

**2015  
Rhode Island  
Executive Office of Health and Human Services  
Ryan White Consumer Survey**

**The Division of Medicaid, HIV Provision of Care Unit at the Executive Office of Health & Human Services (EOHHS)**

**Survey Developed and Analyzed by:  
John Snow, Inc.**

**June 2016**



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## Executive Summary

This survey of people living with HIV/AIDS (PLWHA) who access care services in Rhode Island was undertaken by the Rhode Island Executive Office of Health and Human Services, Medicaid Division, HIV Provision of Care & Special Populations Unit (EOHHS) through a contract with John Snow, Inc. (JSI).

The goals of the survey effort were to (1) assess service utilization, barriers to care, needs that are not being met by current services, and risk and prevention behavior and (2) determine social, demographic, and economic characteristics of PLWHA which might contribute to their risk for lack of healthcare access and poor health outcomes.

A strong aspiration towards health equity deeply informed survey development and analysis. The focus on social determinants of health aims to empower HIV care and prevention programs in Rhode Island to be able to precisely target their approach towards the populations in greatest need. It is important to not only know *what* barriers to care exist but also *who* is at greatest risk for being impacted by them.

The following summarizes six key findings and strategic recommendations.

### Key Findings

- Health disparities by racial, social, and economic categories among PLWHA were a strong theme throughout nearly all of the results from the survey.
- Heterosexual women with HIV may be an underemphasized subpopulation of PLWHA in RI.
- While substance use issues impact a small subset of the overall PLWHA in RI, those with substance use were significantly less likely to report always taking their medication as prescribed and being virally suppressed.
- Depression and other mental health issues are the most commonly reported medical or personal issues that PLWHA in RI face in addition to HIV. Over half of this survey's respondents reported needing mental health services.
- Case managers represent a great opportunity to help consumers access the medical and support services they need, especially mental health and substance use services. The results of this survey did not show significant health process and outcomes differences between those respondents that have a case manager and those that do not. This is likely due to inconsistency among case managers across agencies and individuals.
- In most areas, gay men (men who have sex with men—MSM) are performing as well or better than straight men in terms of economic social determinants of health, health processes, and health outcomes. This speaks to the continued success of prevention, outreach, and care programs that focus specifically on the MSM population.

### Strategic Recommendations

- HIV medical and non-medical services, need to be continually evaluated on whether their services are ***easy to find, access, and use*** by impoverished and minority populations.
- Target heterosexual women in prevention and care outreach activities.
- Promote coordination between HIV medical providers and substance use treatment centers and recovery clinics, with a particular focus on peer recovery services.
- Better integrate mental health care into HIV medical care by either co-locating mental health services within HIV medical clinics or by ensuring that all patients receive a brief mental health screening with every visit to their HIV medical provider.
- Explore ways make case management services more consistent by identifying and promoting regular professional development and training opportunities, best practices and quality management improvements.
- Continue care, prevention, outreach, and education efforts that target gay men and men who have sex with men.

These survey results provide robust data to support future Ryan White program care planning, improvement, and evaluation activities. Specifically, these data will be used to support Rhode Island's Integrated HIV Prevention and Care Comprehensive Plan, including the Statewide Coordinated Statement of Need, CY 2017-2021. Survey data combined with additional needs assessment results will also be used to inform ongoing program needs.

## Introduction

### Purpose

The Rhode Island Executive Office of Health and Human Services, Medicaid Division, HIV Provision of Care & Special Populations Unit (EOHHS) contracted with John Snow, Inc. (JSI) to implement a survey of people living with HIV/AIDS (PLWHA) who access care services in Rhode Island. The goals were to

- (1) assess service utilization, barriers to care, needs that are not being met by current services, and risk and prevention behavior and
- (2) determine social, demographic, and economic characteristics of PLWHA which might contribute to their risk for lack of healthcare access and poor health outcomes.

The survey was offered to consumers through HIV/AIDS care, treatment, and service agencies contracted with EOHHS, physician practices, and other health and social service agencies that provide services to people living with HIV/AIDS in Rhode Island. The target population for the survey was PLWHA in Rhode Island who are 18 years of age or older.

The consumer survey is part of a broader effort by EOHHS to conduct a needs assessment of PLWHA in Rhode Island. The needs assessment includes the following components:

- Epidemiological profile
- Provider Capacity and Capability Survey
- Consumer Survey
- Focus groups with consumers
- Resource Inventory & Referral Guide

Results from each of these elements will be integrated to provide a better total picture of available resources, barriers to care, HIV epidemiology, and needs in the PLWHA population in Rhode Island. They will also support Rhode Island's *Integrated HIV Prevention and Care Comprehensive Plan*, including the *Statewide Coordinated Statement of Need, CY 2017-2021*, to be submitted to the Centers for Disease Control and Prevention's (CDC) and Health Resources and Services Administration's (HRSA) in September 2016.

## Background

Surveys are a standard research tool used to better understand the experiences of HIV consumers. This survey was designed to evaluate consumer engagement and experiences with care and treatment services, with a focus on the HIV care continuum stages from diagnosis to viral suppression. Its structure allowed for demographic groups to be compared in terms of their likelihood of experiencing specific barriers to care. Thus, the development of the survey tool and resulting analytic approach allows the results to build on our understanding of the impact of social and economic determinants of health and well-being for PLWHA.

The following two subsections provide further explication of the HIV Care Continuum and summarize the literature on social determinants of health in PLWHA.

### *HIV Care Continuum*

The HIV Care Continuum presents an analytic framework for states to use to evaluate their HIV system of care from a population health perspective. It is oriented around the ultimate goal of HIV treatment: viral suppression in the individual, which promotes longevity and quality of life and reduces the likelihood that the individual will transmit the virus to someone else. Achieving viral suppression requires the individual to successfully progress through several steps from being diagnosed, to being connected with an HIV medical provider, to being prescribed the right medications. The continuum was designed to be reflective of that necessary progression towards viral suppression.

The Care Continuum consists of five stages from 'diagnosed' to 'viral suppression' and requires the calculation of the percentage of people living with HIV/AIDS at each stage. The five stages are as follows:

1. **Diagnosed** with HIV infection
2. **Linked to care**, meaning they visited a health care provider within three months after learning they were HIV positive
3. **Engaged or retained in care**, meaning they received medical care for HIV infection
4. **Prescribed antiretroviral therapy** to control their HIV infection
5. **Virally suppressed**, meaning that their HIV viral load – the amount of HIV in the blood – is at a very low level

(Centers for Disease Control and Prevention, 2014)

The continuum is useful in determining at what stage in this progression towards viral suppression consumers are not getting what they need. Are they being diagnosed and not seeing a HIV medical provider within 3 months? Are they seeing an HIV provider but not being prescribed antiretroviral therapy? Or are they not receiving medical care on regularly basis? However, the care continuum by itself does not explore the *how*, the *why*, or the *who* behind the summary statistics at each stage.

For this reason, it is important for assessment of need processes to include research mechanisms that harness the power and insight of the consumer voice. Consumer surveys and focus groups excel at not only uncovering the barriers to care along the continuum but also identifying which demographic groups are most adversely affected.

This survey-based data collection effort was intentionally designed to align with the care continuum. The questions were included to explore the challenges that consumers might face at each stage and were written to be consistent with the operationalization of each metric.

### *Social Determinants of Health*

Social determinants of health (SDH) are “economic and social conditions that influence the health of individuals and communities” (Dean & Fenton, 2013). Inherent to geographic locations and social demographics, they define how physical resources and personal agency are distributed across a population and determine who is subjected to stigma and discrimination. Lack of education, adequate income, or appropriate housing makes it more difficult for individuals to engage in appropriate prevention, health promotion, and self-care activities. The literature clearly demonstrates that educated, resource-rich individuals are more likely to be healthy while the less-educated, resource-poor are more likely to be unhealthy and lack adequate access to healthcare (Abbott & Williams, 2015).

HIV/AIDS is no exception. Its aggressive pathophysiology necessitates complex treatment, regular self-care, and consistent follow-up, making it especially difficult for resource-poor individuals to manage. Not only is it disproportionately present in minority populations such as Latino and Black gay men (i.e. men who have sex with men (MSM)), but those groups also have worse health outcomes when compared to their non-Latino or white peers (Howe et al., 2014; Mugavero et al., 2009; Oster et al., 2013). A primary mechanism for these observed disparities are missed medical visits, which are much higher among black and injection drug use patients and have been statistically shown to account for lack of viral suppression in these populations (Howe et al., 2014; Mugavero et al., 2009; Zinski et al., 2015).

This survey-based data collection effort chose to focus on social determinants of health in an effort to empower HIV care and prevention programs in Rhode Island to be able to precisely target their approach towards the subpopulations in greatest need. It is important to not only know *what* barriers to care exist but also *who* is at greatest risk for being impacted by them. For as history has shown, constant diligence is required to ensure that certain groups do not fall through the cracks while others prosper.

## Methodology

### Survey Administration

#### *Recruitment*

Recruitment took place for approximately two and a half months, starting in mid-November 2015 and ending on January 31, 2016. Recruitment utilized support from HIV/AIDS care, treatment, and service agencies contracted with EOHHS, physician practices, and other health and social service agencies that provide services to PLWHA in Rhode Island. Agency staff and/or case managers at these agencies identified eligible consumers and facilitated their completion of the survey either in person or online.

#### *Survey Distribution and Administration*

The survey was available via paper and online modalities. The paper version was available in both English and Spanish. The online version was available in English only.

Agency staff and/or case managers were given copies of the RI RW HIV Care and Services Consumer Survey and cards printed with the online survey weblink (herein called “weblink cards”). Paper surveys were only administered by agency staff and were completed onsite at the agency. If the respondent preferred to complete the survey offsite, agency staff gave the individual a weblink card with instructions to complete the survey online or allowed the respondent to complete the paper survey offsite and return the completed survey at a later time. Each agency kept completed surveys in a locked cabinet or box. JSI staff picked up completed surveys from each agency on a monthly basis.

#### *Consent process*

Respondents accessing the survey through case managers were verbally consented to participate. Due to the sensitive nature of disclosing one’s HIV status and the field-based aspects of these activities, having written consent forms linking respondents’ names to the purpose of these activities was deemed an unnecessary risk of disclosure of a respondent’s HIV status. Only agency staff consented respondents. IRB-approved consent information was included with the paper and online version of the survey to ensure each respondent:

1. had full understanding of the activities he or she is being asked to participate in;
2. had the ability to ask any clarifying questions regarding these activities; and,
3. was provided with the name and contact information for the JSI Project Associate for these activities.

The IRB-approved consent information included in the online and electronic survey was replicated in the weblink card.



### *Respondent Screening*

Before handing out weblink cards or paper surveys to consumers, agency staff determined whether a respondent was eligible to respond. These questions were asked verbally. Should a respondent screen ineligible to complete the survey, case managers did not administer the survey or handout weblink cards. The questions were as follows. The required response is underlined.

1. Do you live in Rhode Island?
  - Yes
  - No
2. Are you HIV+?
  - Yes
  - No
3. Are you 18 years old or older?
  - Yes
  - No

These questions also appeared in the survey itself.

Case managers also asked respondents if they had taken the survey prior through their case manager or at another agency.

### *Survey Tracking*

All surveys had a unique ID associated with them. This unique ID was numeric and appeared random to the respondent (e.g. "5613906"). It encoded for the survey administration type (electronic vs paper), the distribution point (agency name), and the sequential survey number. JSI maintained a master list of ID numbers, associating each unique ID with the administration type and distribution point. This enabled JSI staff to track the number of respondents resulting from each agency. Unique IDs were not linked with any identifying information from the respondent at any point during the survey administration or analysis process.

All paper surveys were pre-printed with the unique ID on each page. All weblink cards were also pre-printed with unique ID numbers. When a respondent accessed the survey online, he/she was prompted to enter the unique ID. Like with the paper versions, agency staff were responsible for tracking the unique IDs distributed in this way.

Agency staff were responsible for letting JSI staff know if they required additional surveys and weblink cards.

### *Incentives*

Respondents who complete the survey received \$20 gift card to a local grocery chain, Stop & Shop, as a token of appreciation.

Agency staff handed out gifts cards at the completion of the paper survey. Each gift card was recorded on a gift card tracking form that includes the unique survey ID. No contact information

other than the respondent's initials was included on this form. It was not possible to associate contact information with survey responses.

For respondents who complete the survey online, they were directed to a separate online survey to complete contact information for a gift card to be mailed to them. It was not possible to associate online contact information with online survey responses. JSI ensured that individuals did not receive more than one gift card by keeping track of names and addresses in a separate system. JSI mailed incentives (\$20 per response) to the respondents who completed the online survey in a timely manner (e.g. once a month). Agency staff informed respondents of this time frame prior to distributing the card with the online link. Additionally, a description of the process and time frame was included in the introduction page of the online survey.

#### *Data Storage, Analysis, and Usage*

Online surveys were administered through SurveyGizmo in Boulder, CO. See **Appendix ##** for the security information from SurveyGizmo.

All data downloaded from Survey Gizmo was housed at secure, password-protected JSI servers and drives and was accessible only to project staff. All paper surveys were stored in a locked cabinet in a JSI office.

#### *IRB Approval*

The JSI Institutional Review Board (IRB) approved the study design on November 11, 2015 (IRB #15-023). The submission received Expedited Review based on the applicable federal regulation. The IRB specifically considered (i) the risks and anticipated benefits, if any, to subjects; (ii) the selection of subjects; (iii) the procedures for securing and documenting informed consent; (iv) the safety of subjects; and (v) the privacy of subjects and confidentiality of the data.

### **Data Analysis**

#### *Data Entry*

JSI manually entered all returned surveys into the online SurveyGizmo system. For questions that were not answered, JSI selected the "Choose not to answer" response option. This response option was only available on the online version of the survey to promote full responses by respondents on the paper version. If a respondent did not answer one of the three screening questions (Q02, Q03, or Q04), the data entry analysts checked corresponding questions in the survey (Q05 for age, Q10 for RI residence, and Q22 for HIV status). Only if the respondent did not answer both questions was the response excluded. If a respondent selected multiple options for a single-select question, then the first option selected was recorded.

For write-in questions, the data entry analyst transcribed the written text to the best of his/her ability. Incorrectly spelled words were not corrected. All Spanish surveys were entered by an analyst with intermediate Spanish reading skills.

### *Data Cleaning*

All data cleaning was completed in the statistical programming language R. Data was downloaded from SurveyGizmo in the SPSS file format and converted to a data frame in R.

JSI ensured that the same unique ID was not used to take the survey more than once. In the event that the same unique ID was used, only one survey response was included. If one survey was more complete than the other, that survey was used. If both surveys were equally complete, then the first survey was used.

If a respondent selected the “other (please specify)” response option and wrote a response that was consistent with an existing response option, that response was recoded to that response option. The JSI analyst consulted with the broader team to make these determinations.

### *Analysis*

All analyses were completed in the statistical programming language R with use of the dplyr, ggplot2, and rmarkdown packages.

For each question, the total number of respondents, total number of eligible respondents (based on the skip logic), and the response percentage (respondents divided by eligible respondents) was calculated.

For single-select questions and multi-select questions, the number of responses for each response option was calculated. This “Count” was divided by the eligible respondents to calculate the “Percentage.” Both the count and percentage were reported in both tabular and graphical format. Single-select questions have percentages that sum to one hundred. Multi-select questions may have percentages that sum to over one hundred because an individual respondent could select more than one response option.

All questions were stratified by 8 demographic questions to identify response differences between racial, ethnic, social, and age groups. The demographic stratifications included gender, sexual identity, race, ethnicity, language, education, household income, and number of years with HIV. Additional stratifications between non-demographic questions were completed based on need. For stratifications, counts were calculated for each response option pair and divided by the total number of eligible respondents in that category. Only respondents that answered both questions were included in the percentage numerators and denominators.

Survey demographic data was compared to 2014 statewide prevalence data to ensure that the sample adequately represents the state epidemic.

Barriers to care data from the 2014 Rhode Island Provider Capacity Survey was included to compare provider perspectives on barriers to care to what the consumers report being most difficult about receiving care.

*Presentation*

Only aggregate data was included in data reporting and presentation. Great effort was made to describe the population who responded to the survey to ensure those reading the findings will clearly understand any possible limitations related to sampling.

## Results

### A. Orientation

The following section presents the results to the consumer survey. Graphs in blue summarize responses to individual survey questions. Graphs in red are stratifications - they summarize frequency cross tabulations between two survey questions. All stratifications (red graphs) have undergone significance testing with Pearson's Chi-square test ( $p < 0.05$ ). As noted in these figures, significance is noted with a '\*' in the graph's title or stratification label.

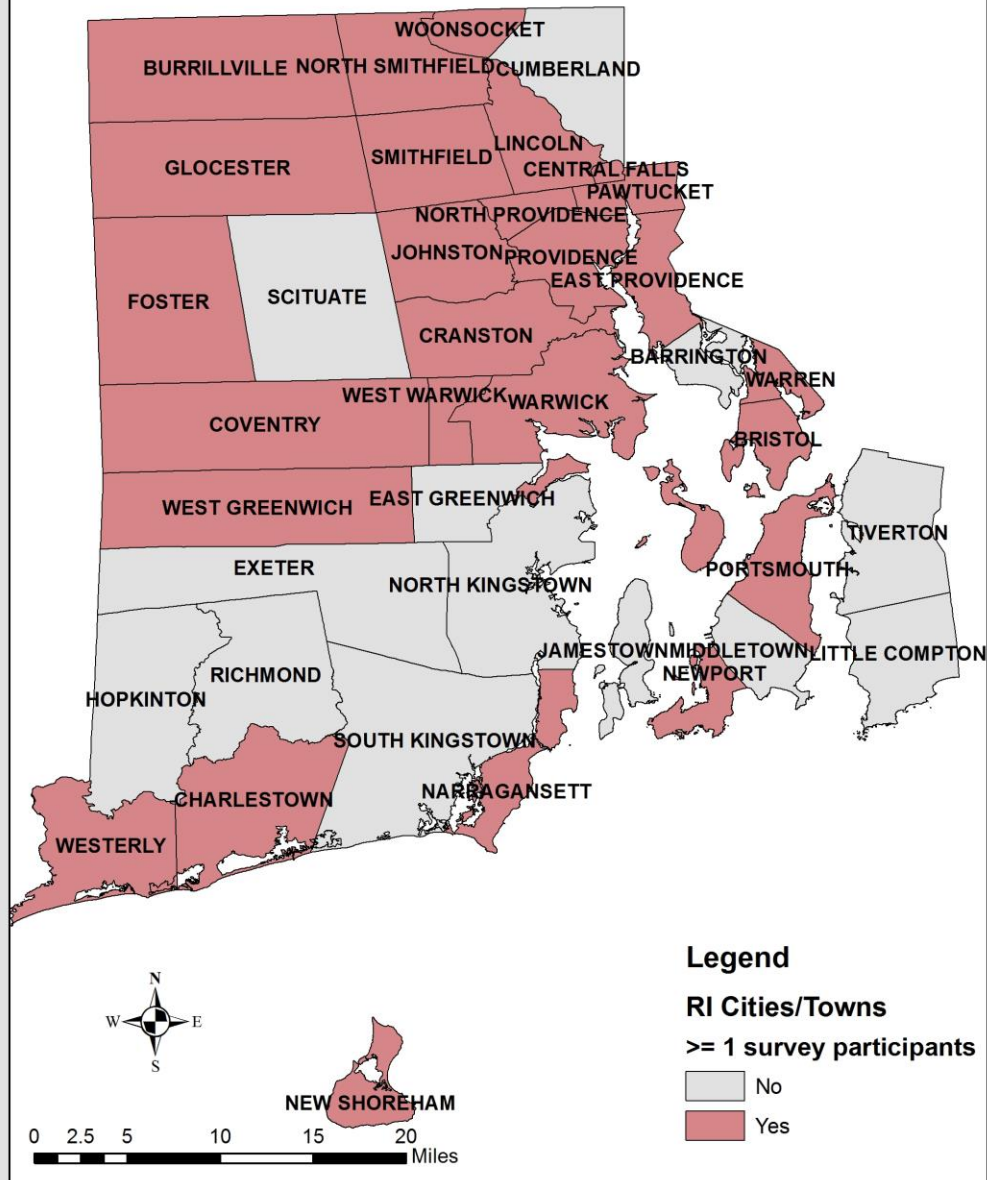
Some graphics represent recoded variables from the survey. These questions were recoded due to small values in individual response categories. Recoded categories were selected to be meaningful from both a programmatic and data distribution perspective.

Some percentages in the text may not sum to 100% due to rounding. Graphical and textual reporting of multi-select questions, where participants were allowed to select more than one response, will also not sum to 100%. Multi-select questions will be marked with an 'm.' in the title. This notation only applies to blue, non-stratified graphics as all red, stratified graphics are specific to one response category.

