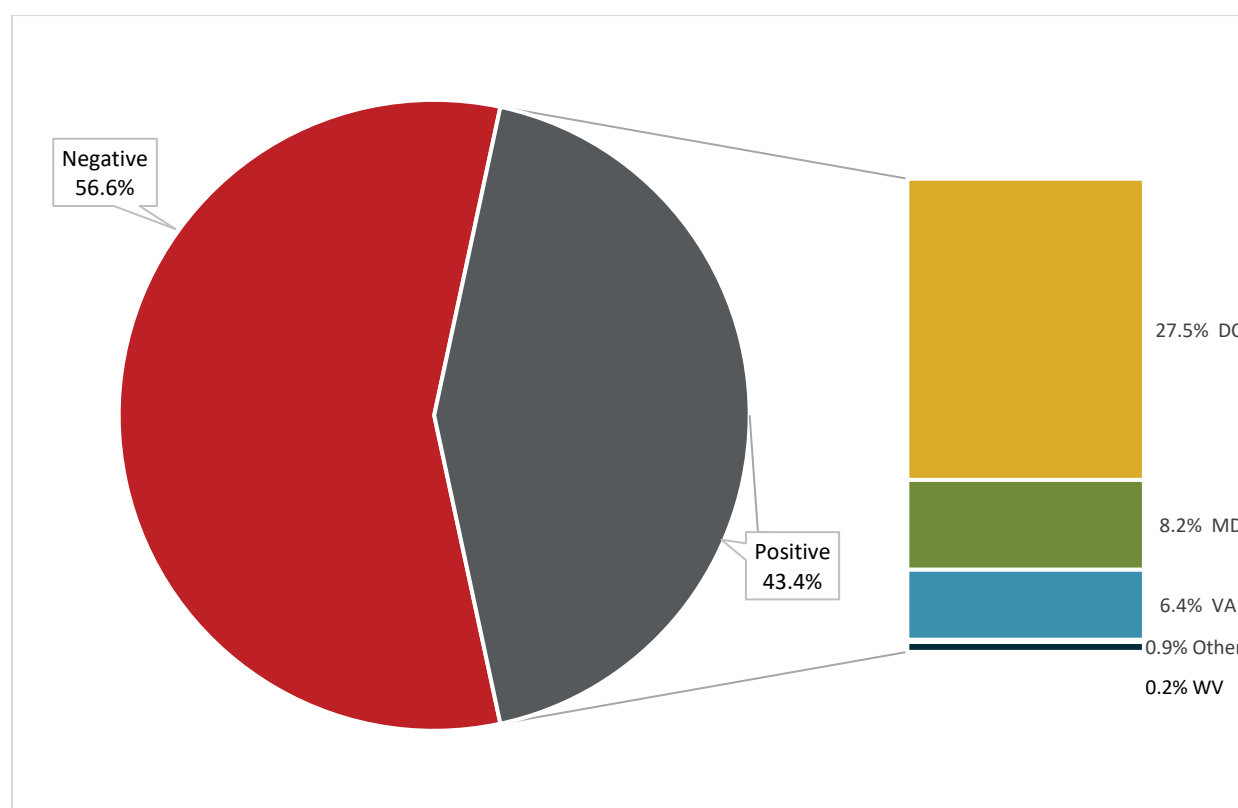
About half of respondents (143 of 313 [45.7%]) are insured by Medicaid, while a third (108 of 313 [34.5%]) are insured by private, employer-sponsored coverage. A higher percentage of respondents

from the District of Columbia are covered under Medicaid (100 of 197 [50.8%])[§] than other jurisdictions likely due to its generous Medicaid eligibility threshold. Maryland had a higher proportion of respondents (31 of 71 [43.7%]) who had private, employer sponsored coverage than other jurisdictions.[§] Two out of three consumers felt that their insurance coverage was affordable (214 of 316 [67.7%]).

HIV Status

A nearly equal proportion of respondents reported being HIV negative (243 of 429 [56.6%]) or positive (186 of 429 [43.4%]). While 52.4% (129 of 246) of respondents from the District of Columbia stated they were HIV negative, DC had a higher proportion of HIV positive respondents (117 of 184 [63.6%]) than Maryland (35 of 184 [19.0%]), Virginia (27 of 184 [14.7%]), West Virginia (1 of 3 [0.5%]), and those living outside the DC EMA (4 of 184 [2.1%]).[§] HIV disproportionately affect Black, not Hispanic in the District of Columbia (85 of 113 [75.2%])[†] and Maryland (26 of 34 [76.5%]), and Latino/a or Hispanic in Virginia (14 of 27 [51.9%]). Figure 4. shows the distribution of HIV status of respondents and the jurisdictional proportions for HIV-positive respondents based on the percentage of the total.

Figure 4. Distribution of Respondents' HIV Status, 2022-2023^a



^aDC represents Washington, DC; MD represents Maryland; VA represents Virginia; Other represents respondents who reside outside of the DC EMA; WV represents West Virginia

Sixty-two of 182 respondents (34.1%) have lived with HIV for more than 20 years, 49 of 182 respondents (26.9%) for 11 to 20 years, 34 of 182 (18.7%) for 6-10 years, and 25 of 182 (13.7%) for 1-5 years. There was some variability at the jurisdictional level, with 37.1% (13 of 35) of Maryland respondents and 37.6% (44 of 117) of District of Columbia respondents reporting living with HIV for 11-20 years, and 36% (9 of 25) of Virginia respondents reporting living with HIV for more than 20 years.[§] Black, not Hispanic represented the highest proportion of those living 11-20 years (38 of 47 [80.9%]) and more than 20