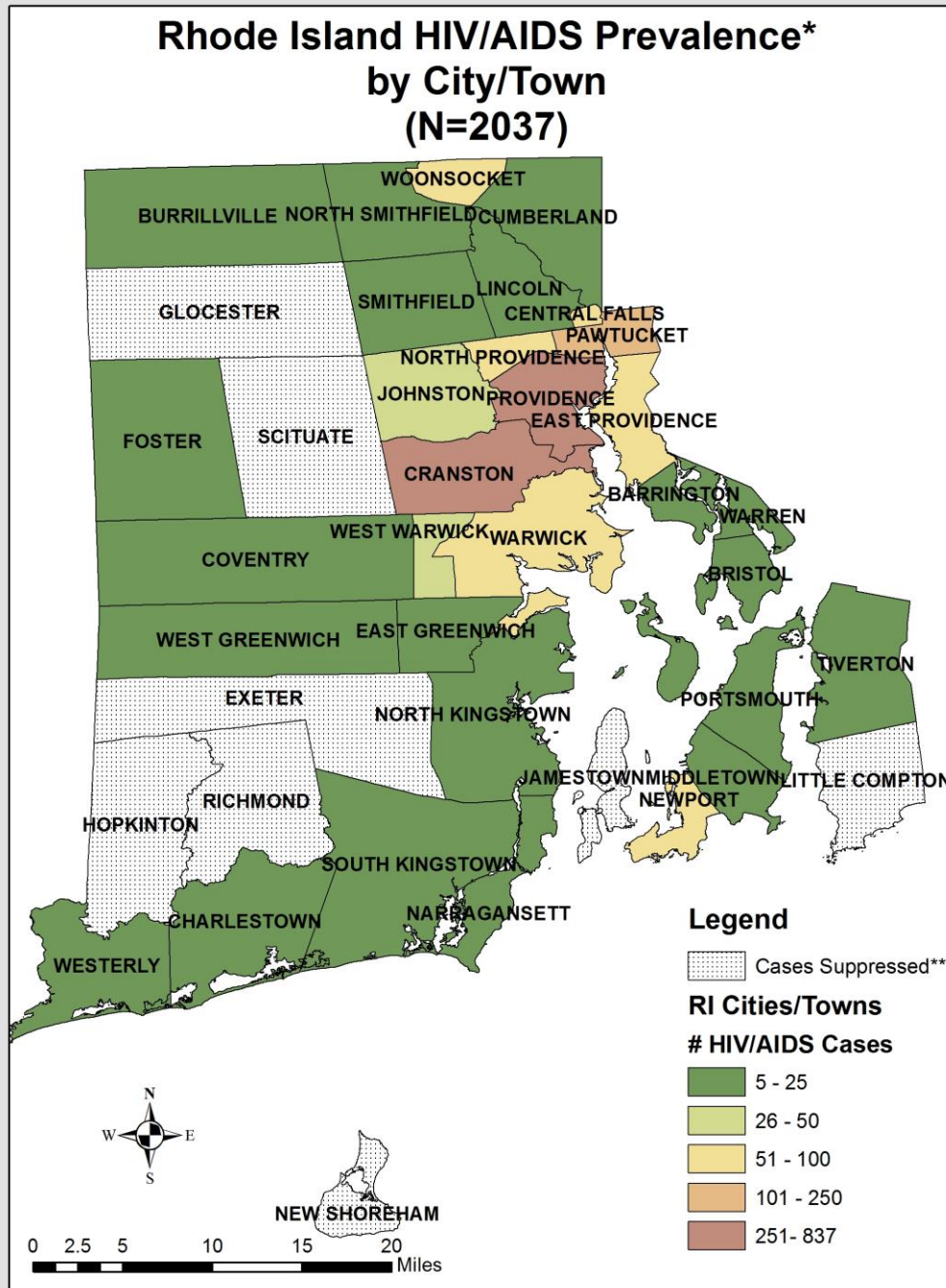
### B. Response

Three-hundred and four (304) people completed the survey. Eight (8) were deemed ineligible. Participants were required to be 18 years of age or older, have an HIV diagnosis, and be living in Rhode Island. The total number of eligible survey responses was 296. As shown in the figure below, participants came from all around Rhode Island. The towns with the highest number of respondents were Providence and Pawtucket. Fifteen percent (15%) of the surveys were completed in Spanish.

### Rhode Island Ryan White Consumer Survey Cities and Towns with $\geq 1$ Survey Participants, 2015-2016 (N=296)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey



\* Prevalence is reported through February 3, 2014.

\*\* Data are suppressed for cities/towns with <5 cases.



### **C. Survey Demographic Data vs 2014 RI Prevalence Data**

The following tables compare Rhode Island HIV & AIDS prevalence data from 2014 with the consumer survey results. The survey aligns well with the 2014 RI demographic data in all categories. The consumer survey did report higher percentages of Black and Hispanic consumers, perhaps because the 2014 prevalence data reports race and ethnicity together whereas the consumer survey asked the questions separately. Regardless, a higher percentage of racial and ethnic minorities may help to better address potential disparities among these groups.

The comparison between the survey demographic data and the 2014 prevalence demographic data is highly informative. First, it is clear that people in care (the population from which the survey sample was derived) are demographically reflective of the epidemic in Rhode Island. And secondly, the close demographic match lends credibility to the results contained in this report.



Table 1: Age Group Comparison

Age Group	Prevalence 2014	Consumer Survey
0-12	0.4% (9)	
13-19	0.4% (9)	0.3% (1)
20-29	6.0% (125)	7.1% (21)
30-39	13.7% (288)	11.0% (32)
40-49	27.3% (574)	29.7% (87)
50-59	37.7% (791)	37.2% (109)
60 and over	14.4% (303)	14.7% (43)
Total	100.0% (2099)	100% (293)

Table 2: Race and Ethnicity Comparison

Race and Ethnicity	Prevalence 2014	Consumer Survey
White	45.8% (962)	45.4% (122)
Black	24.4% (512)	34.6% (93)
Hispanic	25.9% (544)	36.4% (84)
Asian/HI Native/Pacific Islander	1.7% (36)	1.5% (4)
American Indian / AK Native	0.5% (10)	6.3% (17)
Multi/Unk/Other	1.7% (35)	17.1% (46)
Total	100.0% (2099)	

Table 3: Exposure Category Comparison

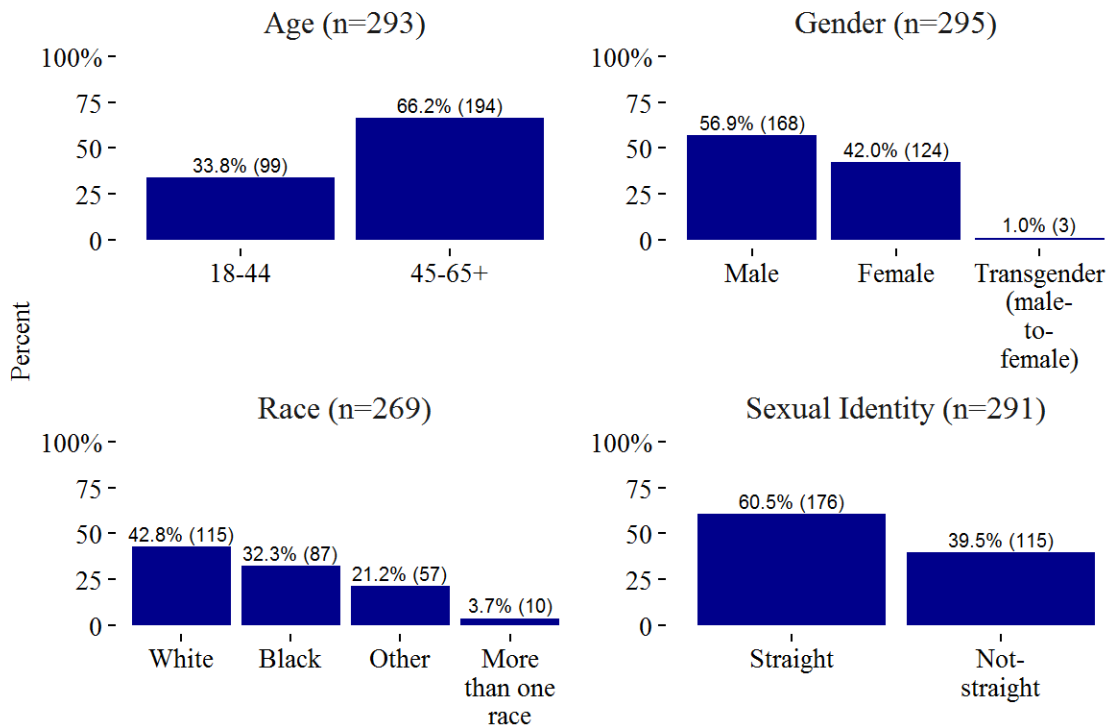
Exposure Category	Prevalence 2014	Consumer Survey
Blood Recipient	0.5% (10)	1.0% (3)
Heterosexual	25.1% (526)	26.6% (78)
IDU	17.8% (373)	19.1% (56)
MSM	38.4% (805)	32.8% (96)
MSM/IDU	3.6% (75)	5.5% (16)
Perinatal	1.1% (24)	1.4% (4)
No risk reported / Unknown	13.7% (287)	13.6% (40)
Total	100.0 (2099)	100.0% (293)

Notes: Prevalence 2014 data as of November 3, 2015. Data from the Rhode Island HIV Surveillance Program at the Rhode Island Department of Health. Data are provisional and subject to change. Prevalence, and the calculation of PLWHA in RI calculated, based on national guidance, using 'current residence' information to account for in migration and out migration. For the consumer survey, the lowest age category was 18-19; race and ethnicity was asked as two separate questions; Race was asked as a multi-select question; and the 'no risk reported / Unknown' risk category included both 'I do not know' and 'Other (please specify)'.

### D. Demographics

Sixty-six percent (66%) of respondents were above the age of 45 and 34% were between the ages of 18 and 44<sup>1</sup>. Sixty-one percent were straight and 40% were not-straight<sup>2</sup>. Forty-two percent (42%) were female and 57% were male. Forty-three percent (43%) were white, 33% black, 22% other, and 4% more than one race<sup>3</sup>.

Figure 3: Age, Gender, Race, Sexual Identity



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

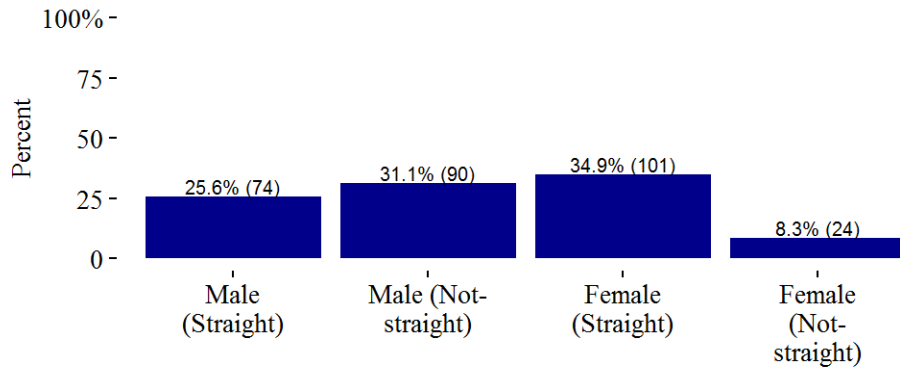
<sup>1</sup> Age was asked in 5 year increments starting at 18: '18-19,' '20-24,' '25-29,' etc.

<sup>2</sup> Sexual Identity: 'Not-straight' included 'gay or lesbian (homosexual)', 'bisexual', 'queer', 'questioning', and 'other (please specify)'

<sup>3</sup> Race: 'Other' includes 'American Indian/Alaska Native', Native Hawaiian/Other Pacific Islander', 'Asian', and 'other (please specify). Race was asked as a multi-select question but then converted to a single-select using the 'more than one race' category.

For analytic purposes, four categories were created from the sexual identity variables: Male (Straight), Male (Not-Straight), Female (Straight), and Female (Not-Straight). Straight Females were the most frequent category with 35% of respondents, followed by Not-Straight Males (31%), Straight Males (26%), and Not-Straight Females (8%).

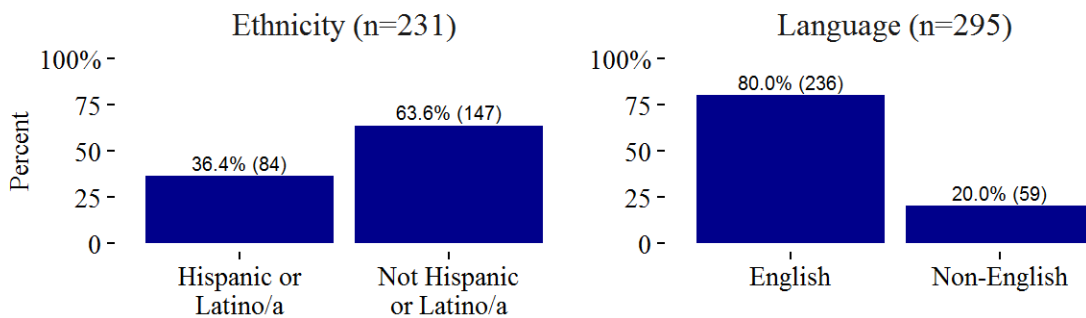
Figure 4: Sexual Identity & Gender (n=289)



Data Source: 2015 Rhode Island Executive Office of Health and Human Service  
Ryan White Consumer Survey

Sixty-four percent (64%) of respondents reported not Hispanic or Latino/a and 36% reported Hispanic or Latino/a. Eighty percent (80%) reported that their primary language was English and 20% that their primary language was not English<sup>4</sup>.

Figure 5: Ethnicity, Language

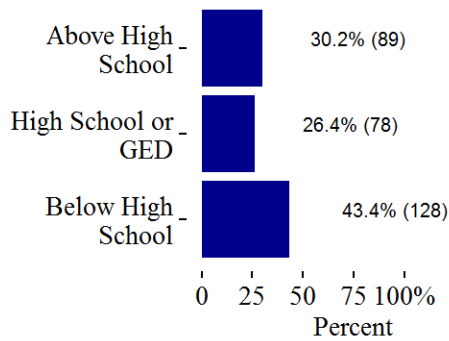


Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
Ryan White Consumer Survey

<sup>4</sup> 'Non-English' includes 'Spanish', 'French', 'Portuguese', and 'Other (please specify)'.

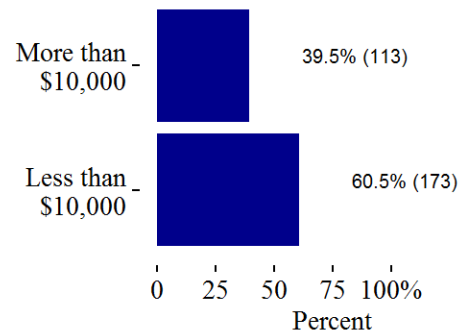
Thirty percent (30%) reported their education level to be above high school, 26% at high school or GED, and 43% at below high school. Sixty percent reported a household income of less than \$10,000 per year and 40% at more than \$10,000<sup>5</sup>. Only 10% of respondents reported a household income over \$30,000 per year.

Figure 6: Education  
(n=295)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Figure 7: Household Income  
(n=286)

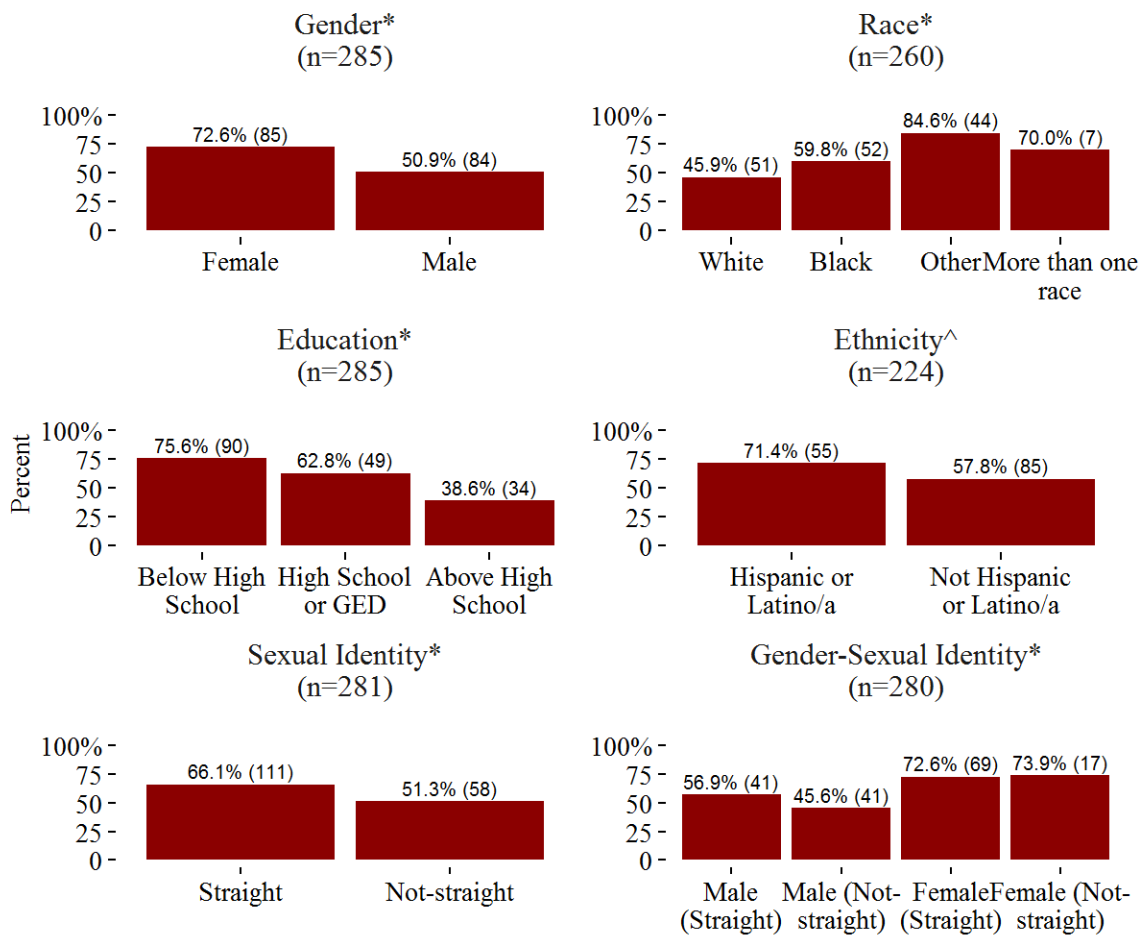


Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

<sup>5</sup> Income was asked in \$10,000 increments from \$0 to \$70,000+.

Women (73%) were significantly more likely than men (51%) to have a household income less than \$10,000. Significant demographic disparities were also found across racial, education level, and sexual identity categories. People in the racial categories of other race (85%), more than one race (70%), and black (60%) were significantly more likely to have a household income less than \$10,000 when compared to white (46%) as were individuals with a below high school education (76%) and a high school or GED education (63%) when compared to those with above a high school education (39%). Respondents who identified as straight (66%) were significantly more likely than those who identified as not-straight (51%) to have a household income less than \$10,000. Not-straight males (46%) were significantly less likely to have a household incomes less than \$10,000 compared to straight males (57%), straight females (73%), and not-straight females (74%).

Figure 8: Household Income is Less than \$10,000



Notes: '\*' indicates significance, Pearson's Chi-squared test ( $p < 0.05$ )

^ indicates borderline  $p$  value of  $< 0.07$

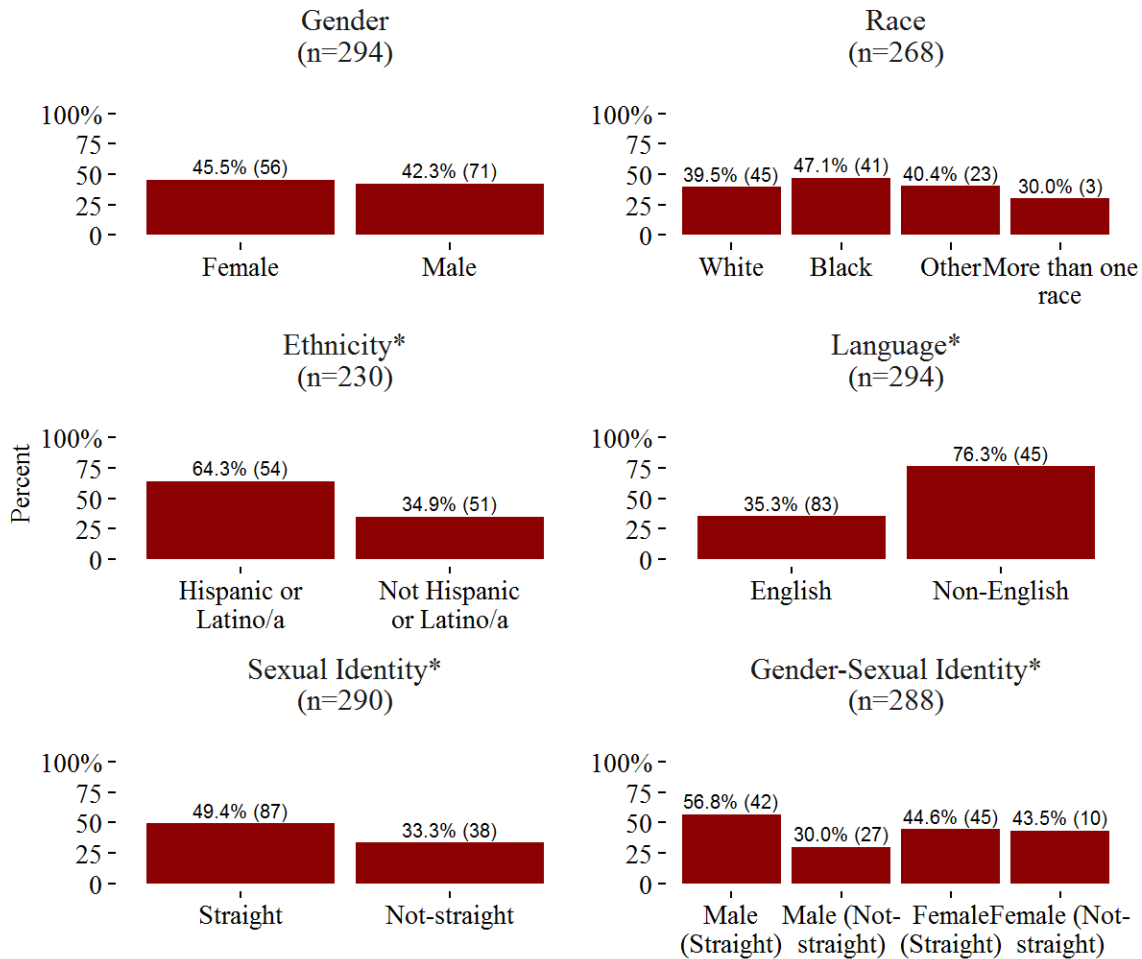
Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
Ryan White Consumer Survey

Respondents who identified as Hispanic or Latino/a (64%) were significantly more likely to report an education level below high school than non-Hispanic or Latino/a respondents (35%). Respondents who reported a non-English language as their primary language were also significantly more likely to report an education level below high school than respondents who indicated English (35%).

Interestingly, respondents who identified as not-straight (33%) were significantly less likely than straight respondents (49%) to report an education level of below high school. The same was true for not-straight males (30%), compared to straight males (57%), straight females (45%), and not-straight females (44%).

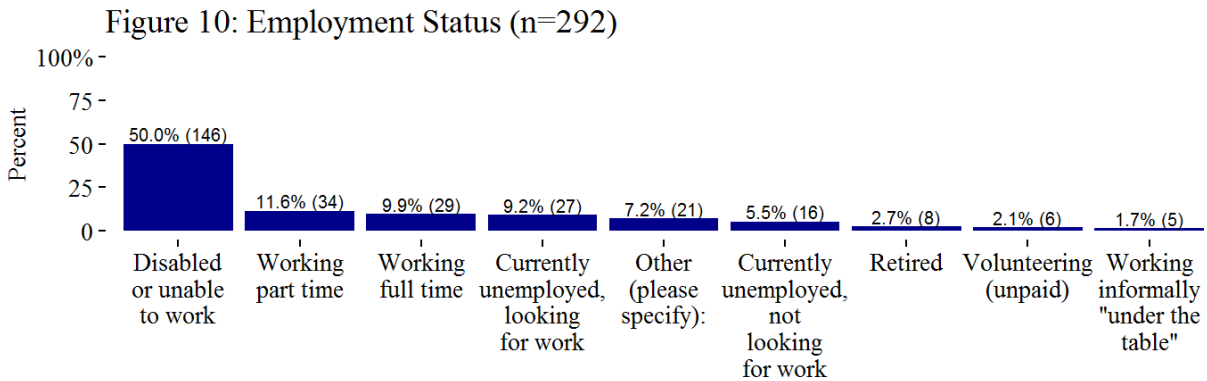
Black respondents (47%) were notably more likely than white (40%), other race (40%), and more than one race (30%) respondents to report an education level of below high school but the differences were not significant. There was not a notable or significant difference in education level between men and women.

Figure 9: Education Level is Below High School



Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

Fifty percent (50%) of respondents reported that they were disabled or unable to work. Twelve percent (12%) reported that they were working part time, 10% working full time, 9% currently unemployed but looking for work, 7% other, 6% currently unemployed and not looking for work, 3% retired, 2% volunteering (unpaid), and 2% working informally "under the table".

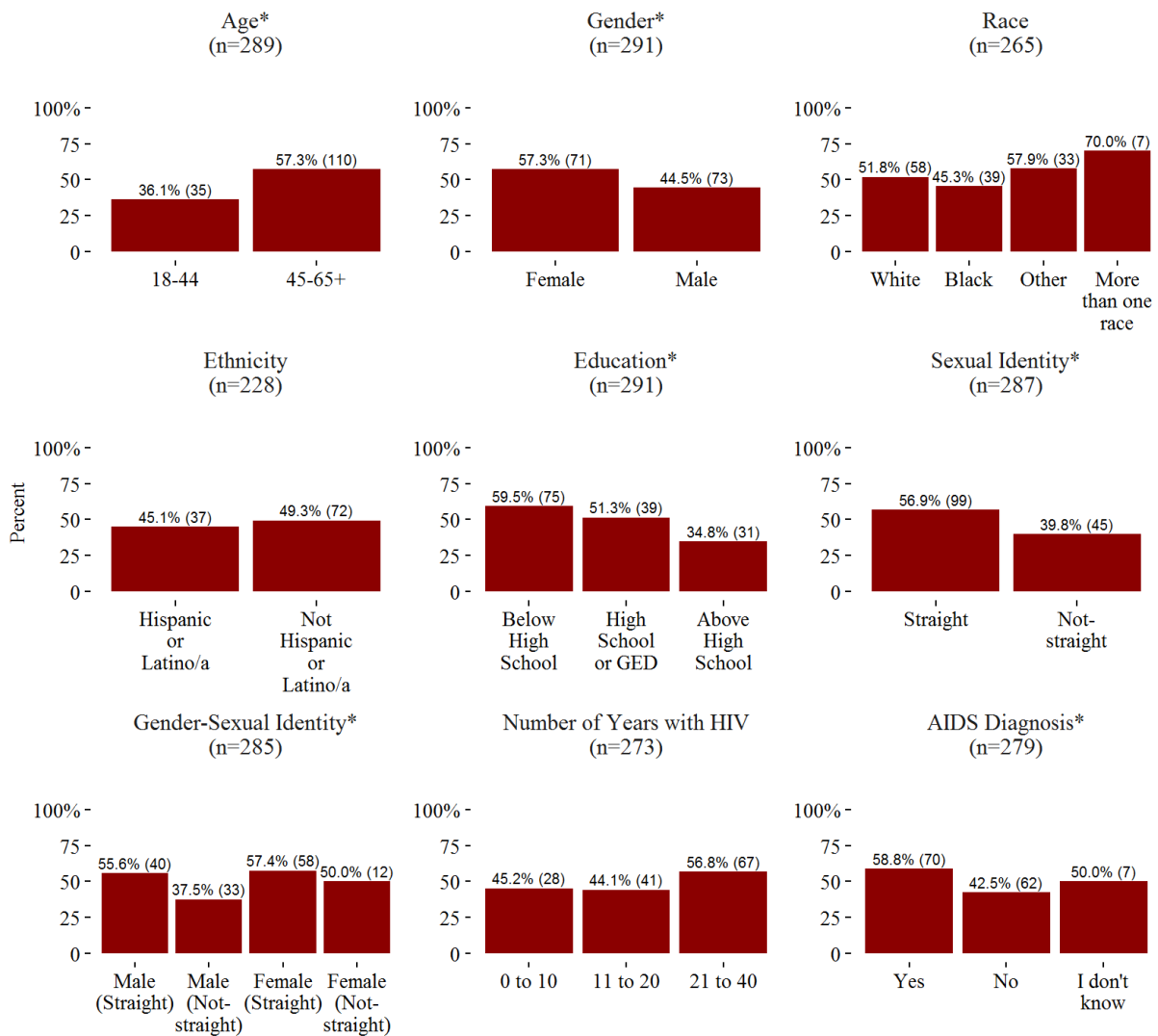


Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
Ryan White Consumer Survey



Demographic disparities in working status were found among gender, age, sexual identity, and education level groups. Women (57%) were significantly more likely than men (45%) to report that they were disabled or unable to work, as were those 45-65+ years old (57%) when compared to those 18-44 years old (36%), those who indicated they were straight (57%) when compared to those that indicated they were not-straight (40%), and those with below a high school education level (60%) when compared to those with a high school or GED education level (51%) and those with above a high school education level (35%). Not-straight males (38%) were significantly less likely than straight males (56%), straight females (57%), and not-straight females (50%) to report being disabled or unable to work. Respondents who reported an AIDS diagnosis (59%) were also significantly more likely to report being disabled or unable to work than those without an AIDS diagnosis (43%). Some differences were identified between racial categories but they were not determined to be significant.

Figure 11: Employment Status is 'disabled or unable to work'

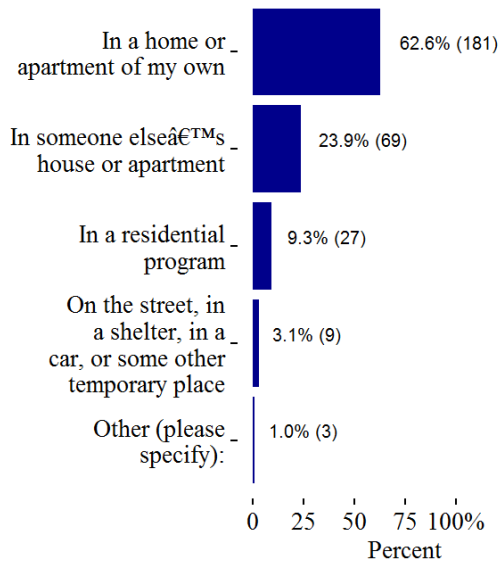


Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

Sixty-three percent (63%) of respondents reported that they are currently living in a home or apartment of their own, 24% in someone else's house or apartment, 9% in a residential program, 3% on the street, in a shelter, in a car, or some other temporary place, and 1% other. As this survey was not designed to explicitly reach those that are hard to reach or out of care, it is likely that the percentage of PLWHA in Rhode Island living on the street, in a shelter, in a car, or in some other temporary place is higher.

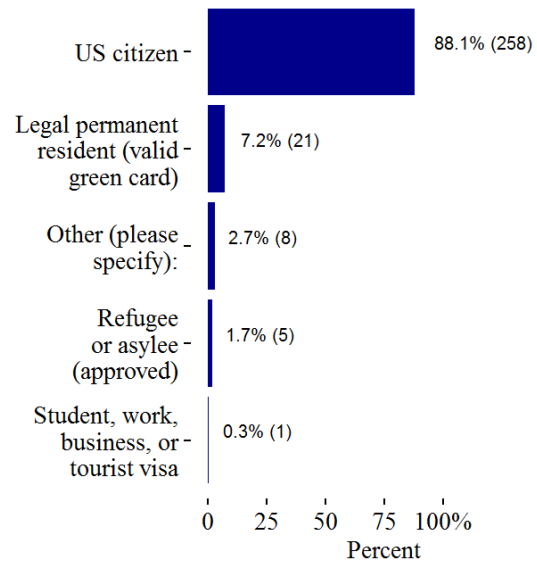
Eighty-eight percent (88%) reported that they are citizens of the United States, 7% legal permanent residents with a valid green card, 3% other, 2% refugee or asylee (approved), and <1% student, work, business, or tourist visa. It is likely that some of the 3% who reported 'other' are unapproved immigrants.

Figure 12: Housing (n=289)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Figure 13: Immigration (n=293)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Seventy-eight percent (78%) of respondents have been diagnosed with HIV for more than 11 years and 43% have for more than 21 years. A majority (53%) reported that they do not have AIDS. Forty-two percent (42%) reported an AIDS diagnosis.

Figure 14: Number of Years with HIV (n=275)

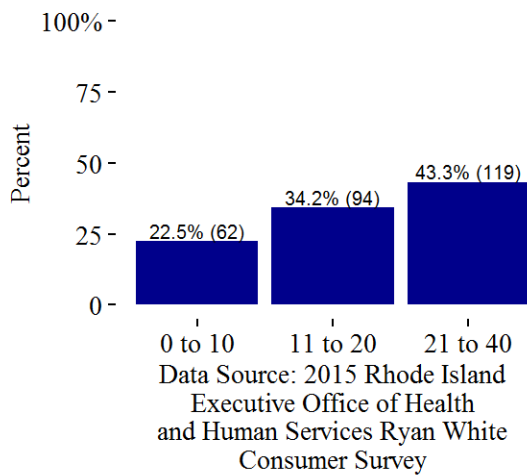
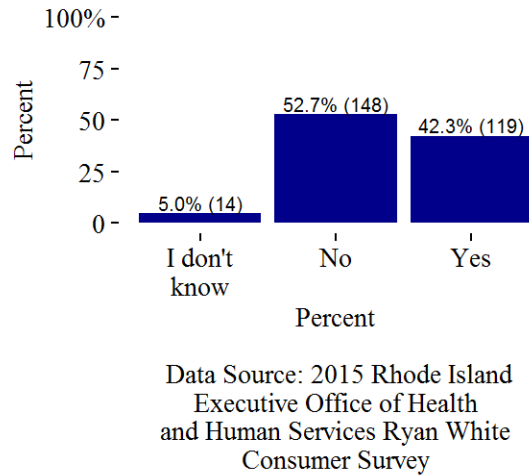
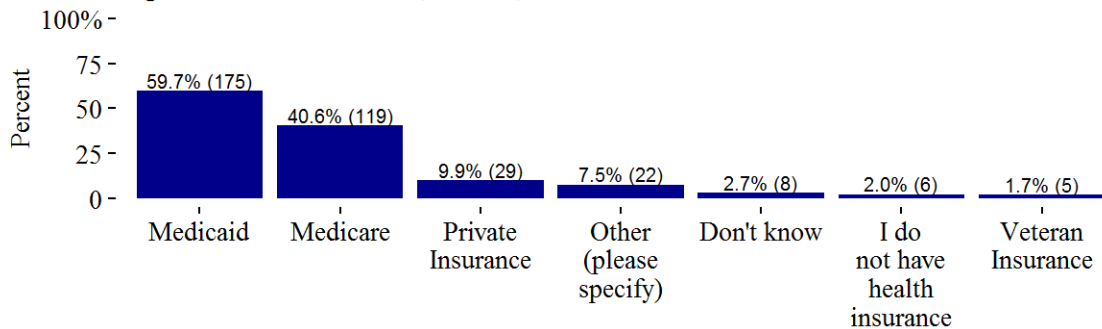


Figure 15: AIDS Diagnosis (n=281)



Sixty percent (60%) of respondents reported that they use Medicaid, 41% Medicare, 10% private insurance, 8% other, and 2% veteran insurance. Only 2% reported that they do not have health insurance.

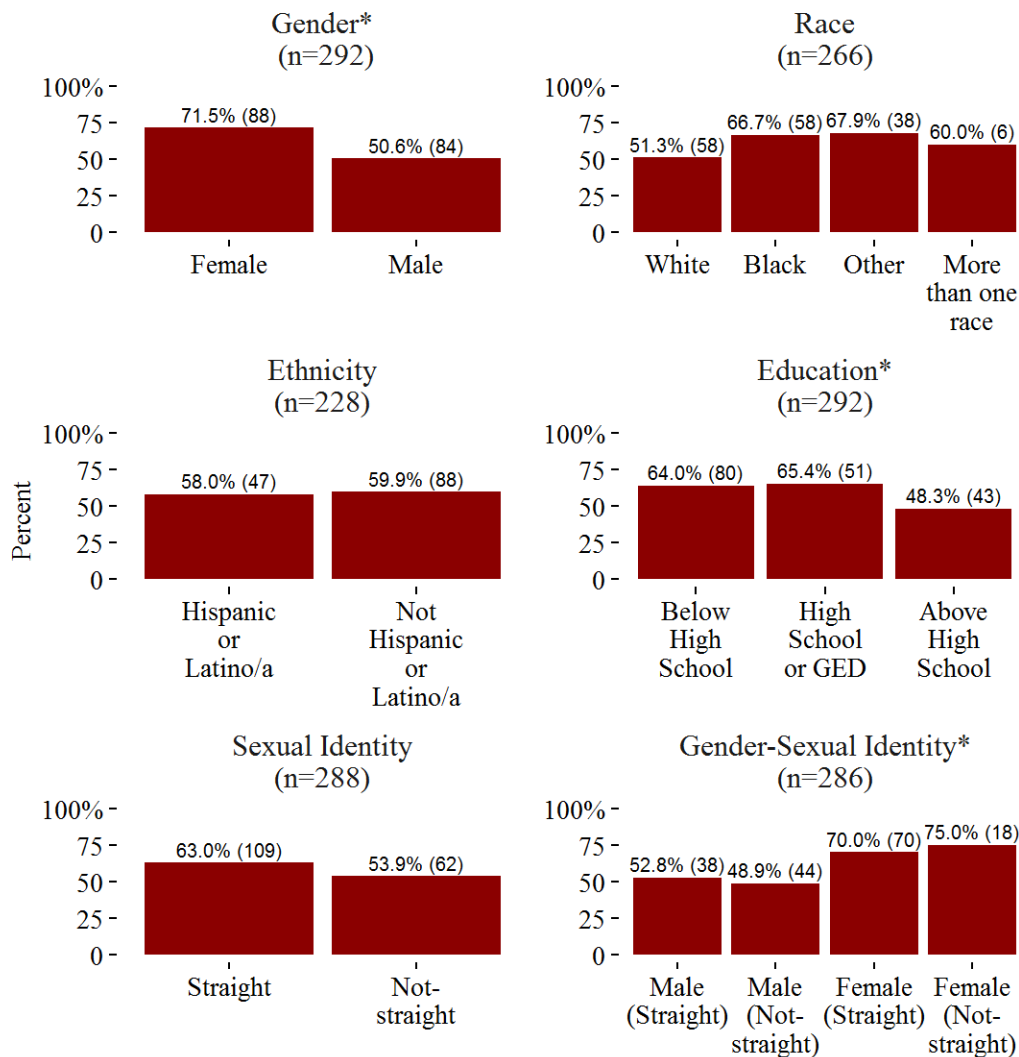
Figure 16: Insurance (n=293), m.



Notes: 'm.' indicates multi-select question.  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

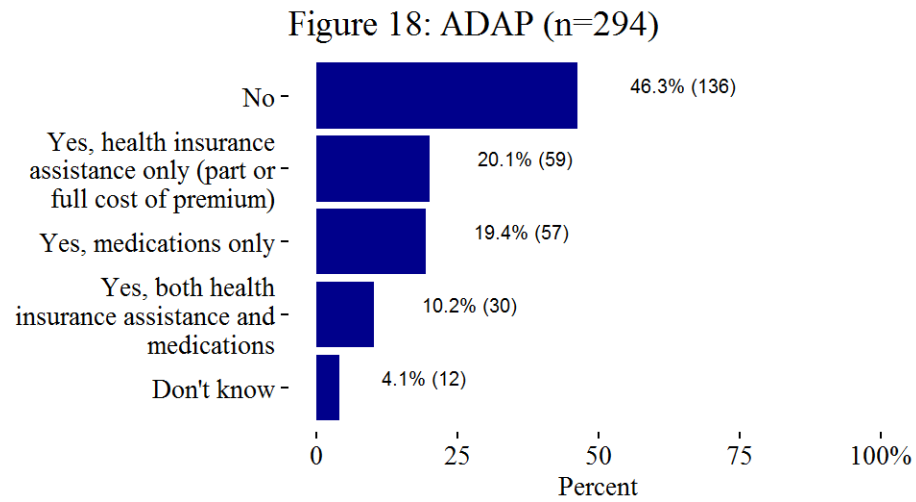
Sixty-four percent (64%) of respondents with below high school education reported they use Medicaid, compared to 65% of those with a high school education or GED, and 48% of those with above a high school education. Seventy-two percent (72%) of females reported Medicaid compared to 51% of males. Fifty-one percent (51%) of white respondents reported Medicaid compared to 67% of black, 68% of other, and 60% of more than one race. Sixty-three percent (63%) of straight respondents reported Medicaid compared to 54% of not-straight. Not-straight males (49%) were significantly less likely to report Medicaid compared to straight males (53%), straight females (70%), and not-straight females (75%). There were not any notable differences by ethnicity.

Figure 17: Insurance is Medicaid



Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

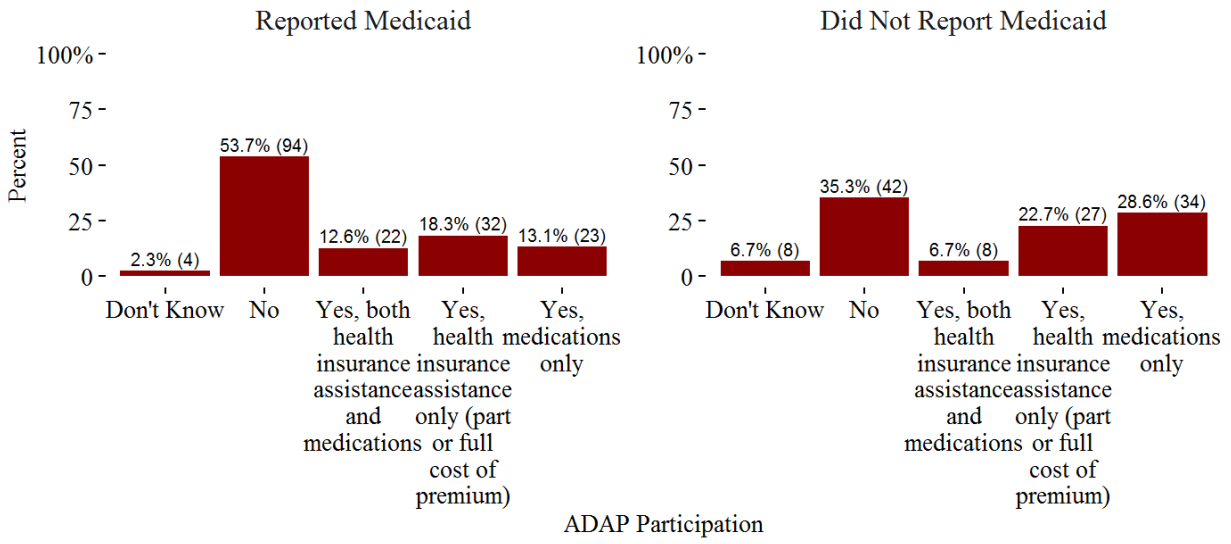
Fifty percent (50%) of respondents indicated that they use Rhode Island's AIDS Drug Assistance Program (ADAP) and 46% that they do not. Twenty percent (20%) of respondents indicated that they use ADAP for health insurance assistance only, 19% for medication only, and 10% for both health insurance assistance and medications.