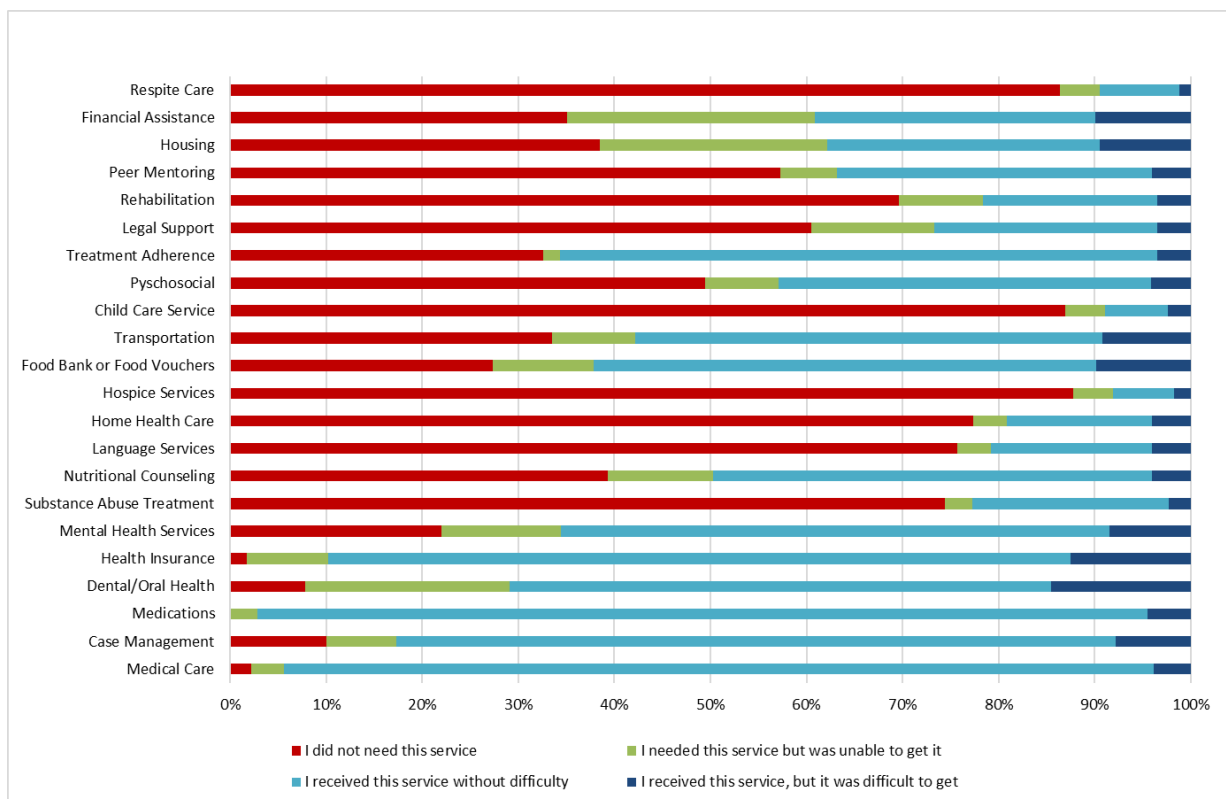
years (39 of 61 [63.9%]) with HIV.[§] Approximately 73% of respondents who were 65 years and over (16 of 22) and nearly half of 55-64 year olds (23 of 48 [47.9%]) have been living with HIV for more than 20 years.

People living with HIV between the ages 55 and 64 were the largest age group of respondents living with HIV (48 of 170 [28.2%]) followed by those ages 35 to 44 (33 of 170 [19.4%], ages 45 to 54 (30 of 170 [17.6%]), 25 to 34 (28 of 170 [16.5%]), 65 and older (22 of 170 [12.9%]), and ages 18-24 (9 of 170 [5.3%]). People living with HIV for longer tended to be older, however, there were still 10 respondents between the ages of 18 and 34 who reported living with HIV for 11 to 20+ years.

Service Utilization

Respondents were asked to rank the ease with which they were able to receive care across 22 service areas. Figure 5. shows the met and unmet needs of respondents.