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Respondents who reported that they use Medicaid for insurance (54%) were more likely than those who did not (35%) to report that they did not use ADAP. Respondents who reported Medicaid (13%) were also less likely than those who did not (29%) to report using ADAP for medications only. These difference were not found to be significant.

Figure 19: Medicaid and ADAP Participation

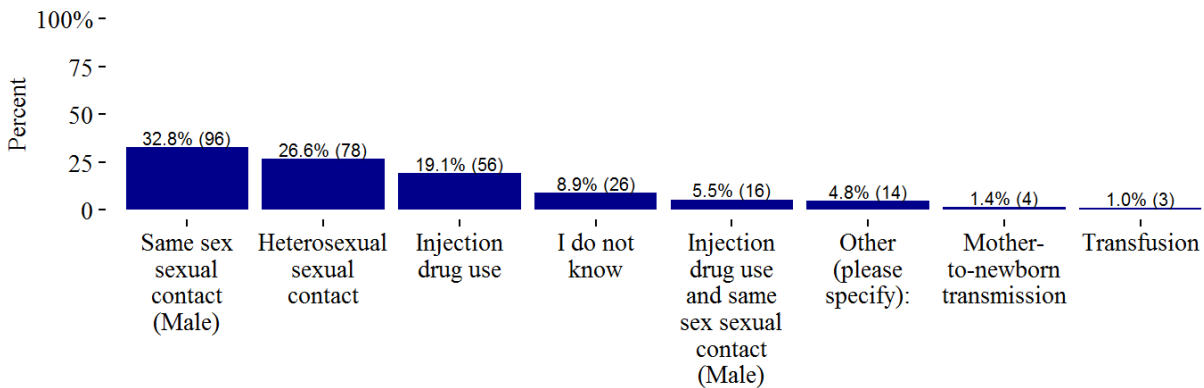


Notes: not statistically significant, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

### E. Transmission & Sexual Behavior

Thirty-three percent (33%) of respondents reported same sex sexual contact (Male) as how they think they got HIV, 27% heterosexual contact, 19% injection drug use, 9% did not know, and 6% injection drug use and same sex sexual contact. Less than 5% reported other, mother-to-newborn, and transfusion. While the incidence of HIV infections through the transmission category of injection drug use has declined over recent years, it is important to recognize that these data reflect those currently with the disease, not new infections.

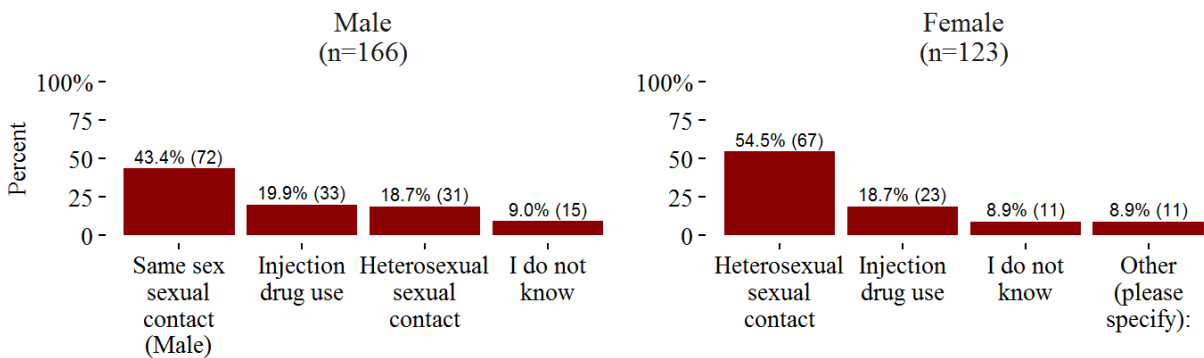
Figure 20: HIV Transmission Categories (n=293)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

For men, same sex sexual contact (43%) was the most common transmission category. For women, the most common transmission category was heterosexual sexual contact (55%).

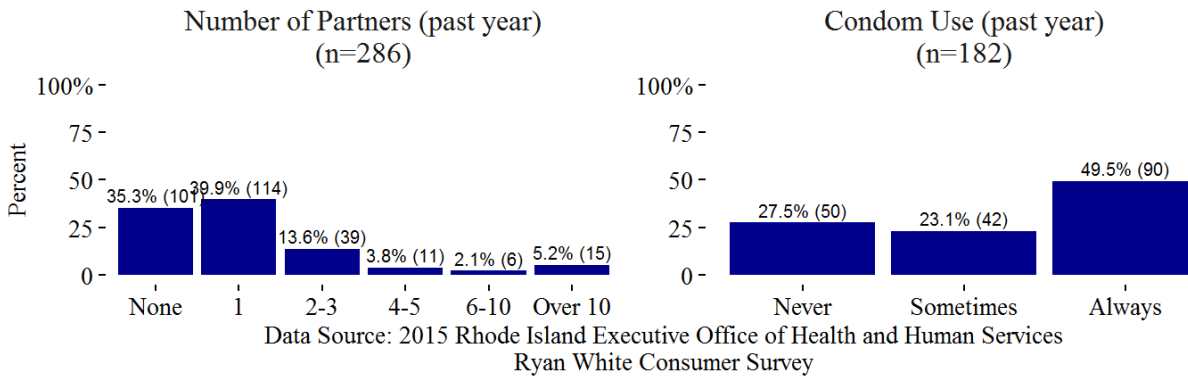
Figure 21: HIV Transmission by Gender



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

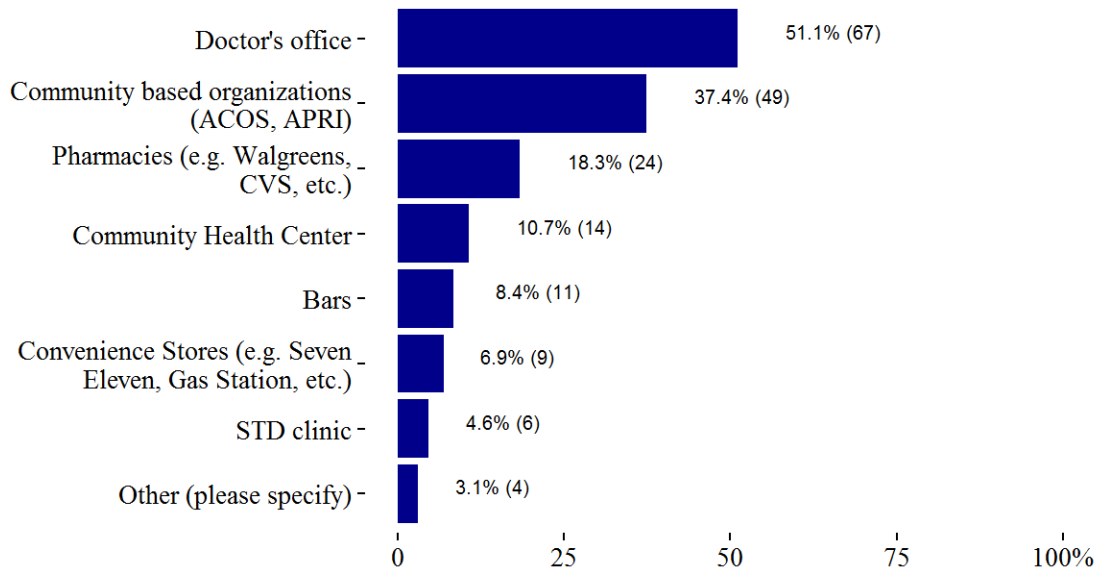
A majority of respondents (75%) reported 1 or no partners in the past year, 14% reported 2-3, 4% 4-5, 2% 6-10, and 5% over 10. Fifty percent (50%) of respondents reported always wearing a condom but over 25% reported never wearing one.

Figure 22: Number of Partners, Condom Use



Doctor's office (51%) was the most common reported place to get condoms, followed by community based organizations like ACOS and APRI (37%), pharmacies (18%), community health centers (11%), bars (8%), convenience stores (7%), STD clinics (5%), and other (3%).

Figure 23: Where do you get your condoms? (Top 8) (n=131), m.

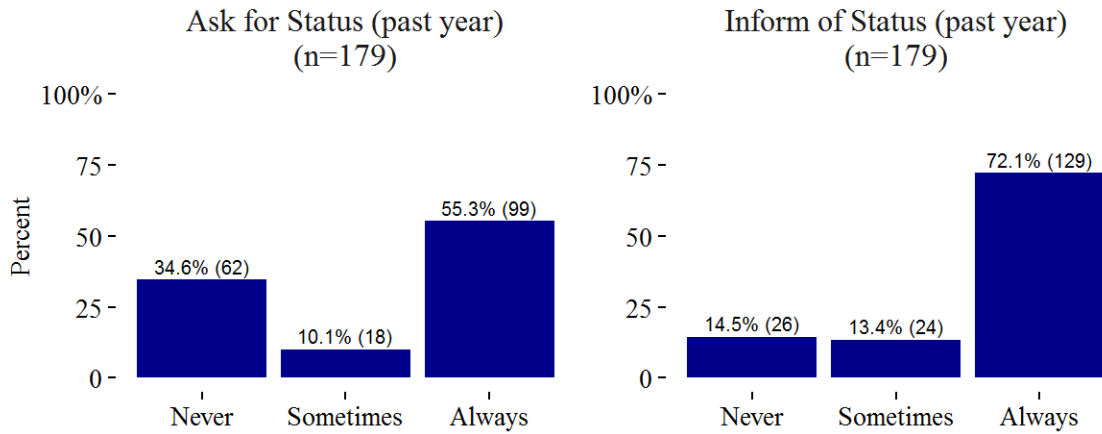


Notes: 'm.' indicates multi-select question.  
Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
Ryan White Consumer Survey



Respondents were significantly more likely to report always sharing their status with their partner (72%) than always asking their partner for their status (55%).

Figure 24: Ask for Status, Inform of Status

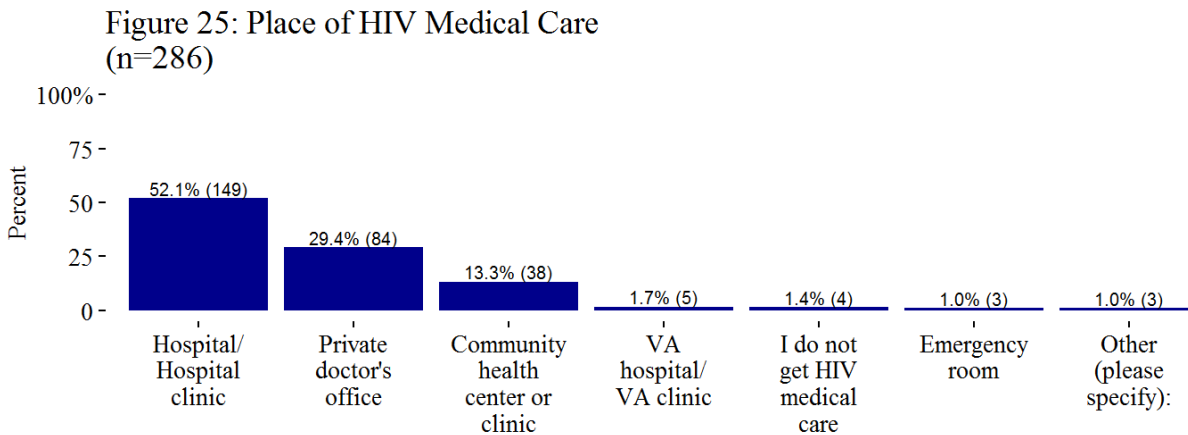


Notes: statistically significant, Pearson's Chi-squared test ( $p < 0.05$ )  
Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
Ryan White Consumer Survey

### F. Continuum of Care

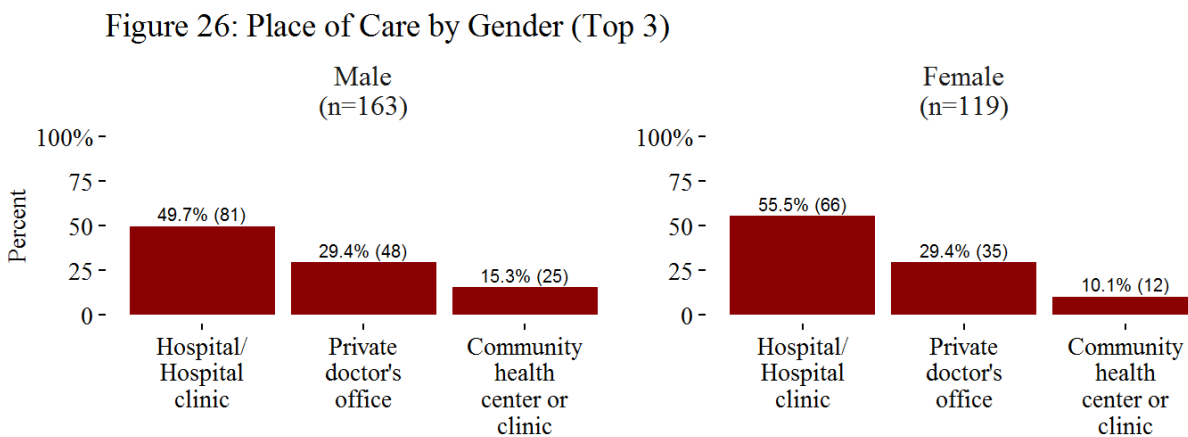
The data in this section are reflective of the stages in the continuum of care. Survey questions were asked in manner that aligned with the CDC's care continuum. However, it is important to note that the data here are not an attempt to construct a continuum of care.

The most common place of HIV medical care for respondents was a hospital or hospital clinic (52%) followed by a private doctor's office (30%), a community health center or clinic (13%), and a VA hospital/VA clinic (2%). Only 1% reported that they get their HIV care in an emergency room and only 1% reported that they do not get HIV medical care at all.



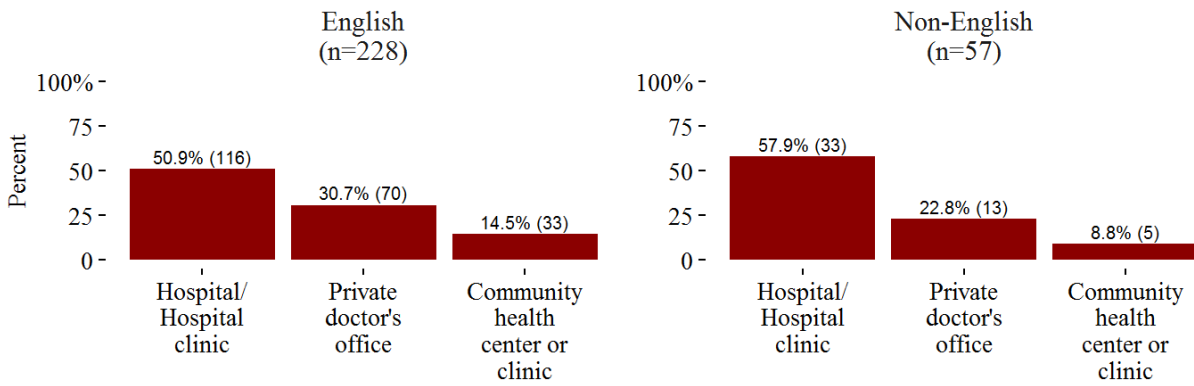
Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Men and women were equally likely to report receiving their HIV care at hospitals, private doctor's offices, and community health centers (Figure 26). Respondents who listed a language other than English as their primary language were significantly more likely to report receiving their HIV medical care from a hospital.



Notes: not statistically significant, Pearson's Chi-squared test ( $p < 0.05$ ) Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Figure 27: Place of Care by Language (Top 3)



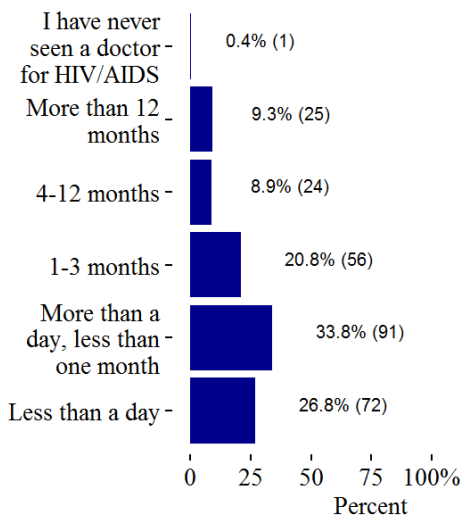
Notes: borderline statistically significant, Pearson's Chi-squared test ( $p < 0.07$ )  
Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
Ryan White Consumer Survey

*Visits to HIV Medical Provider*

Sixty-one percent (61%) reported that they had a doctor visit for HIV/AIDS less than on month after their diagnosis. Twenty-seven percent (27%) reported less than one day. Beyond the one month mark, 21% reported 1-3 months, 9% 4-12 months, and 9% more than 12 months. Less than one percent (<1%) reported that they have never seen a doctor for HIV/AIDS.

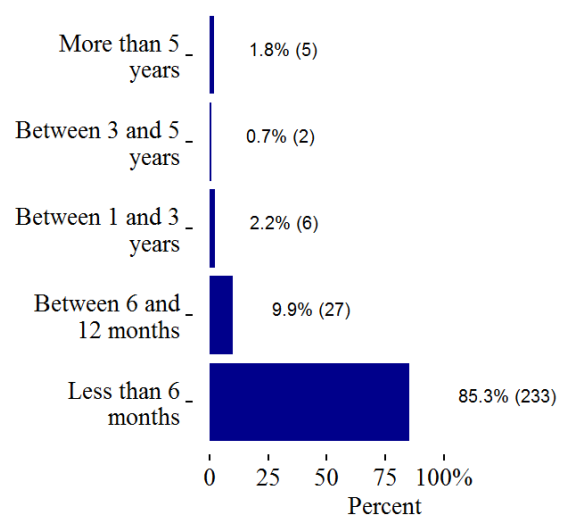
Eighty-five percent (85%) reported that their last visit to an HIV provider occurred in the last 6 months. Ten percent (10%) reported that their last visit was between 6 and 12 months, 2% between 1 and 3 years, and 2% more than 5 years.

Figure 28: Doctor visit for HIV/AIDS after Diagnosis(n=269)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

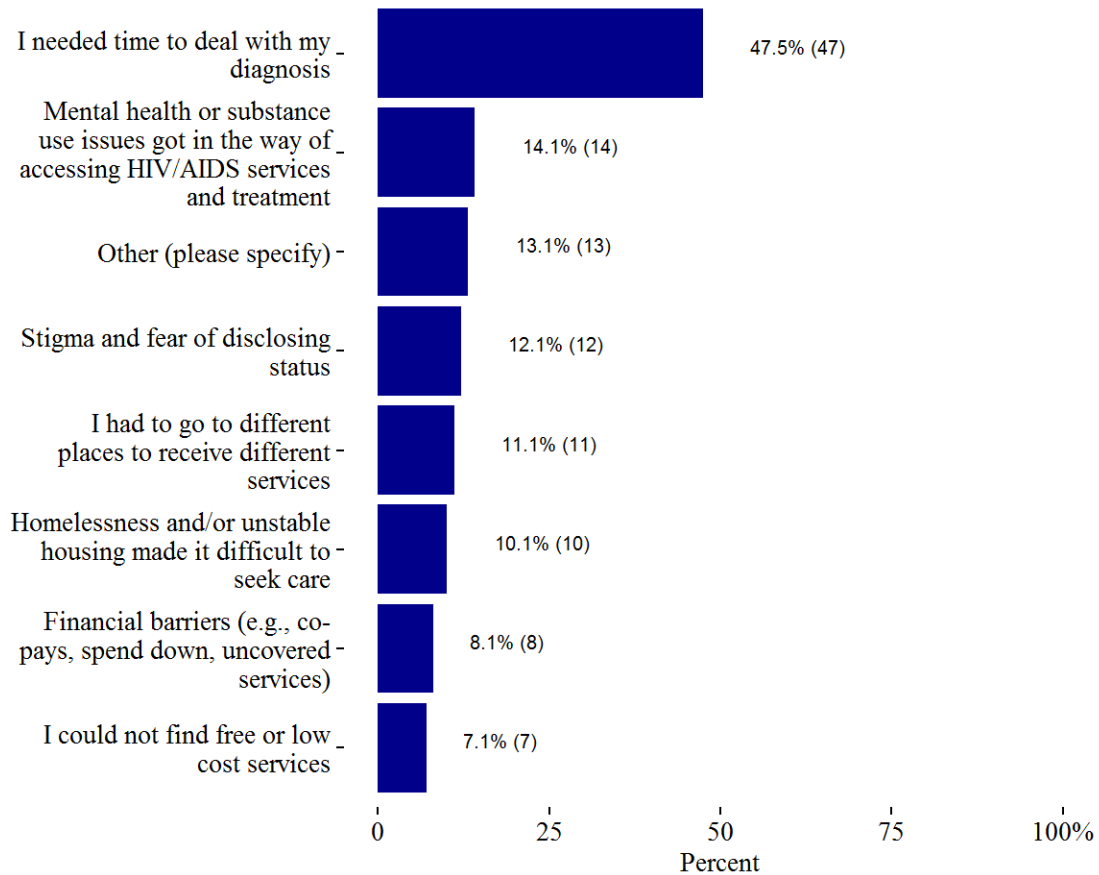
Figure 29: Last Visit to HIV Provider(n=273)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