Figure 5. Met and Unmet Needs, 2022-2023

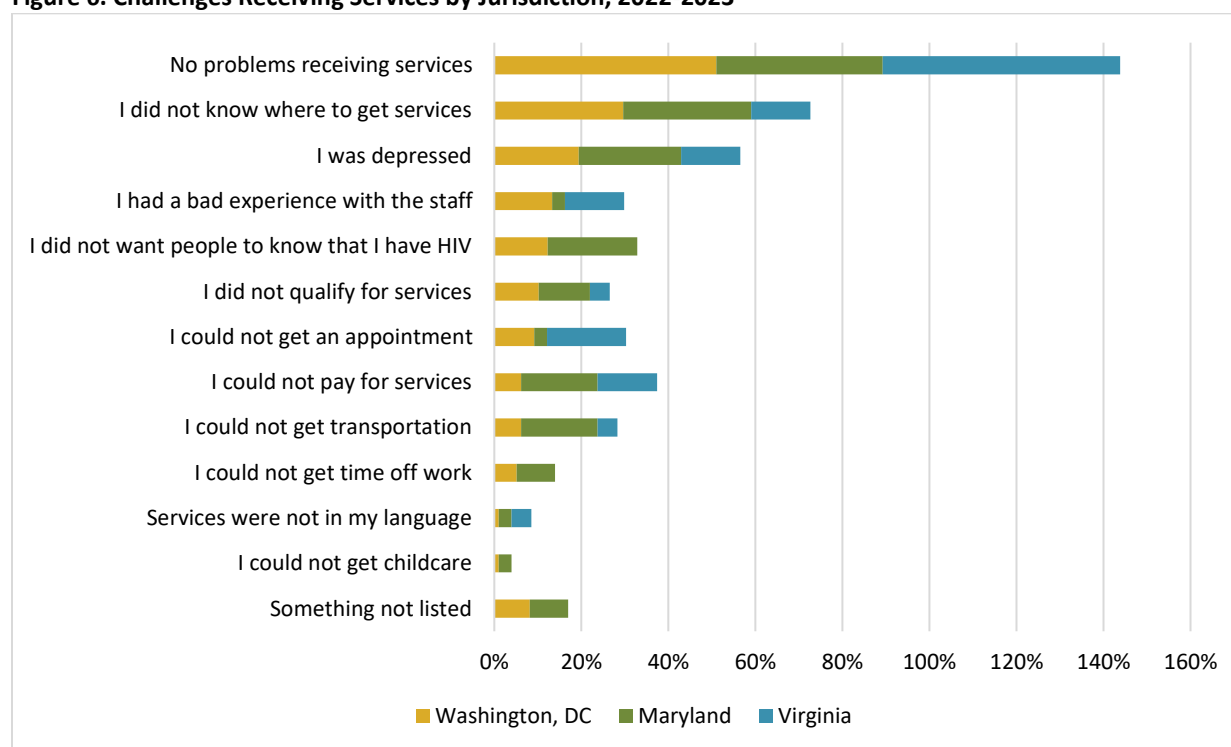


Respondents reported receiving medication services (165 of 178 [92.7%]), health insurance (136 of 176 [77.3%]), case management (134 of 179 [74.9%]), and medical care (163 of 180 [90.6%]) without difficulty. Unmet needs were reported to be low with some services received, but difficult to get, including dental/oral health services (26 of 179 [14.5%]), health insurance (22 of 176 [12.5%]), food bank vouchers (17 of 172 [9.9%]), and transportation services (16 of 173 [9.2%]). Financial assistance (44 of 171 [25.7%]), housing (40 of 169 [23.7%]), and dental/oral health services (38 of 179 [21.2%]) were needed, but not received by respondents. Maryland respondents were more likely to report needing financial assistance (15 of 34 [44.1%])[†] and housing (11 of 33 [33.3%]) but were unable to get the

services. Respondents from Virginia (8 of 26 [30.8%]) were more likely to need dental/oral health services but were unable to get them than other jurisdictions.[†] Respondents specifically listed grief counseling and wellness services as service areas that they needed but were unable to get. Respite care (146 of 169 [86.4%]), rehabilitation (119 of 171 [69.6%]), childcare (146 of 168 [86.9%]), hospice (151 of 172 [87.8%]), home health care (133 of 172 [77.3%]), language services (131 of 173 [75.7%]), and substance abuse services (131 of 176 [74.4%]) were identified as not needed by respondents.

When HIV-positive respondents across the DC EMA were asked about the reasons why they did not access a specific service related to HIV, 27.7% (44 of 159) reported it was because they did not know where to obtain the service they required. Virginia had the lowest proportion of respondents (3 of 22 [13.6%]) who did not know where to get services. Approximately 12.6% (20 of 159) of respondents did not want people to know about their HIV status, with Maryland respondents more likely to report not wanting other people to know (7 of 34 [20.6%]).[§] Mental health played a role in service utilization as well, with 19.5% (31 of 159) respondents stating that their depression prevented them from accessing the services. Figure 6. summarizes the challenges causing people to not have access to services by jurisdiction.

Figure 6. Challenges Receiving Services by Jurisdiction, 2022-2023^a



^aNo responses were received from West Virginia

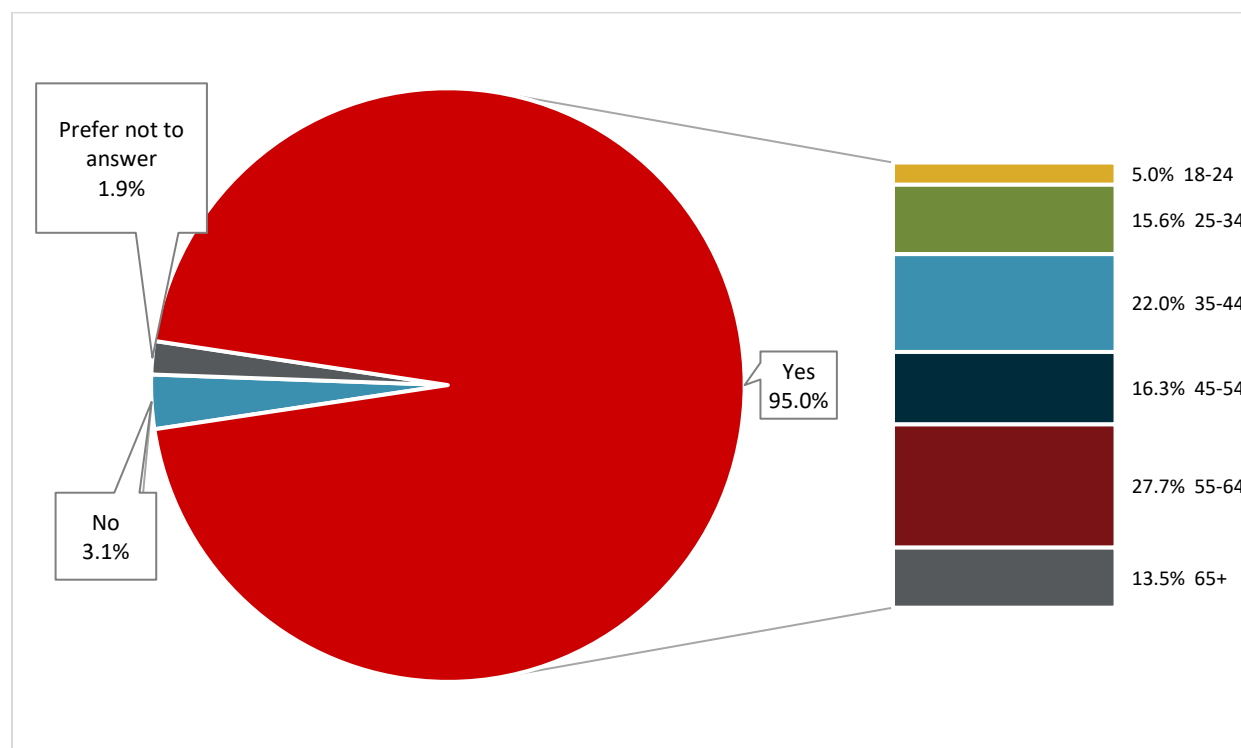
HIV Treatment and Prevention

For respondents living with HIV, adherence to the continuum of care was reported to be high with respondents engaged in care, retained in care, and adhering to antiretroviral therapy. HIV-positive respondents reported that within the last six months, they have seen their medical provider for HIV treatment (144 of 161 [89.4%]), seen their case manager (94 of 158 [59.5%]), and were informed of their viral load count (141 of 160 [88.1%]). Respondents have also been taking ART (152 of 160 [95.0%]) and are virally undetectable (130 of 162 [80.2%]). Three out of every four HIV-positive respondents reported

taking their ART medication all of the time over the last 30 days (120 of 159 [75.5%]) and another 15.1% (24 of 159) reported taking their ART medication most of the time over the same period. Among the consumers who have not taken ART consistently in the last 30 days, missed dosage was due to forgetfulness (41 of 82 [50.0%]).

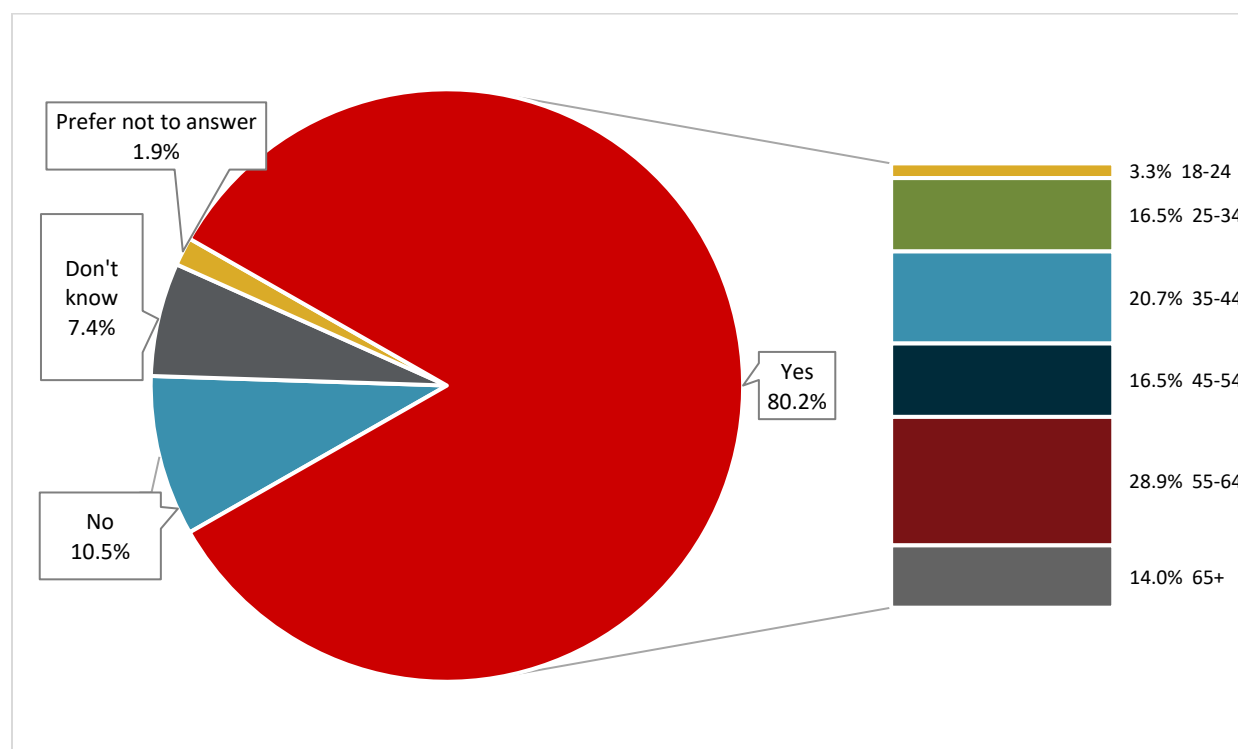
ART adherence across jurisdictions by race and/or ethnicity was relatively consistent with 81.3% (26 of 32) of Black, not Hispanic respondents currently taking ART in Maryland^s and 79.6% (74 of 93) of Black, not Hispanic respondents in the District of Columbia taking ART[†]. Of the 21 Latino/a or Hispanic respondents currently taking ART, 61.9% (13) were from Virginia. Figure 7. shows the breakdown of respondents taking ART by age group.

Figure 7. Respondents' Taking ART by Age Group, 2022-2023



A similar pattern for nondetectable levels of HIV viral load was observed across jurisdictions as well. Nearly 83% (24 of 29) of Black, not Hispanic respondents in Maryland reported being virally undetectable and 77.2% (61 of 79) of Black, not Hispanic respondents in the District of Columbia reported being virally undetectable. Of the 18 Latino/a or Hispanic who are virally undetectable, 61.1% (11) were from Virginia. Figure 8. shows the breakdown of respondents who are virally undetectable by age group.