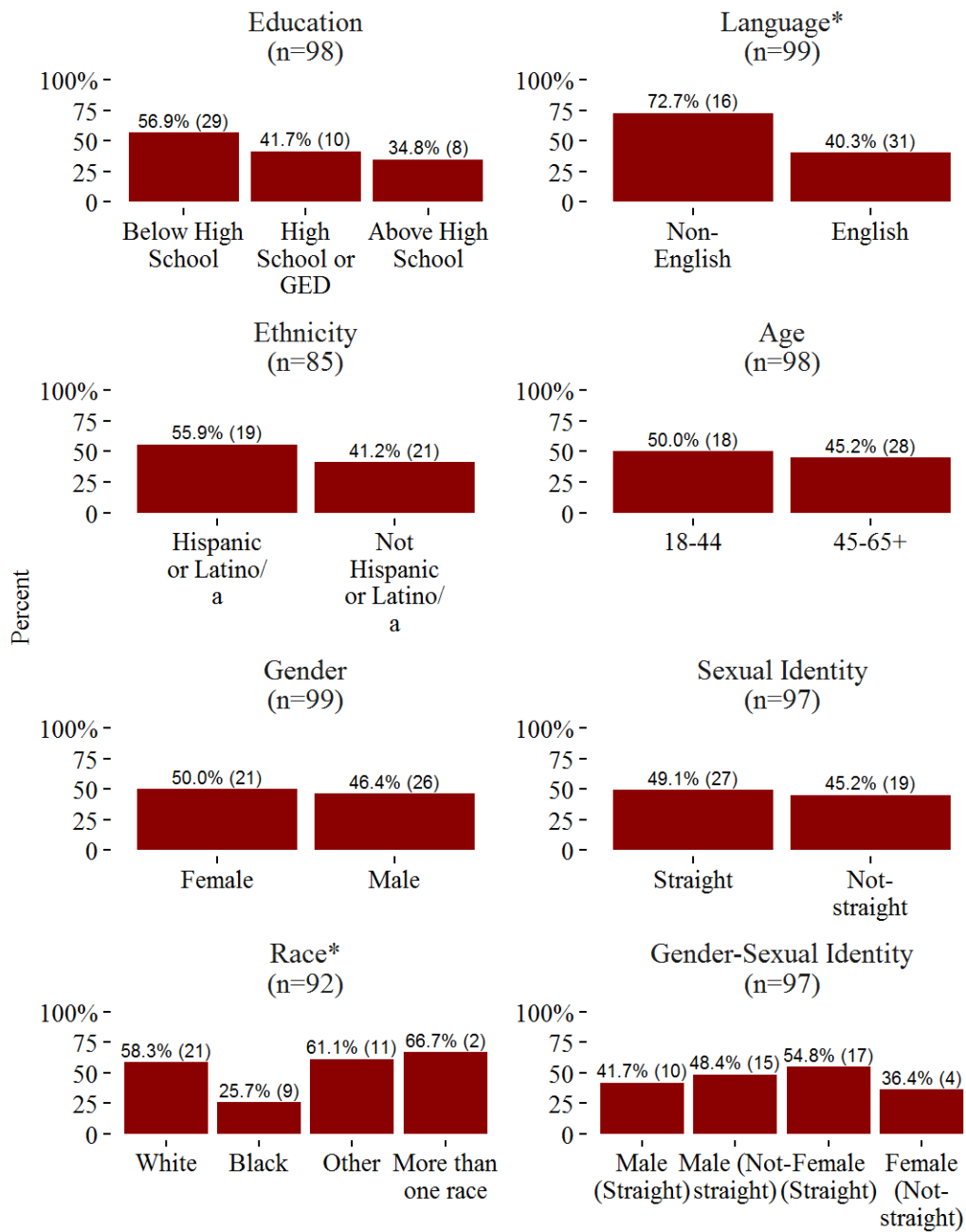
The most common reason for a delayed doctor visit for HIV/AIDS after diagnosis was 'I needed time to deal with my diagnosis' (48%). People who reported a language other than English as their primary language (73%) were significantly more likely than those who reported English (40%) to report that needing time to deal with their diagnosis delayed their doctor visit for HIV/AIDS after diagnosis. Respondents who identified as black (26%) were significantly less likely than those who identified as white (58%), other race (61%), or more than one race (67%). Differences were also observed within education level, ethnicity, gender, sexual identity, gender-sexual identity, and age categories but were not found to be significant. This may indicate that language is the most consistent and impactful cultural barrier that can exist between PLWHA and their medical and non-medical providers.

Figure 30: Reasons for Delayed Doctor Visit for HIV/AIDS after Diagnosis (Top 8) (n=122), m.



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Figure 31: 'I needed time to deal with my diagnosis' as Reason for Delayed Visit to HIV Medical Provider After Diagnosis

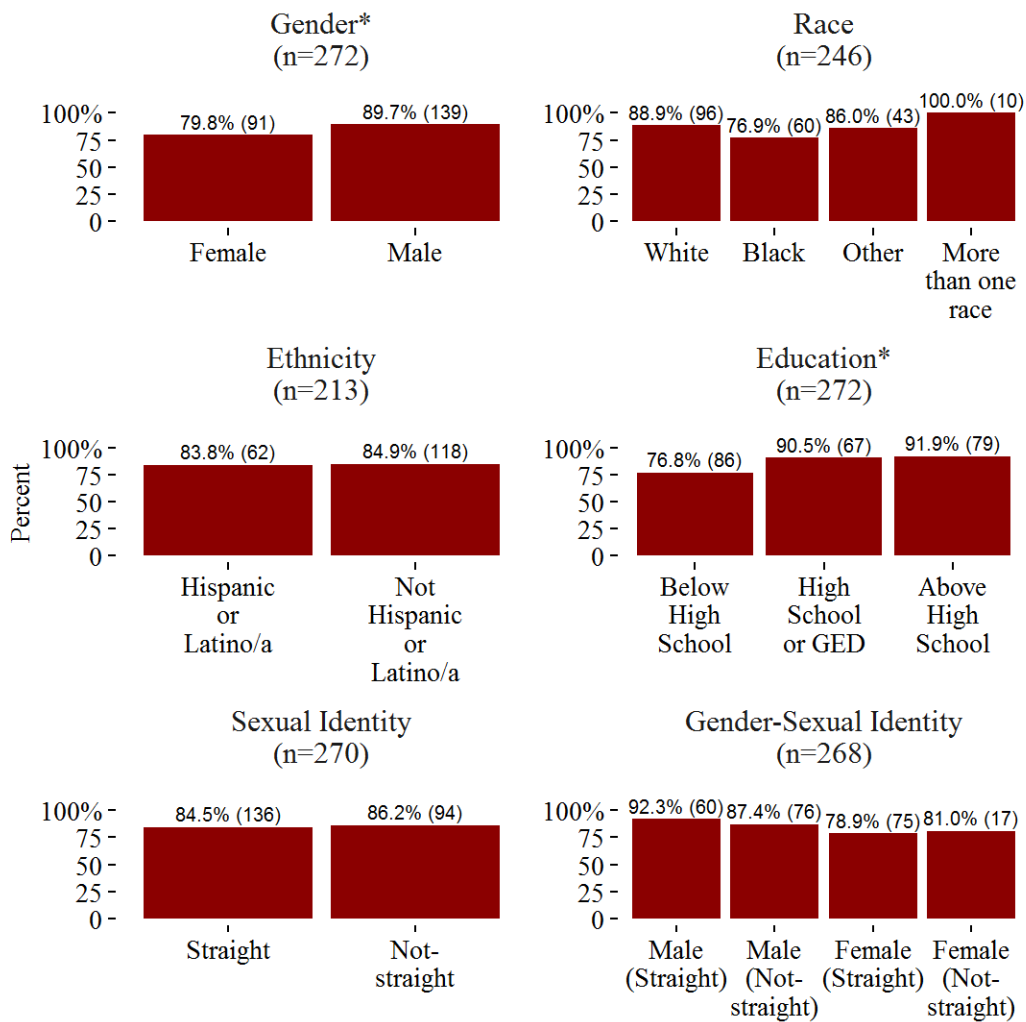


Notes: 'm.' indicates multi-select question.

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Women (80%) were significantly less likely than men (90%) to have had a visit to an HIV medical provider within the last six months. Individuals with above a high school education (92%) and those with a high school or GED-level education were also significantly less likely than those with below a high school education (77%) to have had a visit to an HIV medical provider within the last six months. Not-straight males (87%) were slightly less likely than straight males (92%) to have had a visit to an HIV medical provider within the last six months. When comparing straight to not-straight respondents without gender, there was a not notable or significant difference.

Figure 32: Visit to HIV Medical Provider Within Last 6 Months

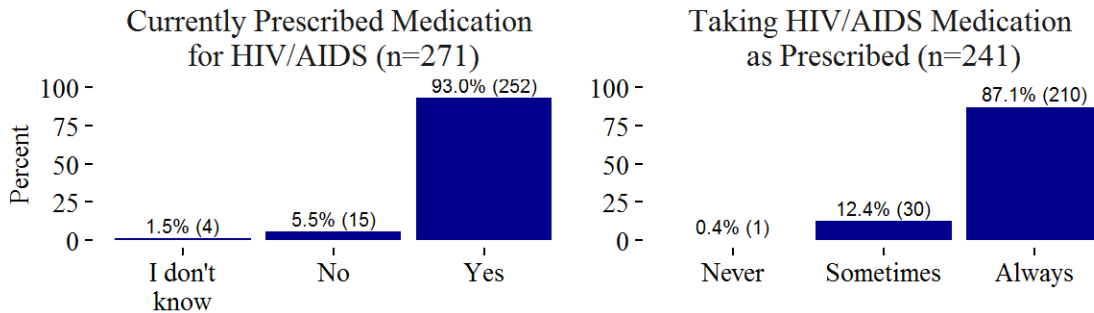


Notes: '\*' indicates significance, Pearson's Chi-squared test ( $p < 0.05$ )  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

Prescriptions and Viral Load

Ninety-three percent (93%) of respondents reported currently being prescribed medication for HIV/AIDS and, of those individuals, 87% reported that they take their medication as prescribed. It is important to recognize that these numbers are self-reported.

Figure 33: Medication Prescriptions and Adherence



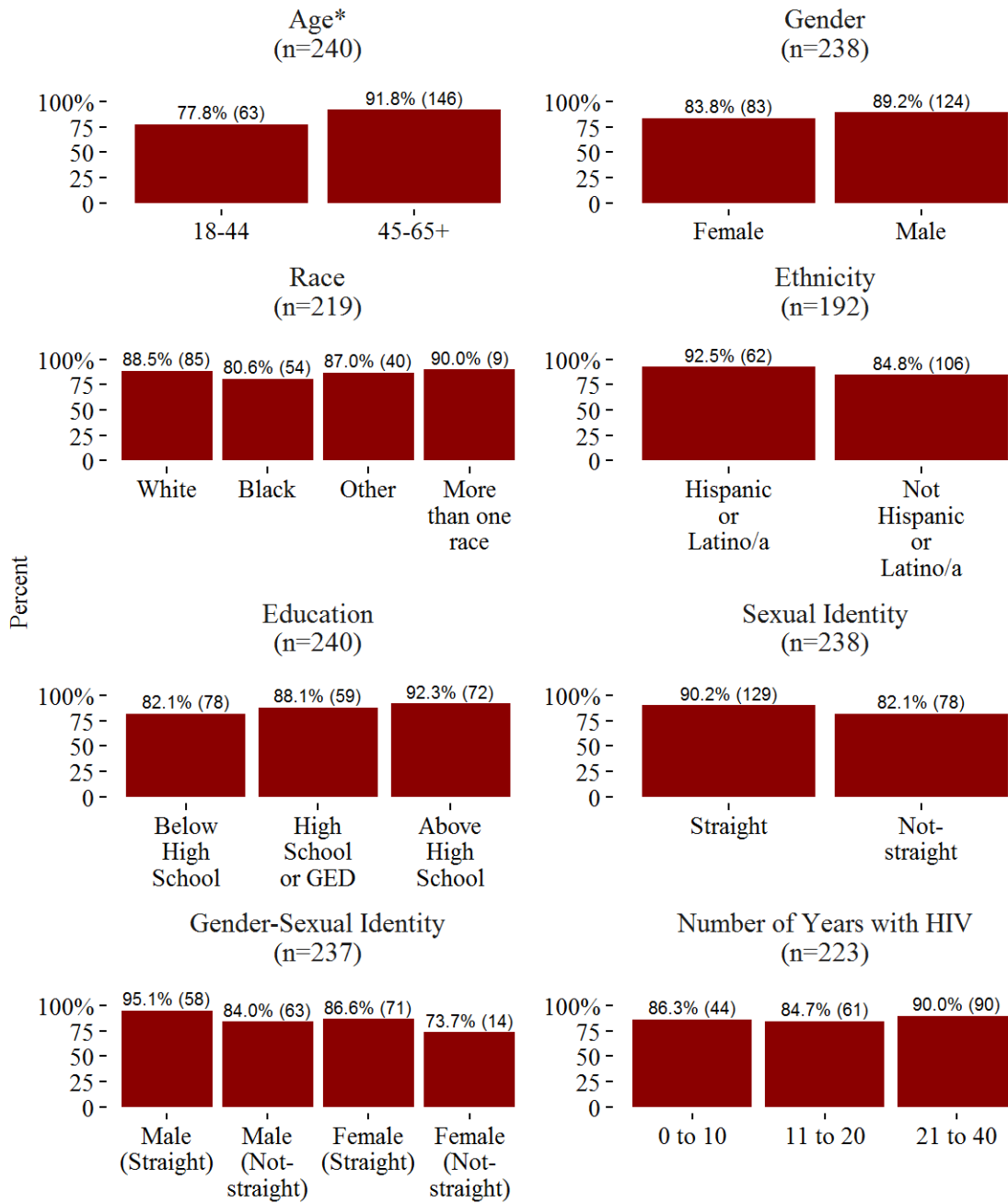
Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
Ryan White Consumer Survey

Age was the only significant predictor of 'always' taking medication for HIV/AIDS as prescribed. Ninety-two percent (92%) of people ages 45-65+ reported always taking medication for HIV/AIDS as prescribed compared to only 78% of people ages 18-44. Interestingly, there were limited differences by number of years with HIV. This may indicate that the wisdom and maturity that comes with aging is more helpful for adherence than the amount of time and experience with having the disease itself.

Men (89%) were more likely to report always taking their medication for HIV/AIDS as prescribed compared to women (84%) but the difference was not significant. Not-straight males (84%) were less likely to always take medication for HIV/AIDS as prescribed than straight males (95%) as were not-straight females (74%) compared to straight females (87%) but the differences were not significant.



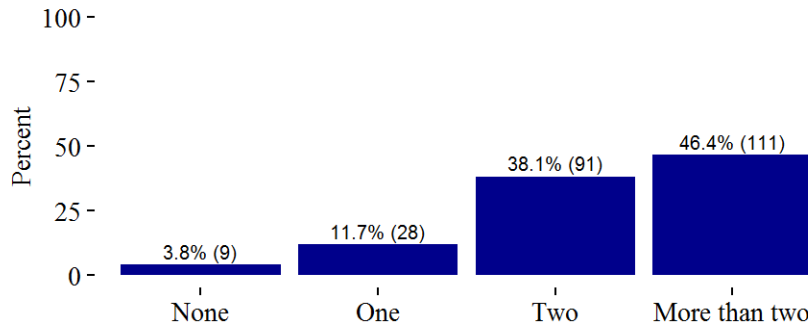
Figure 34: 'Always' Taking Medication for HIV/AIDS as Prescribed



Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

Forty-six percent (46%) of respondents reported receiving more than two viral load tests in the last year. Thirty-eight percent (38%) reported two, 12% one, and only 4% none.

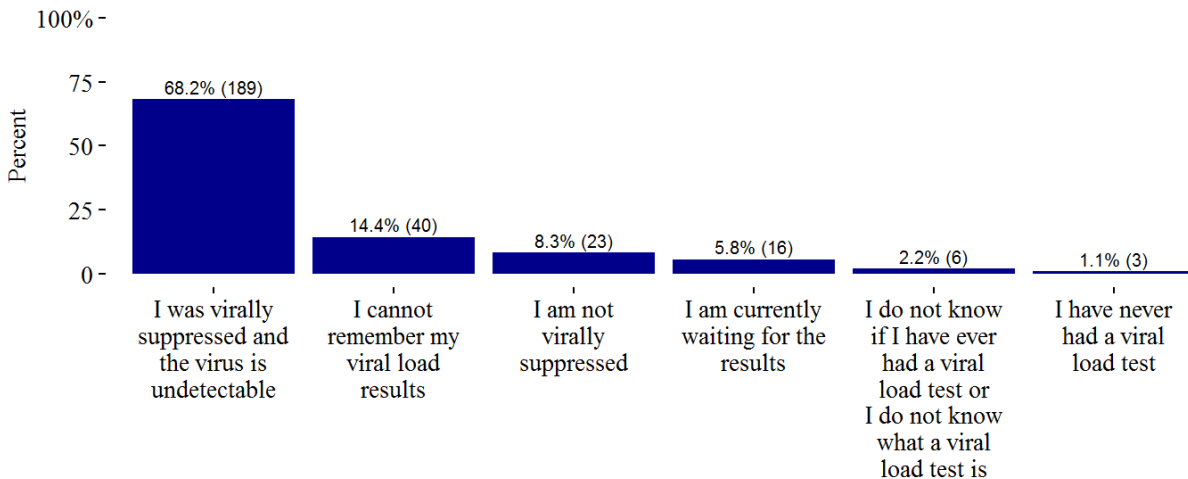
Figure 35: Number of Viral Load Tests in Last Year (n=239)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Sixty-eight percent (68%) of respondents reported that their last viral load test indicated that they were virally suppressed. Fourteen percent (14%) could not remember the results, 9% were not virally suppressed, 6% were currently waiting for the results, 2% did not know if they had ever had a viral load test, and 1% that they had never had a viral load test.

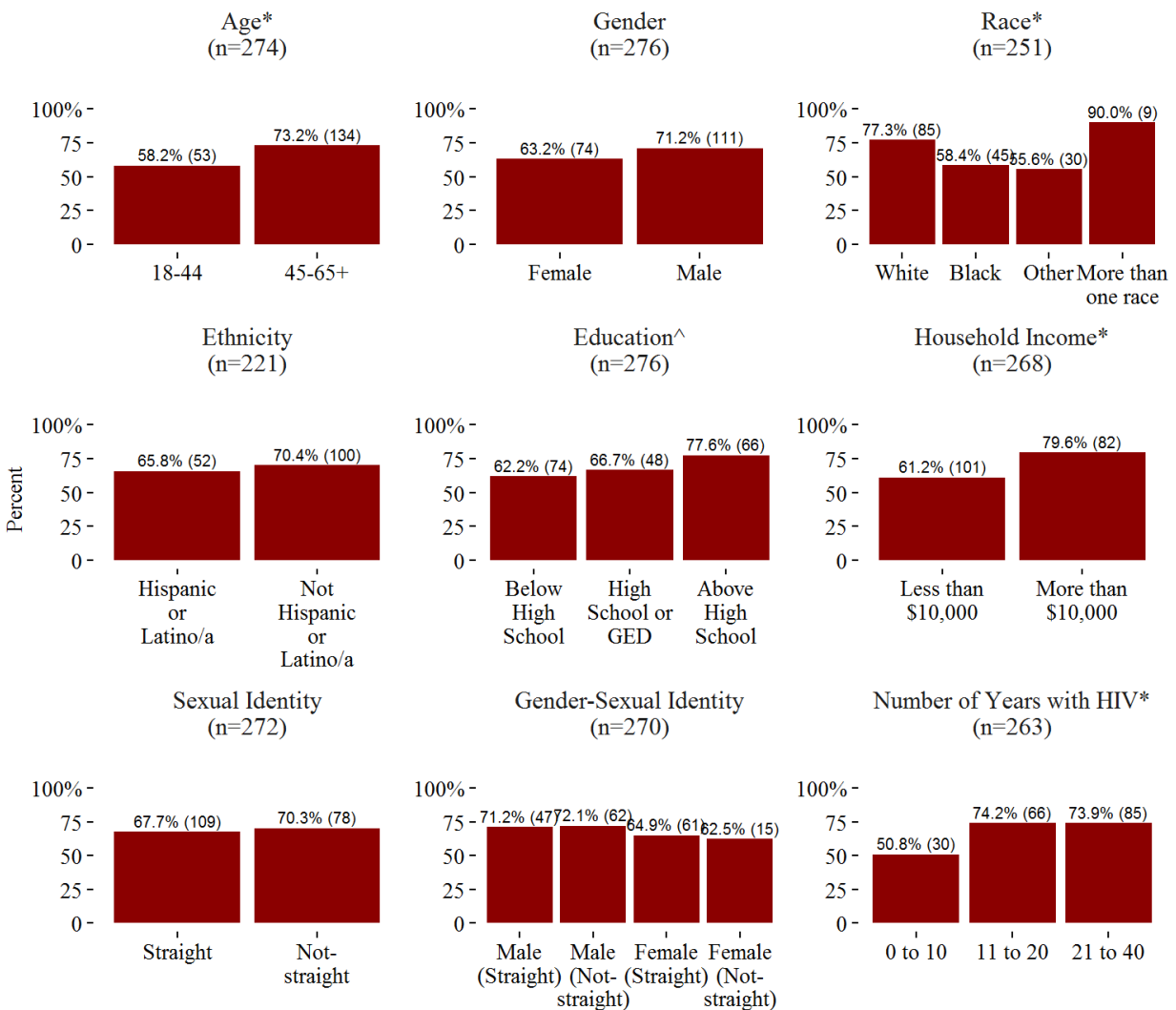
Figure 36: Most Recent Viral Load Test (n=277)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

There were significant differences in reports of viral suppression by age, race, household income, and number of years with HIV. Respondents ages 45-65+ (73%) were more likely than those ages 18-44 (58%) to report viral suppression. The same was true for white (77%) and more than one race (90%) when compared to black (58%) and other (56%), those with a household income of more than \$10,000 (80%) when compared to less than \$10,000 (61%), and those who have had HIV for 11-20 years (74%) and 21-40 years (74%) compared 0-10 years (51%). Men (71%) were more likely to report viral suppression than women (63%) but the difference was not significant. There were not any notable or significant differences in reported viral suppression by sexual identity or the four gender-sexual identity categories.