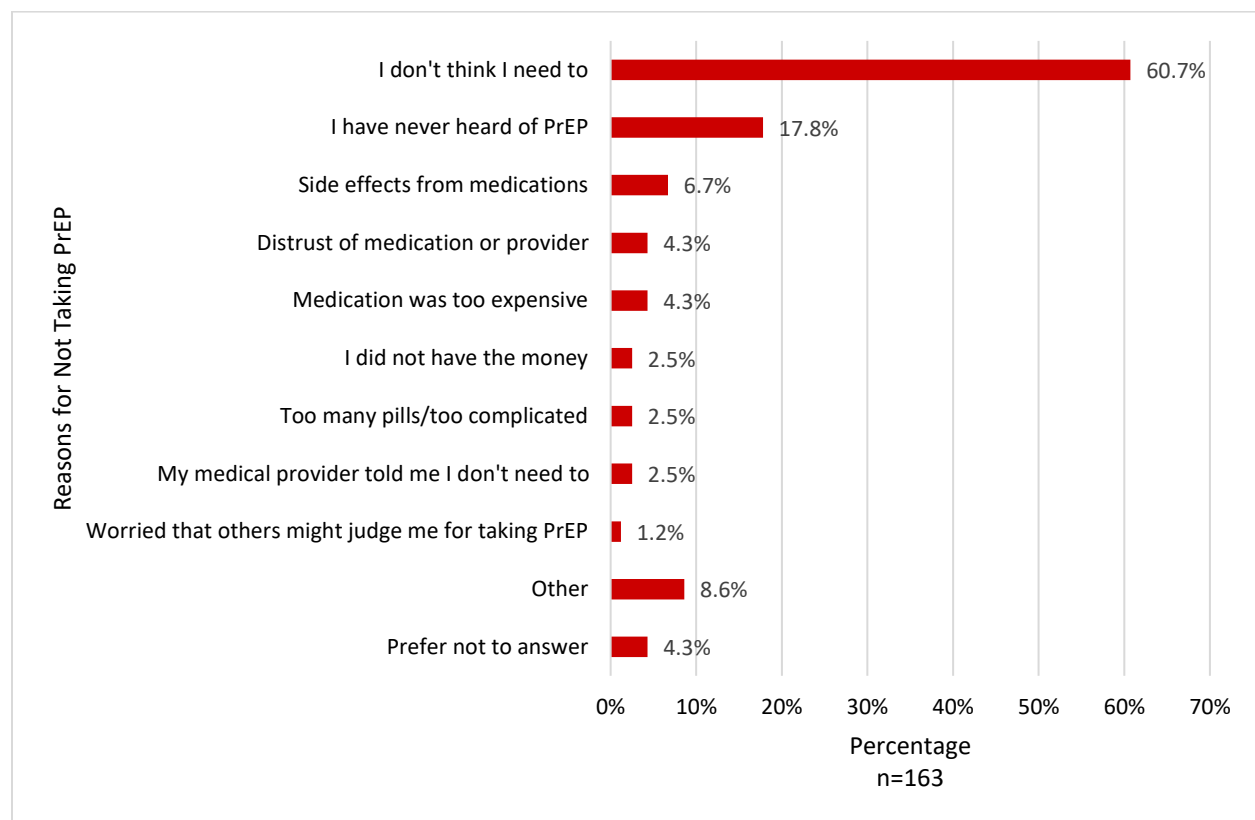
Figure 8. Virally Undetectable by Age Group, 2022-2023



For HIV-negative respondents, 59.4% (133 of 224) have seen their medical provider or doctor for HIV prevention services within the last six months and 17% (38 of 224) have never seen a medical provider for HIV prevention services. Over half (13 of 20 [65.0%]) of respondents felt that they were not at risk of getting infected. One out of every 5 HIV-negative respondents (43 of 225 [19.1%]) currently take pre-exposure prophylaxis (PrEP) medication. Of those who reported taking PrEP, 69.8% (30 of 43) reported taking their PrEP medication all of the time and 23.3% (10 of 43) reported taking their PrEP medication most of the time. The highest proportion of respondents taking PrEP were from the 25-34 age group across jurisdictions. An equal proportion of Black, not Hispanic, and White, not Hispanic in the District of Columbia reported they are currently taking PrEP (11 of 31 [35.5%]).[†] Black, not Hispanic had the highest proportion of people who are not currently taking PrEP in the District of Columbia (52/83 [62.7%])[†] and Maryland (29 of 42 [69%]). All respondents 100% (37 of 37) from Virginia reported not taking PrEP.[§]

Among the reasons that consumers do not use PrEP, 60.7% (99 of 163) reported that they do not believe they need to, 17.8% (29 of 163) have never heard of PrEP and 6.7% (11 of 163) were concerned about side effects from the medication. Figure 9. displays respondents' reasons for not taking PrEP.

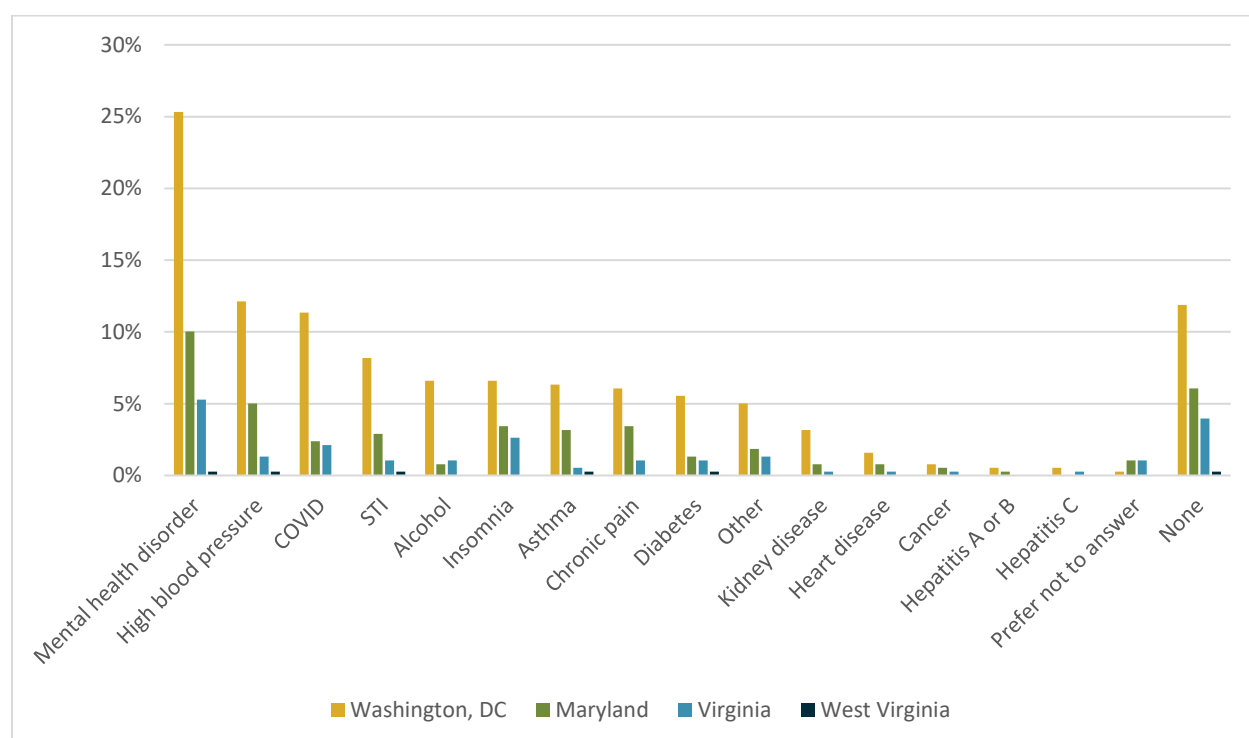
Figure 9. Reasons for Not Taking PrEP, 2022-2023



Other Health Conditions and Substance Use

Among the responses received, many of the respondents experienced several health conditions over the past 12 months of taking the survey. Of these health conditions, the most common condition participants reported was mental health disorder (157 of 381 [41.2%]). Over 19% (73 of 381) indicated high blood pressure and nearly 16% indicated COVID-19 as other areas of struggle over the past 12 months. When prompted, respondents entered monkeypox, surgery, and broken ligaments as other conditions. While the distributions were consistent across jurisdictions, the respondents from the District of Columbia were more likely to have been dealing with COVID-19 over the past 12 months.[§] Figure 10. displays the health conditions by jurisdiction.