Figure 37: Reports Suppression from Last Viral Load Test



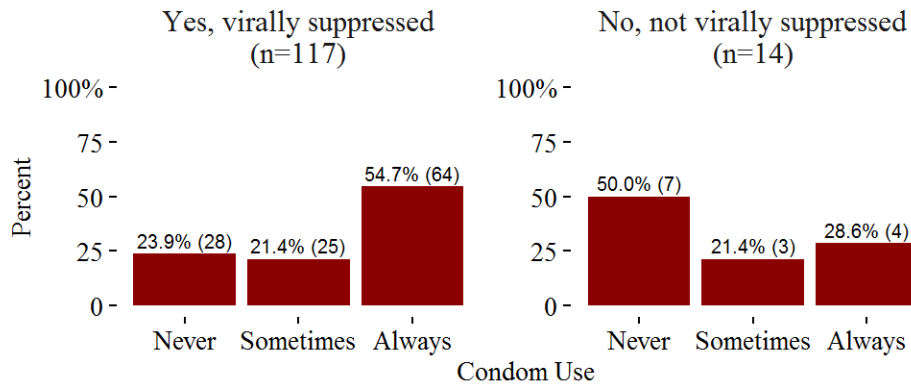
Notes: \* indicates significance, Pearson's Chi-squared test (p<0.05)

^ indicates borderline p-value of <0.07

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Fifty-five percent (55%) of respondents who reported viral suppression and 29% percent of respondents who were not virally suppressed indicated that they always wear condoms. This difference was not determined to be statistically significant. However, that is likely due to the small number of people (n=14) who answered the condom frequency question and reported not being virally suppressed.

Figure 38: Last Viral Load Test & Condom Use

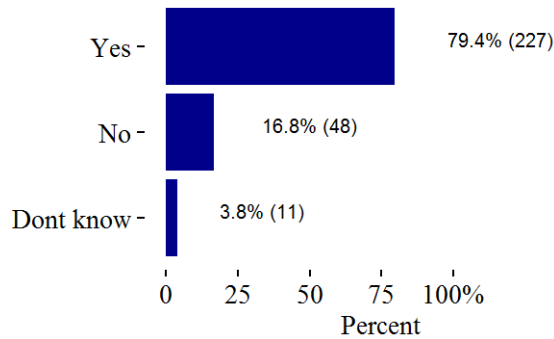


Notes: not statistically significant, Pearson's Chi-squared test ( $p < 0.05$ )  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Service  
 Ryan White Consumer Survey

Case Managers

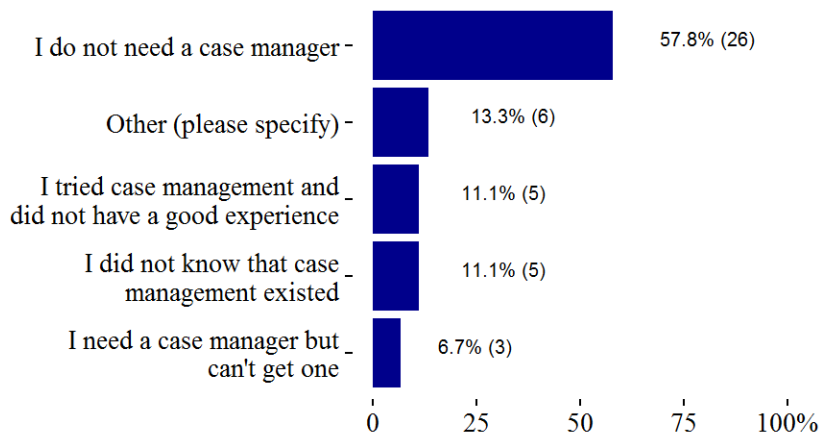
Seventy-nine percent (79%) of respondents indicated that they have a case manager. The most common reason for not having a case manager was 'I do not need a case manager' (58%) followed by 'other' (13%), 'I tried case management and did not have a good experience' (11%), 'I did not know that case management existed' (11%), and 'I need a case manager but can't get one' (7%).

Figure 39: HIV Case Manager (n=286)



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Figure 40: If no case manager, why not? (n=45), m.

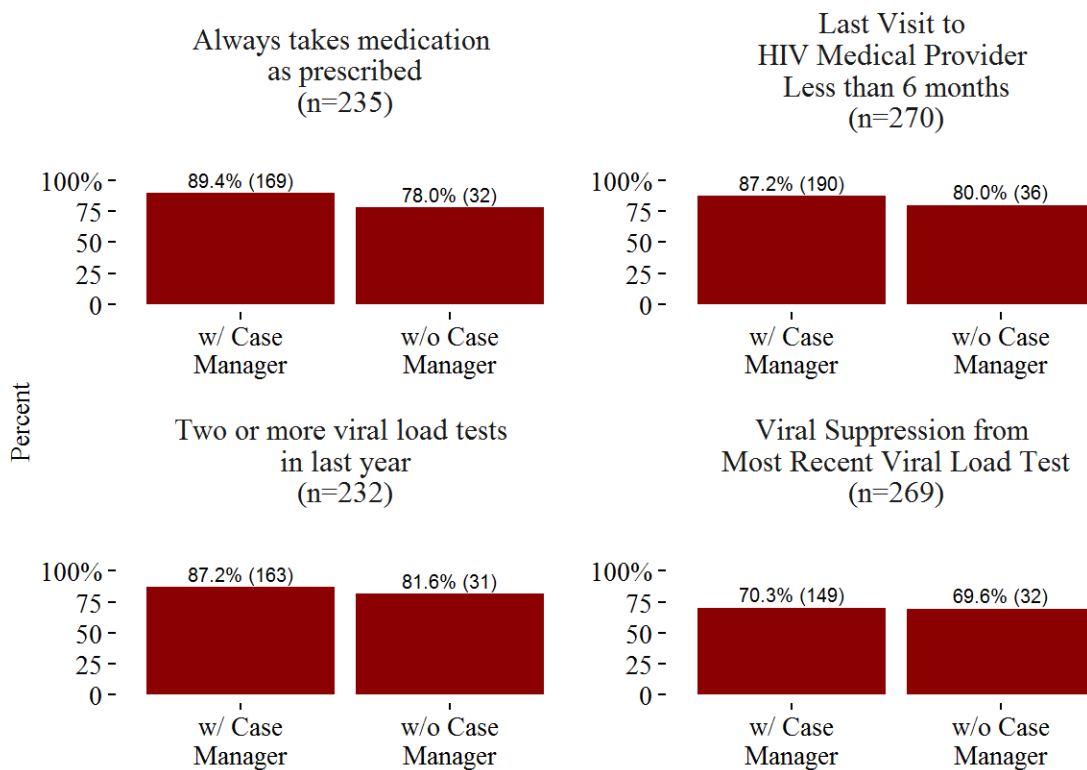


Notes: 'm.' indicates multi-select question.

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

There were not any significant differences in reported health processes or outcomes between the group of respondents with a case manager and the group of respondents without one. There may be several reasons for this. First of all, more people reported having a case manager (227) than not (48). This difference in group size may have made it more difficult to establish statistical significance with a Pearson's Chi-squared test. Secondly, variation in quality of case management across agencies and individuals may have muted the effect of 'good' case managers. This data should not be seen as a 'case against case managers' but rather a 'case for quality improvement.'

Figure 41: Case Managers: Health Process and Outcomes



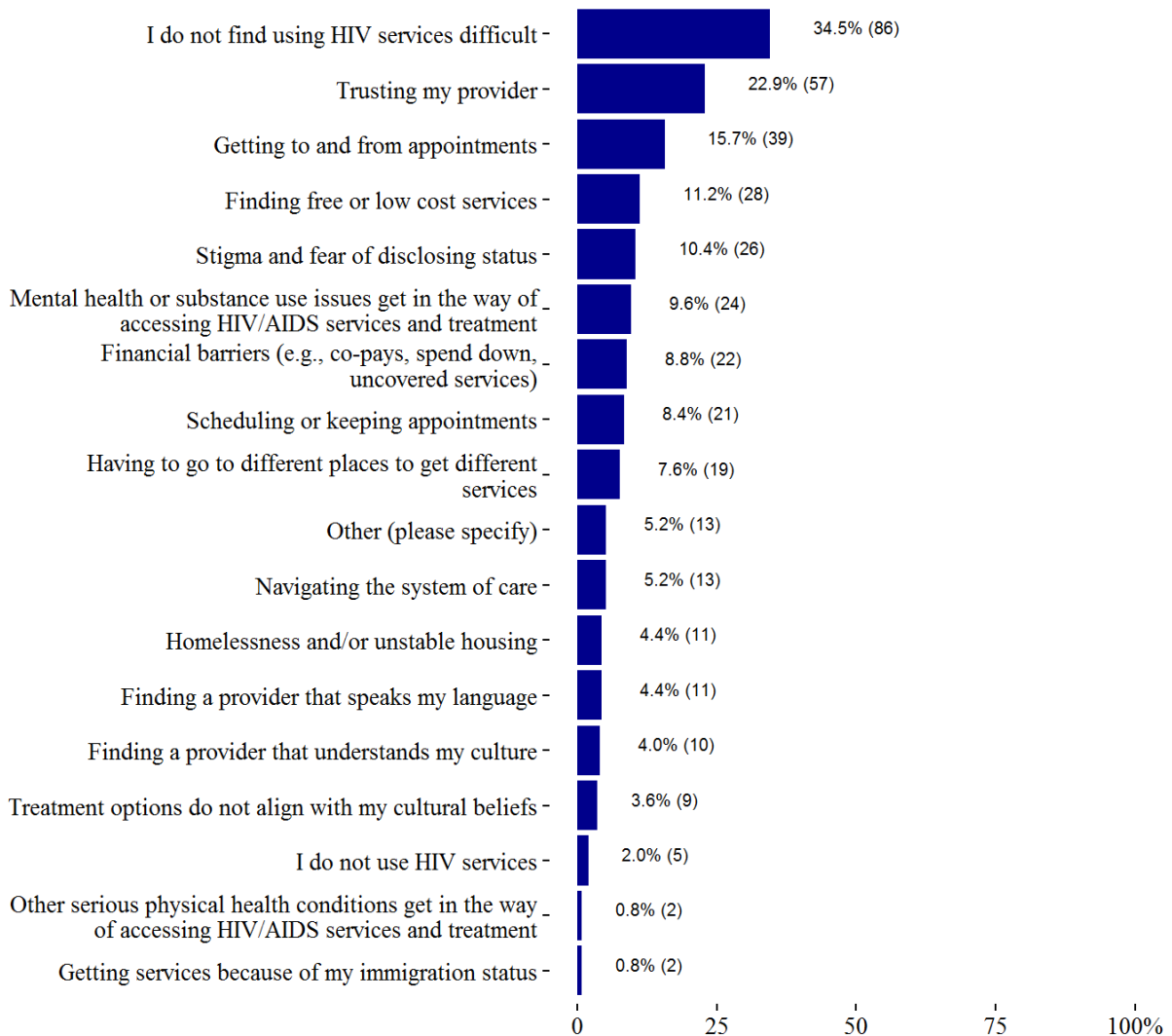
Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

**G. Barriers to Care**

The most frequent reported barrier to care by respondents was 'trusting my provider' (23%) followed by 'getting to and from appointments' (16%), 'finding free or low cost services' (11%), 'stigma and fear of disclosing status' (10%), mental health or substance use issues (10%), 'scheduling or keeping appointments' (8%), and 'having to go to different places to get different services' (8%). Thirty-five percent (35%) of respondents reported that they do not find using HIV services difficult.

The following graphic shows the percentage of consumers that indicated that a barrier response category was one of the most difficult parts about using HIV services for them.

Figure 42: Most Difficult about Using HIV Services(n=249), m.

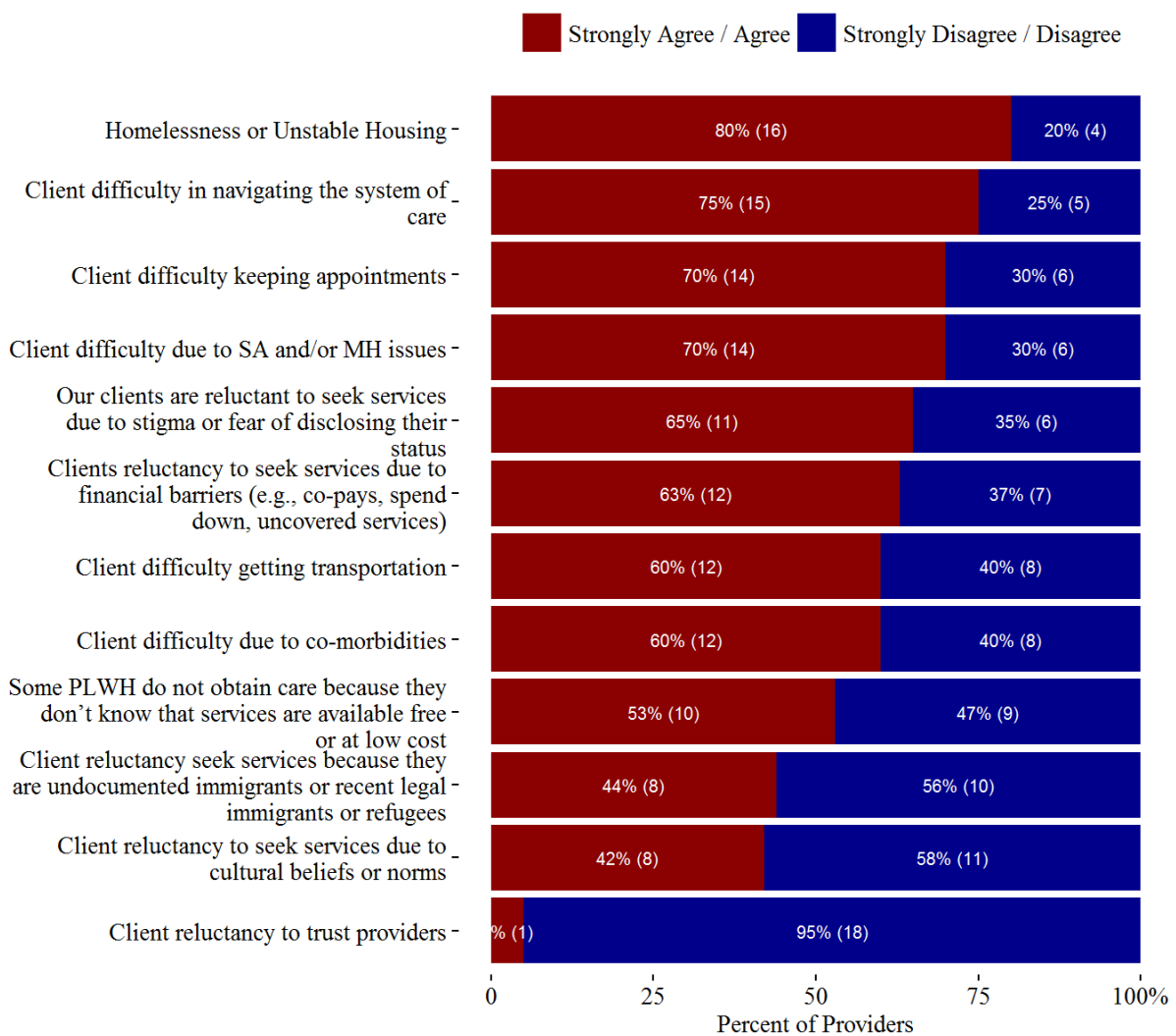


Notes: 'm.' indicates multi-select question.  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

The following graphic shows the percentage of providers that indicated that they either agreed or disagreed that a response category was a barrier to care for the PLWHA that they work with. It is important to recognize that the percentages in this graph are *not* directly comparable to the percentages in the previous graph. As the questions were asked differently, the percentages have different meanings. Care was taken to ensure that barrier response categories in the 2013 survey of providers were reflected in the 2015-2016 survey of consumers.

Only 5% of providers identified 'client reluctance to trust providers' as a barrier care when asked during the during the 2013 Provider Capacity Capability Survey. In contrast, 'trusting my provider' was the top listed barrier to care by consumers in this survey.

Figure 43: Barriers to Care: Provider Survey 2013



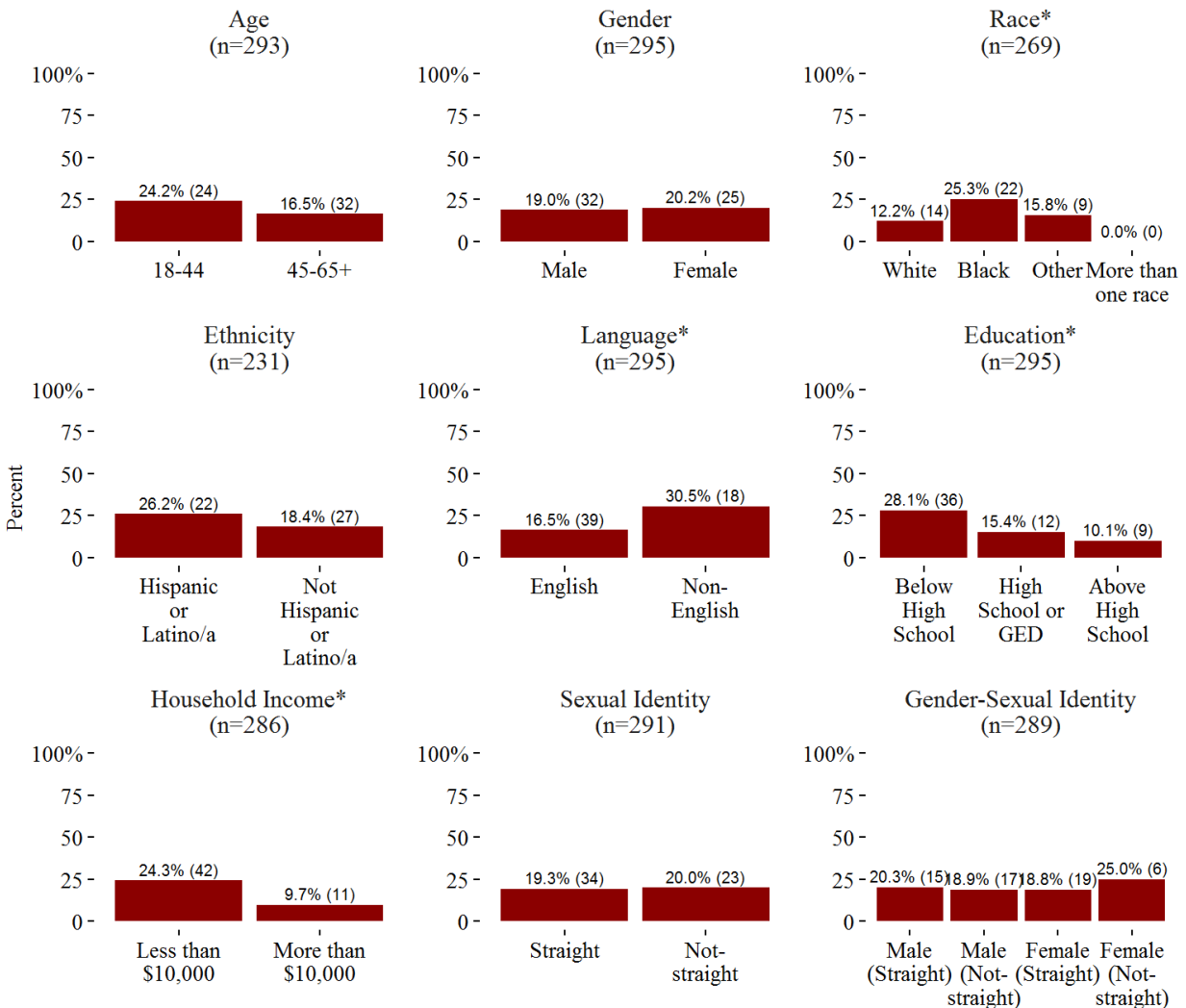
Data Source: Provider Capacity Capability Survey 2013, RI Executive Office of Health and Human Services (EOHHS)



Black respondents (25%) were significantly more likely than white respondents (12%) to report 'trusting their provider' as a barrier to care. The same was true for those with a primary language other than English (31%) when compared to English (17%), those with an educational level below high school (28%) when compared to high school or GED (15%) and above high school (10%), and those with a household income of less than \$10,000 (24%) when compared to more than \$10,000 (10%). Respondents who identified as Hispanic or Latino/a (26%) were more likely than non-Hispanic or Latino/a respondents (18%) but the difference was not significant.

There were not any notable or significant differences by gender, sexual identity, age, or the four gender-sexual identity categories.

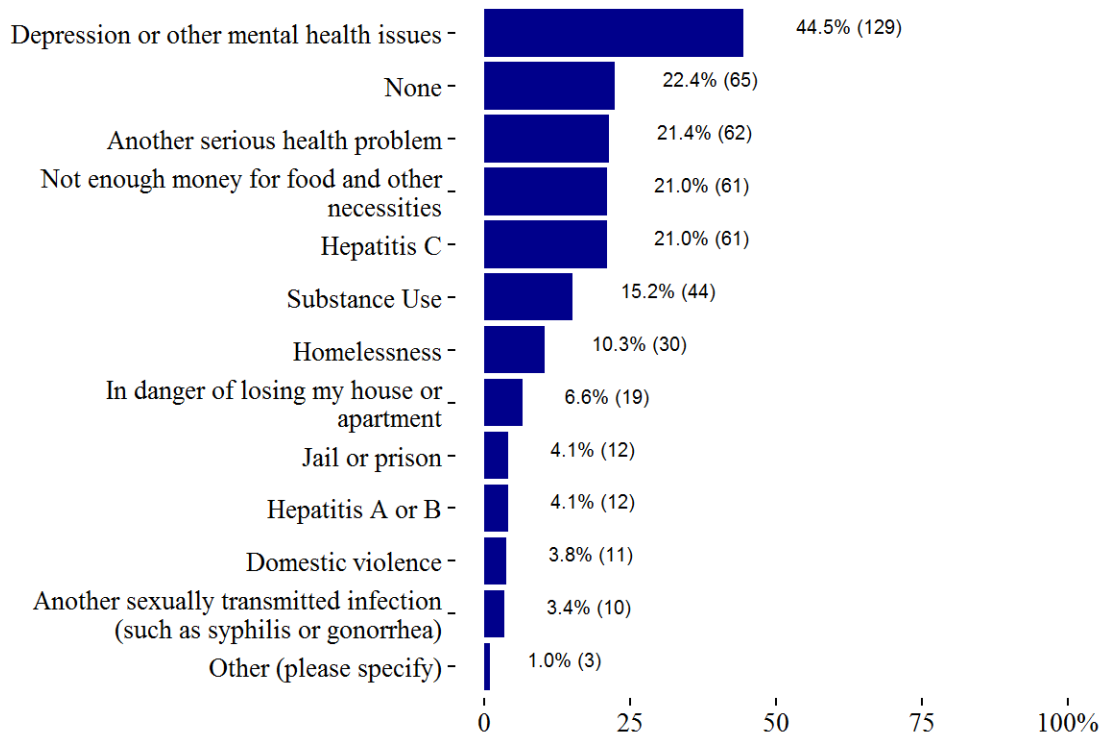
Figure 44: Reported 'trusting my provider' as most difficult about using HIV services



Notes: \* indicates significance, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

The most common disease, health condition, or life situation in addition to HIV/AIDS that respondents had been dealing with over the past 12 months was depression or other mental health issues (44.5%) followed by 'none' (22%), another serious health problem (21%), not enough money for food and other necessities (21%), hepatitis C (21%), substance use (15%), and homelessness (10%).

Figure 45: Other Medical & Personal Issues (n=290), m.

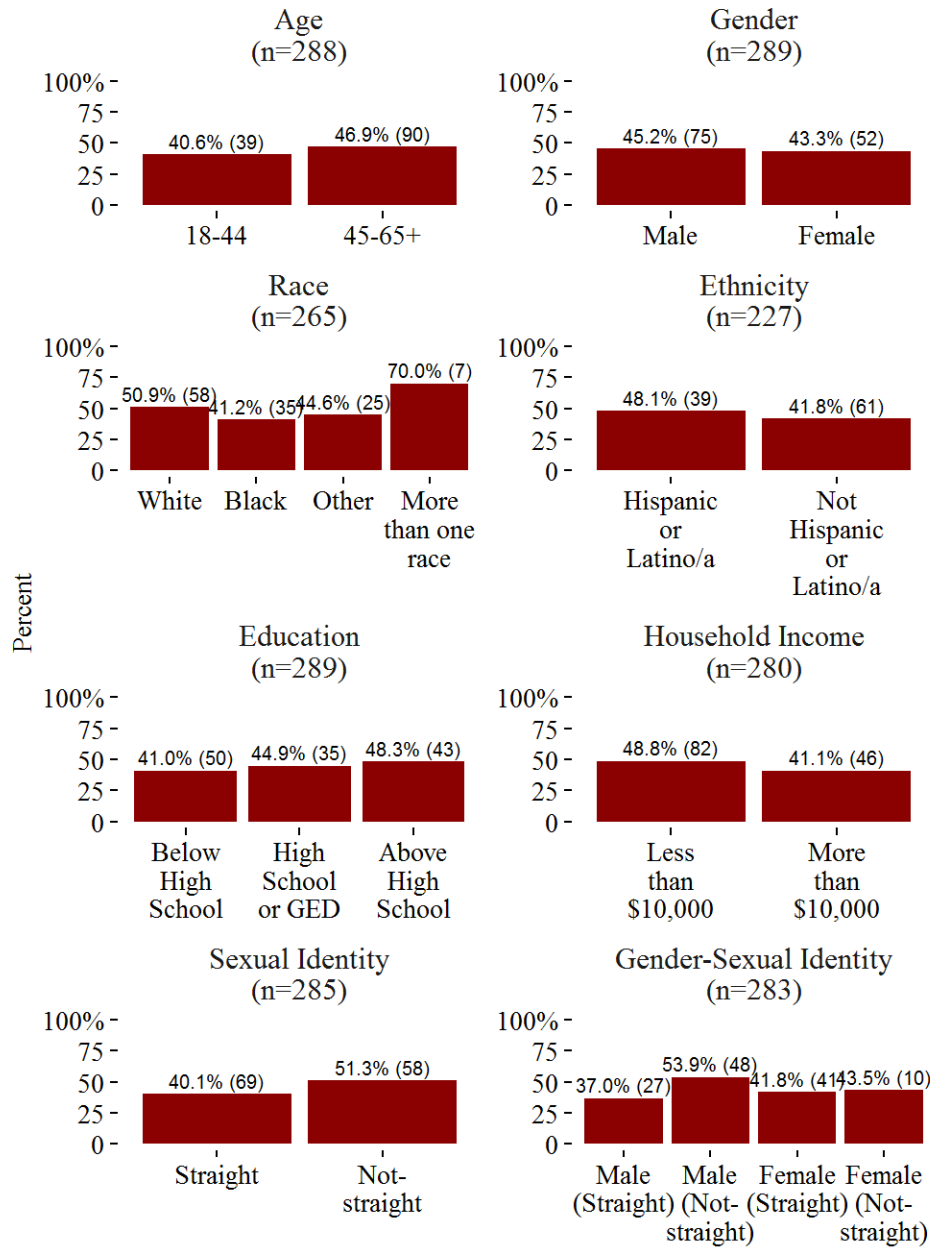


Notes: 'm.' indicates multi-select question.

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

There were no statically significant differences in reports of depression among the categories of age, gender, ethnicity, household income, education, sexual identity, and race. This indicates that depression is a comorbidity that is reflective of the experience of having a chronic, debilitating disease and is not specific to a social, racial, or economic group. In other words, depression can easily impact anyone who has HIV/AIDS. Not-straight men (54%) were notably more likely to report depression than straight men (37%), straight women (42%), and not-straight women (44%) but the differences were not significant.

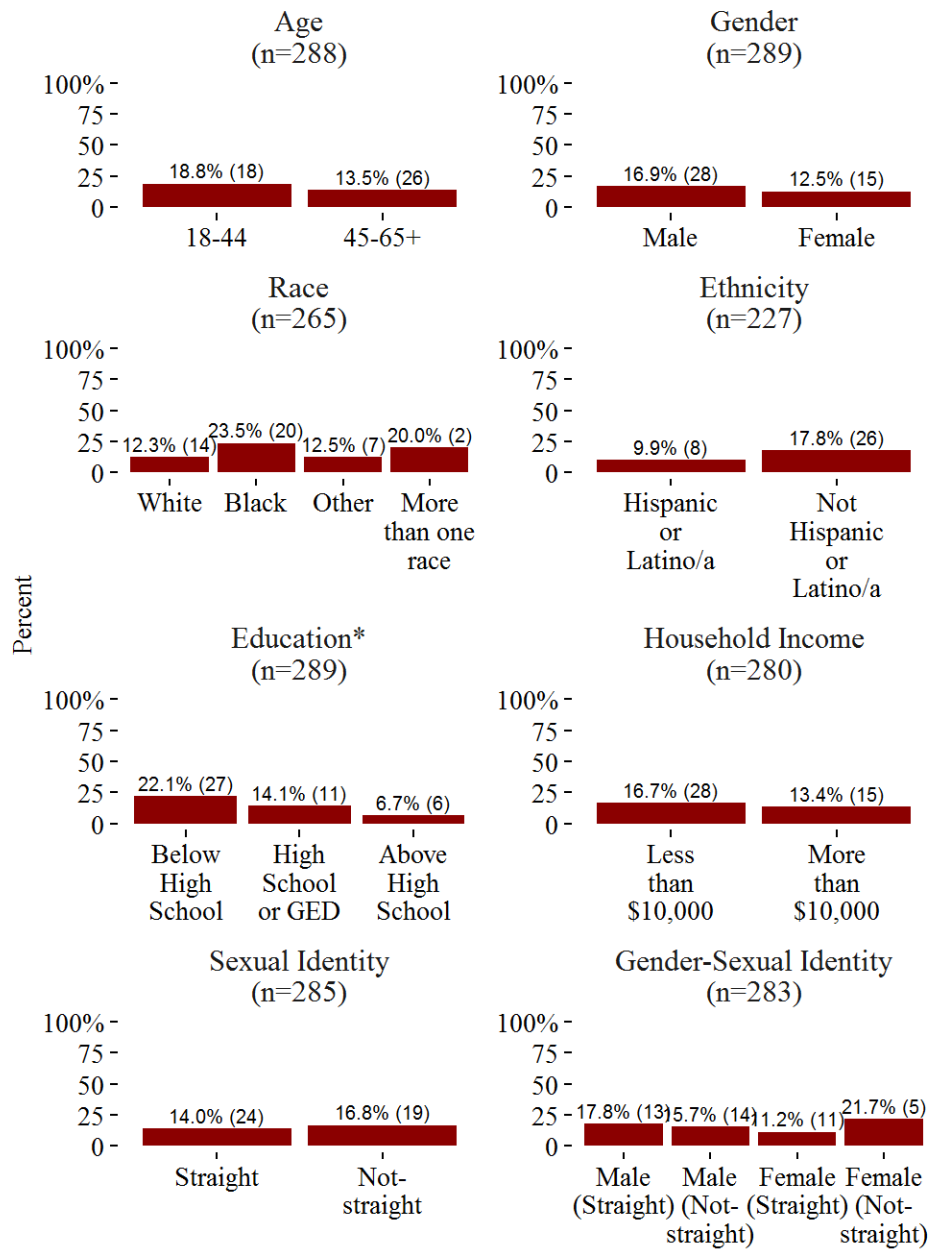
Figure 46: Reports Depression or other mental health issues



Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

There were also no statically significant differences in reports of substance use among the categories of age, ethnicity, household income, gender, sexual identity, and race. There was a significant difference between education levels with respondents with an education level below high school (22%) being more likely to report substance use compared to those with a high school or GED-level education (14%) and those above high school (6.4%). Like depression, this indicates that substance use is a comorbidity that is equally common among racial, social, and economic groups of people living with HIV/AIDS.

Figure 47: Reports Substance Use

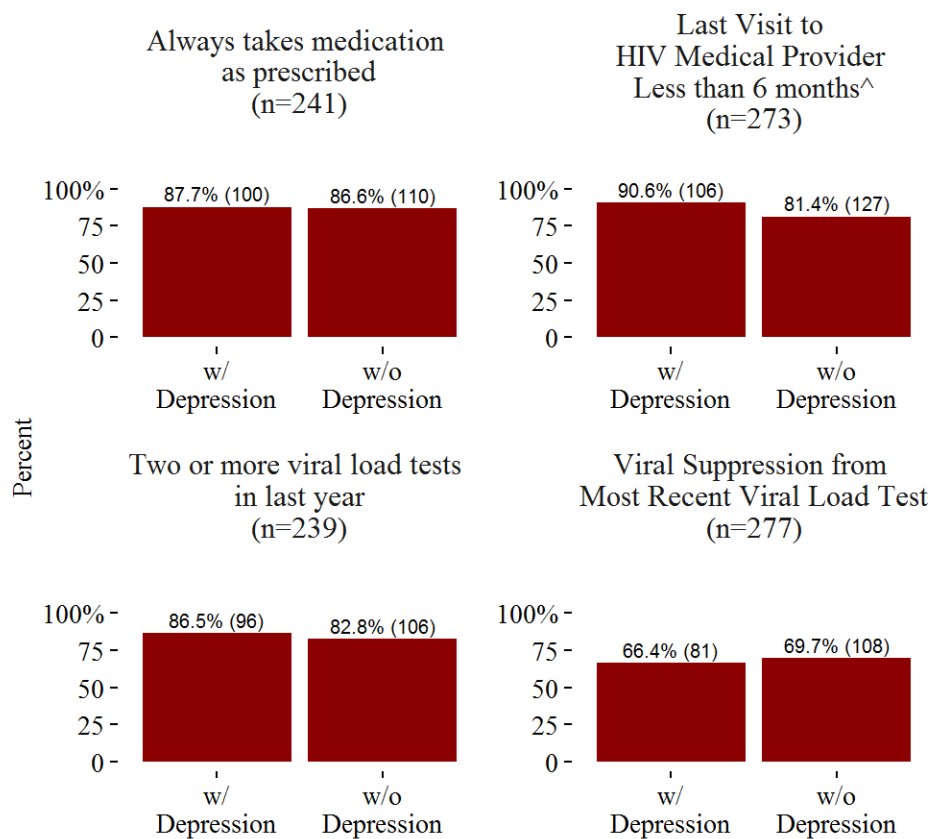


Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Depression was not a consistent predictor of responses to health process and outcomes questions. As an exception, those with depression (91%) were significantly more likely than those without depression (81%) to have a last visit to an HIV medical provider within the last 6 months. This may speak to the high quality of HIV and mental health care in Rhode Island that recognizes that those with depression require more aggressive follow-up or that people with depression may be more likely to seek care due to their need. As those with depression are more likely to be linked to care, their increased contact with medical providers may have facilitated viral load tests and adherence discussions which may lead to viral suppression through increased adherence rates. Thus, the potential effect of having depression was muted by the effect of seeing a provider more frequently.

The lack of statistically significant differences may also be explained by considering that many PLWHA in RI may be suffering from depression but not to the extent that it impacts their HIV self-care. As this survey instrument did not separate between those with well-managed depression and those with unmanaged, the impact of unmanaged depression is muted.

Figure 48: Depression: Health Process and Outcomes



Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)

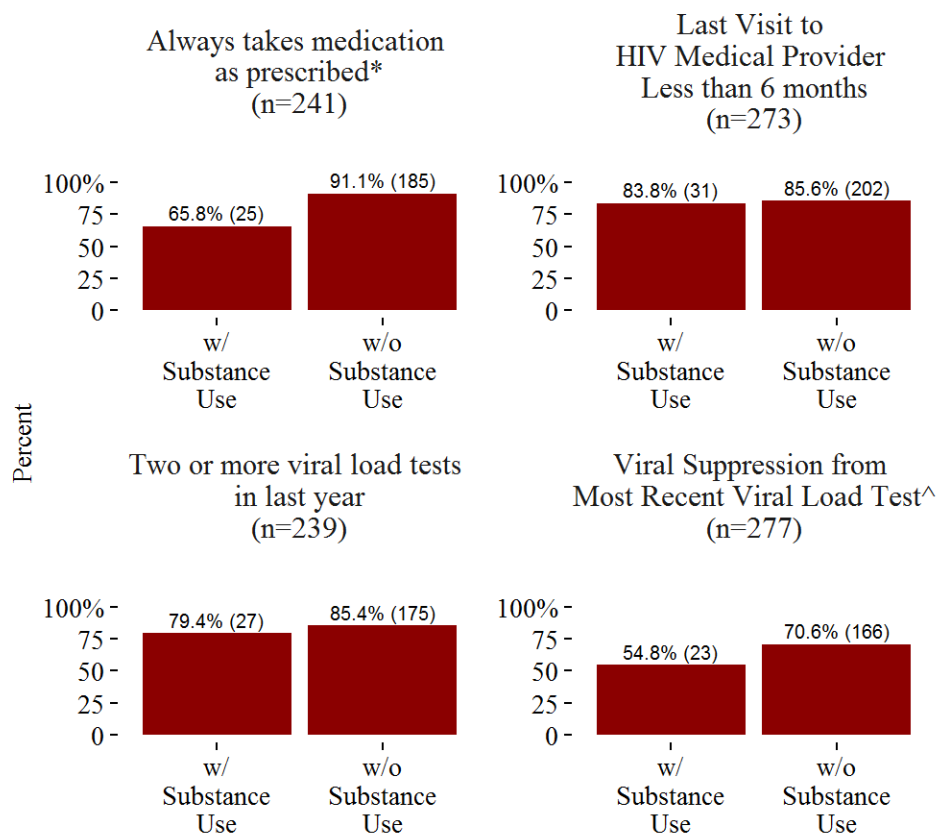
<sup>^</sup> indicates borderline p-value of <0.07

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

In contrast to the depression health process and outcomes stratification, those that reported substance use (66%) were significantly less likely to report always taking their medication as prescribed when compared to those that did not report substance use (91%). Those that reported substance use (55%) were also significantly less likely to report viral suppression when compared to those who did not report substance use (71%).

Surprisingly, those who reported substance use (84%) and those that did not (86%) were equally likely to have had a visit to an HIV medical provider in the last 6 months. This indicates that providers have the opportunity to reach individuals with substance use and HIV and refer them to organizations that can help them in recovery.

Figure 49: Substance Use: Health Process and Outcomes



Notes: '\*' indicates significance, Pearson's Chi-squared test (p<0.05)

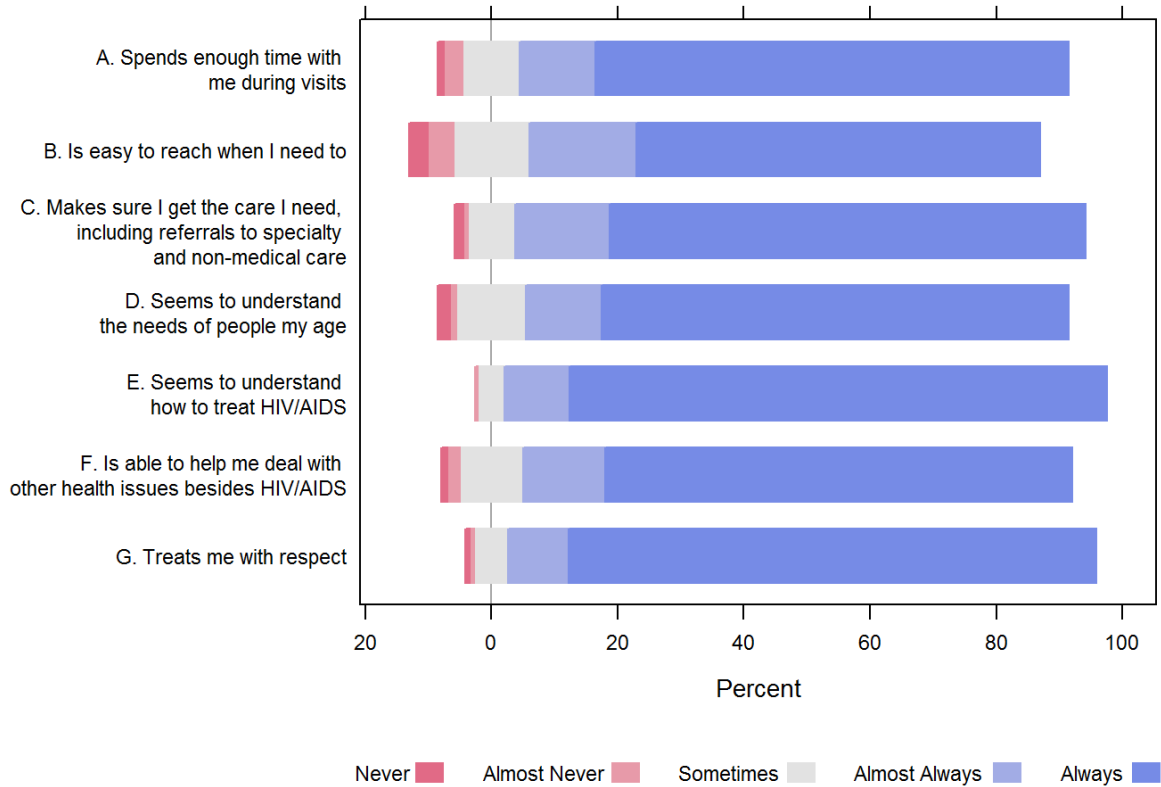
^ indicates borderline p-value of <0.07

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

### H. Satisfaction with Provider

The following graphic summarizes responses to questions around consumers' satisfaction with their HIV medical provider. Positive responses are shown in blue to the right of the '0' axis and negative responses are shown in red to the left. It is clear that consumers are largely very satisfied with their HIV medical providers.

**Figure 50: Provider Satisfaction: My primary HIV medical provider...**



## I. Assessment of Need

The following three graphics represent this survey's findings around assessment of need. Respondents were asked to rate sixteen different services by whether they 'need but can't get the service,' 'need and use the service,' or 'don't need the service.' In this context, need is defined as the number of people who need the services and either are currently receiving it or not receiving it. 'UnMet need' is defined as the number of people who need the service and cannot get it.