Figure 10. Other Health Conditions by Jurisdiction, 2022-2023^a



^aSTI refers to sexually transmitted infections

In the past 12 months, 59.3% (211 of 356) of respondents received care and/or treatment for the selected health conditions. Of these health conditions, the primary conditions that were cared for and/or treated were mental health disorders (104 of 204 [51.0%]), high blood pressure (50 of 204 [24.5%]), and sexually transmitted infections (41 of 204 [20.1%]). Respondents indicated similar other conditions not listed when prompted, including Monkeypox. Across the jurisdictions, Maryland respondents were more likely to have been cared for and/or treated for a mental health disorder (31 of 46 [67.4%]) and asthma (11 of 46 [23.9%]), and the District of Columbia respondents were more likely to have been cared for and/or treated for COVID-19 (27 of 125 [21.6%]).[§]

In addition to mental health issues, 31.9% (122 of 383) of respondents reported using tobacco or nicotine-based products and 32.3% (120 of 372) reported using Marijuana or hashish. Alcohol consumption was commonly reported at a frequency of 2-4 times a month (94 of 381 [24.7%]) or monthly or less (91 of 381 [23.9%]). Nearly 1 of 5 respondents (70 of 383 [18.3%]) reported having a substance use addiction and had received treatment (69 of 381 [18.1%]).

Transgender Services, Health Care and Access to Services

Transgender services were not widely used by respondents with 3.2% (12 of 373) indicating seeking gender-affirming care, 66.7% (8 of 12) successfully accessing care, and 75% (6 of 8) currently taking hormones. Responses to accessing care and taking hormones survey questions were from respondents in the District of Columbia and Virginia.

Respondents were asked about their usual source of health care and an indication of whether their usual place met their needs. For annual check-ups and wellness visits, consumers primarily go to a private medical provider's office (131 of 372 [35.2%]) and community health centers (95 of 372 [25.5%]).

Respondents predominately visited facilities located in the District of Columbia (193 of 330 [58.5%]) and Maryland (77 of 330 [23.3%]). The majority of respondents (288 of 330 [87.3%]) were satisfied with the services they received from their usual place of care for annual check-ups and wellness visits. When sick, consumers sought care from a private medical provider's office (89 of 377 [23.6%]), a community health center (64 of 377 [17%]), or an urgent care facility (62 of 377 [16.4%]). Respondents seeking medical care when sick primarily visited facilities in the District of Columbia (180 of 327 [55%]) and Maryland (87 of 327 [26.6%]). The majority of respondents (286 of 323 [88.5%]) were satisfied with the services they received for sick care and did not experience any challenges when they wanted to see a medical provider (186 of 373 [49.9%]). Measures of consumer-provider encounters were also included in the survey. Respondents reported high levels of comfort talking about sexual health (246 of 380 [64.7%]), feeling cared for (261 of 377 [69.2%]), listened to (263 of 376 [69.9%]), and not stigmatized (269 of 374 [71.9%]).

COVID-19 variably affected healthcare access, with most respondents (179 of 367 [48.8%]) reporting their healthcare access was not affected, 20.4% (75 of 367) reporting a neutral impact, and 30.8% (113 of 367) reporting a negative effect.

DISCUSSION

This study was the first status neutral consumer needs assessment fielded in the DC EMA. It was successful in surveying the needs of both people living with, and behaviorally vulnerable to HIV; just over half of respondents (56.6%) reported they were HIV-negative. While biological factors contribute, HIV transmission is underpinned by the social determinants of health or the conditions in the environments where people are born, live, learn, work, play, worship, and age.⁷ Recognizing the role of these social factors in perpetuating health conditions, including the risk of HIV, is imperative for public health stakeholders in ending the HIV epidemic. Therefore, elevating consumer voices of both those living with HIV as well as those who are behaviorally vulnerable to HIV is essential to maintain viral suppression and prevent HIV acquisition.

The DC EMA survey findings suggest that most respondents living with HIV reside in the District of Columbia. This may be due to a higher respondent rate from the District of Columbia than in other jurisdictions, but it is consistent with jurisdictional annual surveillance reports suggesting a plurality of people living with HIV in the DC EMA (45%) live in DC.⁸ Accordingly, efforts to address HIV in the region must emphasize the impact HIV has on District residents.

Overall, Black, not Hispanic respondents are disproportionately affected by HIV, largely influenced by the disproportionate burden Black individuals bear in DC and Maryland. Virginia respondents with HIV were more likely to be Latino/a or Hispanic than in other jurisdictions. These survey findings are also relatively consistent with epidemiological findings across the EMA that suggest Black individuals have the highest HIV burden overall carried largely by the majority of people living with HIV identifying as

⁷Sprague C, Simon SE. Ending HIV in the USA: integrating social determinants of health. *Lancet*. 2021;398(10302):742-743. doi:10.1016/S0140-6736(21)01236-8

⁸Annual Epidemiology & Surveillance Report: Data Through December 2021. District of Columbia Department of Health, HIV/AIDS, Hepatitis, STI, & TB Administration 2022. Accessed September 6, 2023 at <https://dchealth.dc.gov/service/hiv-reports-and-publications>

Black in DC (68%), Maryland (75%),⁹ and Virginia (48%)¹⁰. Additionally, surveillance data suggest the highest proportion of people living with HIV who are Latino/a or Hispanic reside in Virginia (18% compared to 9% in DC and 11% in Maryland).^{11,12,13}

Survey responses indicate people living with HIV are older and living with HIV for longer. Approximately one out of every three respondents living with HIV reported they are 20+ year survivors and around one in four reported having HIV for between 11 and 20 years. Additionally, a plurality of respondents were between the ages of 55 and 64 and a majority of respondents were 45 or older. Addressing the needs of older people with HIV is important as more people are aging with HIV and will require healthy aging support, as well as support for comorbidities.

Respondents living with HIV reported high adherence to the continuum of care including around nine out of every 10 respondents living with HIV reported seeing their medical provider within the last six months, knowing their viral load count, and taking ART. Similarly, eight out of every 10 respondents living with HIV reported being virally undetectable. These results suggest that when people living with HIV are engaged in treatment they are generally adherent to this treatment. However, any ART adherence rate of less than 100% is an opportunity for education about the benefits of being undetectable.

In contrast, among HIV-negative respondents, just one out of every five are taking PrEP. PrEP is a medicine that is highly effective for preventing HIV when taken as prescribed. Low uptake of PrEP from respondents due to a lack of perceived risk or awareness of PrEP indicates a greater need for PrEP education. Additionally, there may be possible gaps in HIV diagnosis among self-reported HIV-negative respondents (i.e. people who report being HIV-negative may be HIV-positive but lack a diagnosis). Further education on HIV testing and the rest of the care continuum could identify such individuals.

Respondents living with HIV reported difficulty accessing needed services like dental care, financial assistance, and housing services. They also reported dealing with mental health conditions, high blood pressure, and COVID. One in three said their needs were unmet because they did not know how or where to access these services.

Respondents, both living with and behaviorally vulnerable to HIV reported co-occurring mental health conditions most often when asked what other health conditions they had. Addressing mental health

⁹ Maryland Annual HIV Epidemiological Profile 2021. Center for HIV Surveillance, Epidemiology and Evaluation, Maryland Department of Health, Baltimore, MD. 2022. Accessed September 8, 2023 at <https://health.maryland.gov/phpa/OIDEOR/CHSE/SiteAssets/Pages/statistics/Maryland-Annual-HIV-Epidemiological-Profile-2021.pdf>

¹⁰ Virginia HIV Surveillance Annual Report. Virginia Department of Health. 2023. Accessed September 11, 2023 at https://www.vdh.virginia.gov/content/uploads/sites/10/2023/07/VDH_HIV-Surveillance_Annual-Report_2022.pdf

¹¹ Annual Epidemiology & Surveillance Report: Data Through December 2021. District of Columbia Department of Health, HIV/AIDS, Hepatitis, STI, & TB Administration 2022. Accessed September 6, 2023 at <https://dchealth.dc.gov/service/hiv-reports-and-publications>

¹² Maryland Annual HIV Epidemiological Profile 2021. Center for HIV Surveillance, Epidemiology and Evaluation, Maryland Department of Health, Baltimore, MD. 2022. Accessed September 8, 2023 at <https://health.maryland.gov/phpa/OIDEOR/CHSE/SiteAssets/Pages/statistics/Maryland-Annual-HIV-Epidemiological-Profile-2021.pdf>

¹³ Virginia HIV Surveillance Annual Report. Virginia Department of Health. 2023. Accessed September 11, 2023 at https://www.vdh.virginia.gov/content/uploads/sites/10/2023/07/VDH_HIV-Surveillance_Annual-Report_2022.pdf

needs is especially relevant for HIV prevention efforts as research suggests mental health conditions may increase the likelihood of personal HIV acquisition or putting others at risk for HIV acquisition through risk behavior or poor ART adherence.¹⁴ While the survey did not ask specifically about the utilization of syringe services programs, unsafe injection practices are not the sole SUD-related risk factor affecting HIV acquisition; substance use may also affect judgment and inhibition that can lead to people engaging in risk behaviors that make them more vulnerable to acquiring HIV.¹⁵ While few respondents reported needing substance use disorder treatment services, it is possible respondents who meet clinical criteria for substance use disorder have not received a diagnosis yet and thus have not sought out necessary treatment. Accordingly, ensuring access to SUD treatment is a major component of HIV prevention for those in need of it.

Stigma surrounding HIV impacts the mental health of those living with HIV as well.¹⁶ While most respondents reported high comfort levels talking about sexual health; feeling cared for, and listened to; and not stigmatized, approximately 30% of respondents reported neutral or unfavorable experiences. DC Health cannot address the stigma associated with HIV alone but can participate in cross-departmental and cross-jurisdictional efforts to provide more education about HIV that is destigmatizing.

Recommendations

The findings from this study identified five key recommendations to support consumers' care and service needs regarding HIV and overall health:

Survey refinement. To increase participation, consider modifying the survey. Participation rates may have been impacted by factors including survey length (68 questions), duration (15-20 minutes), salience (the importance or current relevance of questions), and complexity (sentences with too many clauses or unusual constructs). Survey data showed that several consumers began the survey but did not continue past the demographic section.

Taking inventory. The first step in addressing consumer needs is taking inventory of what services already exist. Creating inventories of available services and making sure that all providers and/or case managers working across the healthcare and social safety net systems have sufficient knowledge of available services may help connect people living with HIV to critical support services. Additionally, allocating more resources to areas with greater unmet needs may assist in expanding the impact of these services.

Target efforts. Targeted efforts to improve consumer-provider interactions may also help reduce stigma, racial disparities, and the needs of people aging with HIV in care as well. Broadly, future planning could include provider and consumer education to increase awareness of free or low-cost services,

¹⁴ Walkup, J., Blank, M. B., Gonzalez, J. S., Safren, S., Schwartz, R., Brown, L., ... & Schumacher, J. E. (2008). The impact of mental health and substance abuse factors on HIV prevention and treatment. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 47, S15-S19.

¹⁵ National Institute on Drug Abuse. Common Comorbidities with Substance Use Disorders Research Report. Part 3: The Connection between Substance Use Disorders and HIV. 2021. Accessed September 11, 2023 at <https://nida.nih.gov/publications/research-reports/common-comorbidities-substance-use-disorders/part-3-connection-between-substance-use-disorders-hiv>

¹⁶ Walkup, J., Blank, M. B., Gonzalez, J. S., Safren, S., Schwartz, R., Brown, L., ... & Schumacher, J. E. (2008). The impact of mental health and substance abuse factors on HIV prevention and treatment. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 47, S15-S19.

improve consumer satisfaction with service providers, and reduce HIV disparities for people living with or behaviorally vulnerable to HIV.

Joint needs assessment. Because of the cross-jurisdictional nature of the DC EMA, there have been some very preliminary discussions about fielding a joint consumer needs assessment across the entirety of DC, Maryland, and Virginia. Many of the questions asked of consumers across jurisdictions remain similar if not identical. A coordinated consumer needs assessment that includes multiple EMAs (DC and Baltimore) as well as additional counties in Maryland and Virginia would likely require strong data-sharing agreements and heightened cross-jurisdictional cooperation. These hurdles are likely worth the benefit of collecting similar data across EMAs and larger jurisdictions to better compare the efficacy of and coordinate efforts to address the needs of people living with and behaviorally vulnerable to HIV in the region. Jurisdictions should also have the flexibility to include questions in their consumer needs assessments that address the specific goals of their Integrated Plans, which this arrangement would not preclude them from doing.

Field topic-specific surveys. There are statutory requirements for EMAs to field consumer needs assessment once every 3 years. However, EMAs may field consumer needs assessments more frequently. Stakeholders in the DC EMA have discussed fielding smaller, more targeted consumer needs assessments to collect more information about specific areas of need (i.e. housing, financial services) or specific priority populations (i.e. older adults, heterosexual men) between the gap period of the next full consumer needs assessment to gain insights from these efforts to inform programming and future needs assessments.

Limitations

There were several limitations to the generalizability of these findings beyond the technological and logistical challenges of fielding the survey. Although convenience sampling was used and student investigators facilitated data quality and survey completion, the relatively small sample size from some jurisdictions may have led to a sample that is not representative of the population and few of the findings have enough power to be statistically significant. Even findings that have p-values suggesting statistical significance suffer from a majority of the cells under analysis containing fewer than five respondents. These small cell sizes call into question the validity of statistical tests with statistically significant p-values and forced researchers to be conservative in identifying results of statistical significance.

Many of the findings of the consumer needs assessment are consistent with jurisdictional surveillance data which suggests at least some external validity/generalizability. Nevertheless, given the lack of statistical significance and/or sample power for most of the analyses conducted, results of the consumer needs assessment do not indicate any changes in priorities to the 2022-2026 DC EMA Integrated HIV Prevention and Care Plan (DC EMA Integrated Plan) are necessary in the Integrated plan resubmission.

Further, the response burden due to survey length impeded survey participation since the survey tried to capture status neutrality across the DC EMA. Balancing the desire to collect as much information on consumer needs as possible while keeping the survey a manageable length was a challenge. Survey designers were intentional about only collecting pertinent information for DC Health to act upon, but future surveys may require additional trimming of survey questions to improve response rates.

Finally, this consumer needs assessment is subject to the same limitations inherent in any consumer needs assessment: 1) self-reporting bias, 2) selection bias, and 3) recall bias. Respondents who have not

been diagnosed with HIV—or one of the other physical or behavioral health conditions asked in the survey—will likely not report that they need certain services because they are unaware of their need. Self-report bias is a common problem in most observational research study designs. Respondents may not always know what they need and thus cannot express those needs.

Like self-reporting bias, selection bias may have underestimated consumer needs in the DC EMA because the needs assessment recruited participants directly from provider clinics. Respondents who are engaged in care likely have different needs than those who are not engaged in care. Consequently, the consumer needs assessment may have not captured the needs of potential respondents who did not go to a provider clinic or seek care during the study.

Recall bias may have occurred since several survey questions asked respondents to recall past events or experiences. Respondents may have erroneously responded depending on their ability to recall the information. Recall bias may have occurred on questions relating to the length of the recall period (e.g. 12 months, more than a year) and perception of past experiences (e.g. service utilization, barriers to medication adherence).

CONCLUSION

Despite the challenges in fielding the survey, the 2022-2023 DC EMA Consumer Status Neutral Needs Assessment reinforced many of the needs and priority populations identified by surveillance data and prioritized by the DC EMA Integrated Plan. The cross-jurisdictional consumer needs include 1) education to reduce HIV stigma and HIV-related behaviors, 2) education to prevent the spread of sexually transmitted infections, 3) improvement of youth-focused efforts to prevent HIV, 4) engagement with young people in youth programming, 5) increased PrEP/PEP programming, and 6) increased wellness support. While not explicitly prioritized, aging services and models of care for older adults are needed considerations to ensure that people are not just living longer with HIV but are living better. The survey findings provide a part of the HIV DC EMA landscape but in combination with surveillance data, the HIV epidemic in the DC EMA is concentrated in key population groups including Black and Latino MSM, Black heterosexual men, and women, people who inject drugs, transgender individuals, and youth 13-24.

Ultimately, the 2022-2023 DC EMA Consumer Needs Assessment has established a solid framework, both for addressing needs in the DC EMA and fielding future needs assessments.

ACKNOWLEDGMENTS

The authors wish to thank the COHAH Research and Evaluation Committee for their support and development of the needs assessment survey. We are especially grateful to Alan Johnson, MPH for his outstanding guidance and efforts on the first phase of the study. This formal investigation is largely due to his invaluable participation. We would like to acknowledge the DC EMA provider clinics for their tireless efforts in survey recruitment, especially the DC Health and Wellness Center, Children's National Hospital, NovaSalud, Inc., Montgomery County Department of Health and Human Services, and AIDS Healthcare Foundation who hosted the student investigators to facilitate survey completion. The authors also wish to thank Alyssa Conde, Jennifer Conflitti, Shawn Leavey, and Sierra Cary-Brown for assisting with the recruitment efforts in phase one. Provider clinics and student investigators were not compensated for their time.