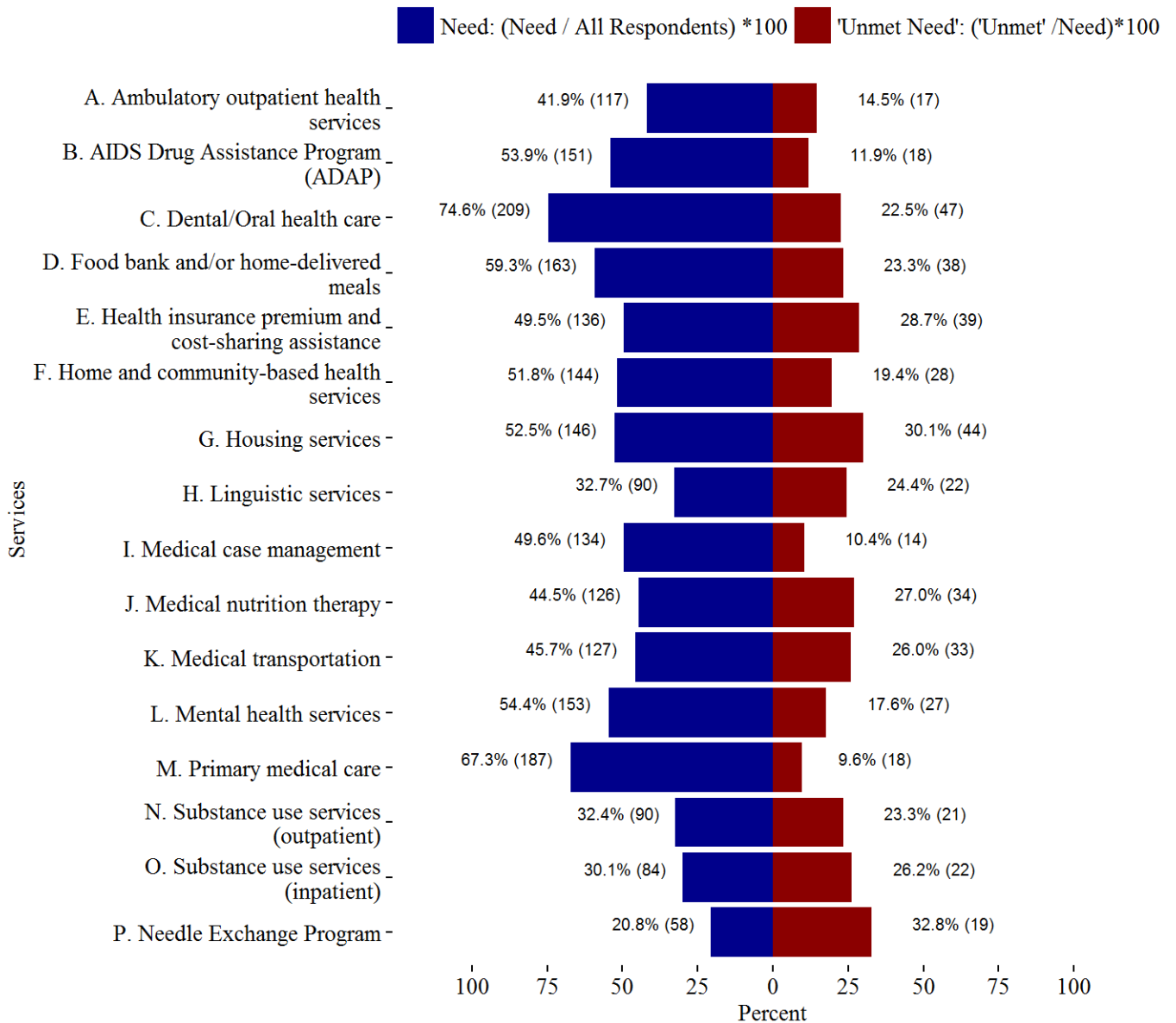
The following graphs show need as a percentage of all individuals who responded to the question in blue. They show UnMet need as a percentage of respondents who indicated a need.

$$\text{Need (Blue): } \frac{\text{Need}}{\text{AllRespondents}} (100); \text{ 'UnMetNeed' (Red): } \frac{\text{'UnMetNeed'}}{\text{Need}} (100)$$

The graphs are presented in three fashions: unsorted, sorted by need (Blue), and sorted by 'unmet need' (Red).



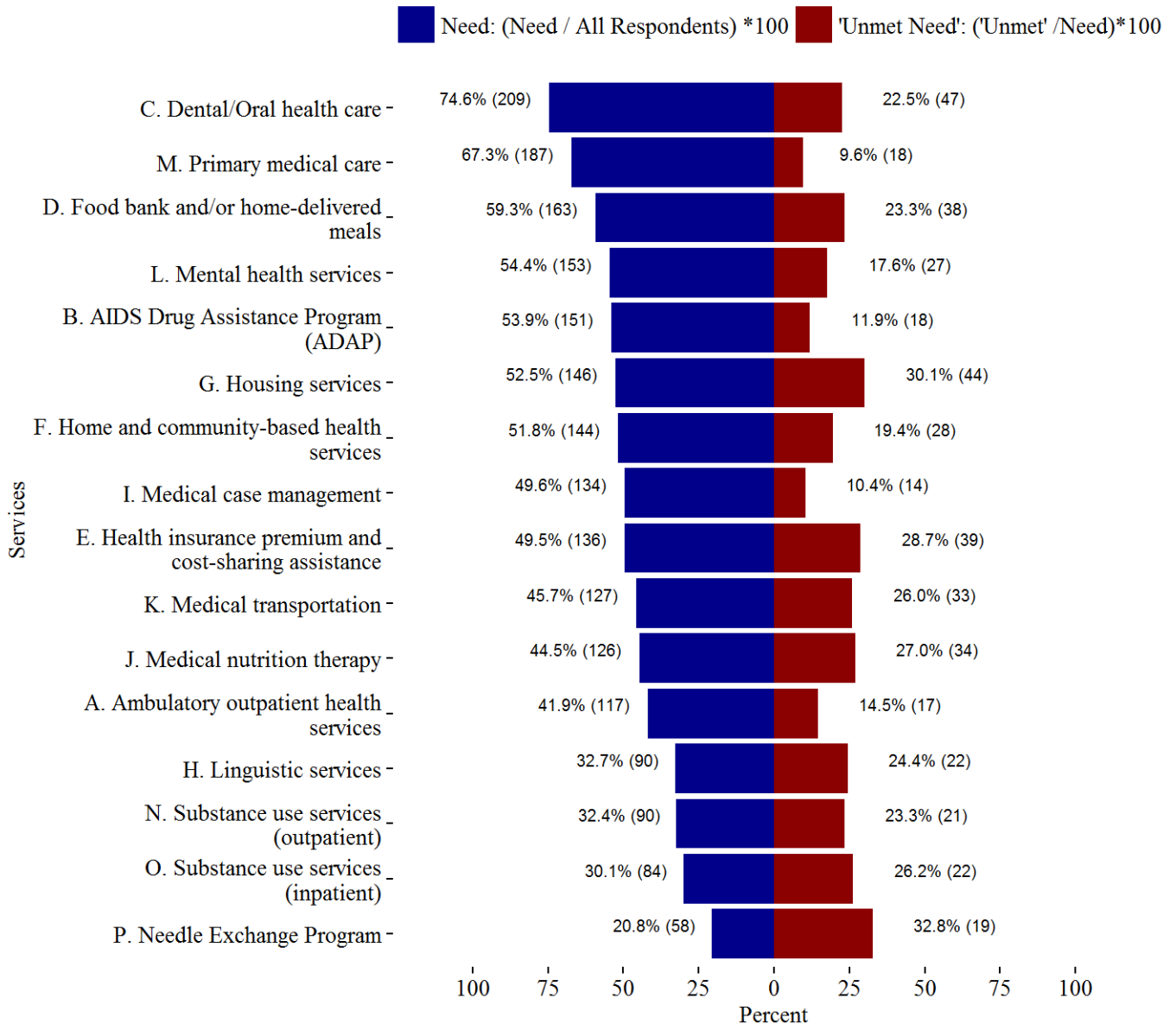
Figure 51: Assessment of Need: Unsorted



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

The following assessment of need graph that is sorted by need highlights the most commonly needed services by PLWHA in Rhode Island. The top eight needed services are Dental/Oral health care (75%), primary medical care (67%), food bank and/or home-delivered meals (59%), mental health services (54%), AIDS Drug Assistance Program (ADAP) (54%), housing services (53%), home and community-based health services (53%), and medical case management (50%). These percentages are reflective of the percent of the PLWHA population in Rhode Island who are in need of the listed service.

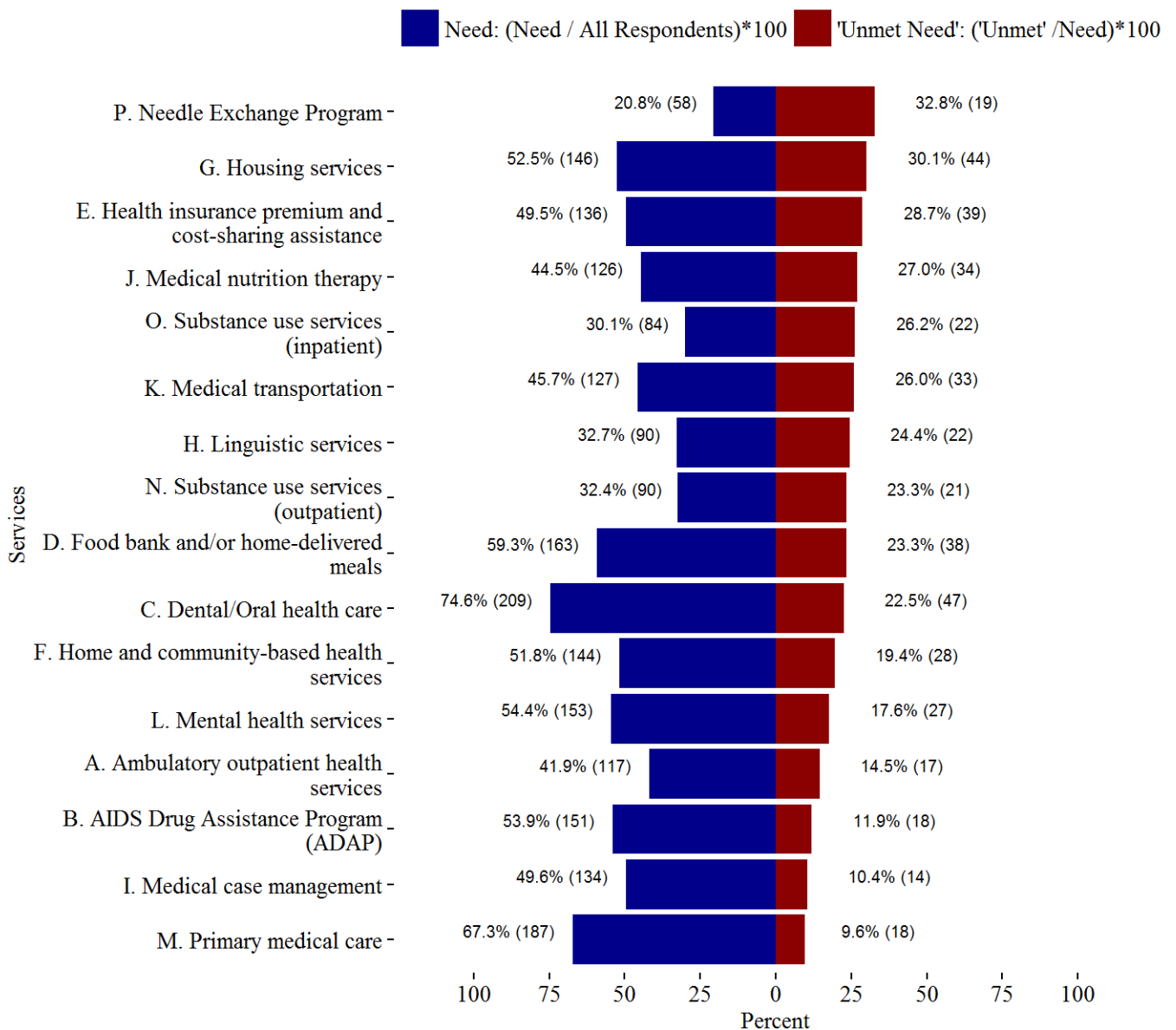
Figure 52: Assessment of Need: Sorted by Need



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

The following assessment of need graph that is sorted by 'unmet need' highlights the services that the highest percentage of people who need them can't get them. The top eight services by percent of need that is unmet are need exchange program (33%), housing services (30%), health insurance premium and cost-sharing assistance (29%), medical nutrition therapy (27%), substance use services inpatient (26%), medical transportation (26%), linguistic services (24%), and substance use services (outpatient) (23%). This graphic shows that while some services are needed by a relatively low percentage of the overall PLWHA population in Rhode Island (e.g. needle exchange, substance use services, and linguistic services), there is still a high percentage of the people who need the service that cannot access the service.

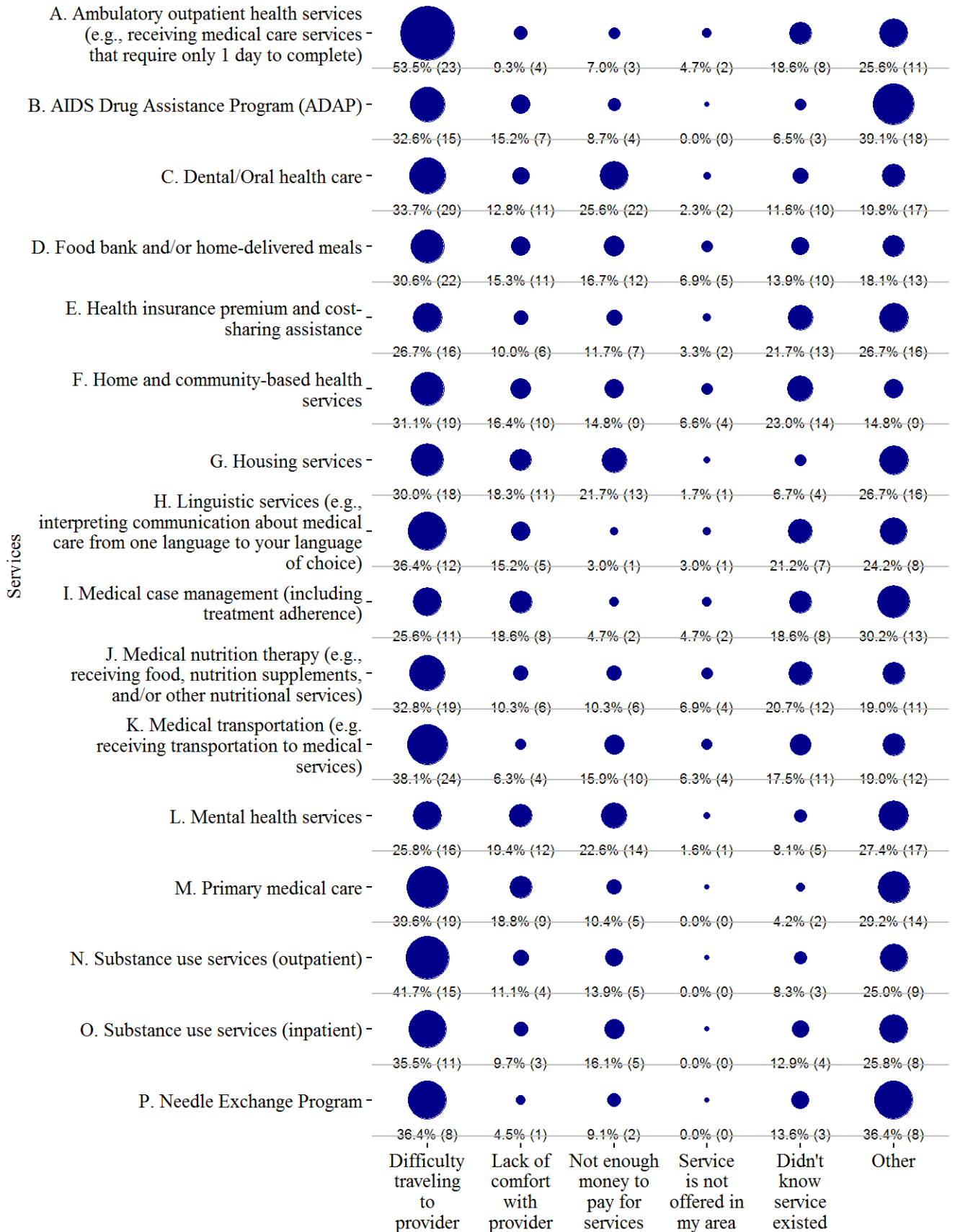
Figure 53: Assessment of Need: Sorted by 'Unmet' Need



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

The following graph breaks the assessment of need services out by specific barriers to care. All responses of "No Challenge Experienced" and "NA" have been excluded so the percentages are specific to people who experience a barrier to care. 'Difficulty traveling to provider' was consistently the highest category across all services and 'service not offered in my area' is consistently the lowest. 'Lack of comfort with provider' was high in mental health services (19%), primary medical care (19%), and medical case management (19%). 'Not enough money to pay for services' was high in dental/oral health care (26%), mental health services (23%), housing services (22%), food bank and/or home-delivered meals (17%), and substance use services (inpatient) (16%). 'Didn't know service existed' was high in home and community-based health services (23%), health insurance premium and cost -sharing assistance (22%), linguistic services (21%), and medical nutrition therapy (21%).

Figure 54: Assessment of Barriers and Challenges - 'No Challenge' and 'NA' Excluded, m.



Notes: 'm.' indicates multi-select question.

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey



## Discussion & Recommendations

This section first presents a framework for achieving health equity and then summarizes key findings, insights, and recommendations.

### *A Framework for Achieving Health Equity*

The results section offered numerous examples of social and economic conditions (e.g. household income, employment, education status), health processes (e.g. visiting the doctor, taking medications), and health outcomes (e.g. viral suppression) that differed by race, ethnicity, age, gender, and sexual identity. These are exceptionally clear real-world examples of social determinants of health. The **Introduction** to this report included a description of social determinants of health in the context of HIV/AIDS (included below).

Social determinants of health (SDH) are “economic and social conditions that influence the health of individuals and communities” (Dean & Fenton, 2013). Inherent to geographic locations and social demographics, they define how physical resources and personal agency are distributed across a population and determine who is subjected to stigma and discrimination. Lack of education, adequate income, or appropriate housing makes it more difficult for individuals to engage in appropriate prevention, health promotion, and self-care activities. The literature clearly demonstrates that educated, resource-rich individuals are more likely to be healthy while the less-educated, resource-poor are more likely to be unhealthy and lack adequate access to healthcare (Abbott & Williams, 2015).

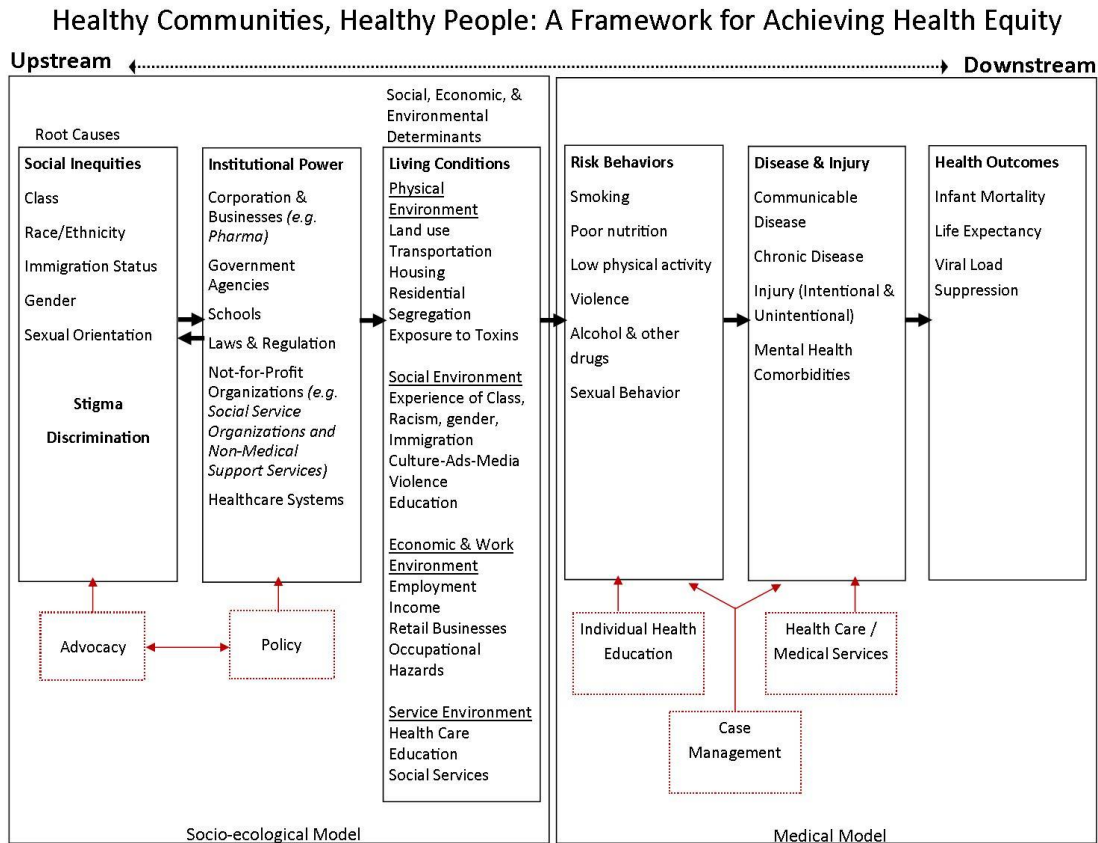
HIV/AIDS is no exception. Its aggressive pathophysiology necessitates complex treatment, regular self-care, and consistent follow-up, making it especially difficult for resource-poor individuals to manage. Not only is it disproportionately present in minority populations such as Latino and Black gay men (i.e. men who have sex with men (MSM)), but those groups also have worse health outcomes when compared to their non-Latino or white peers (Howe et al., 2014; Mugavero et al., 2009; Oster et al., 2013). A primary mechanism for these observed disparities are missed medical visits, which are much higher among black and injection drug use patients and have been statistically shown to account for lack of viral suppression in these populations (Howe et al., 2014; Mugavero et al., 2009; Zinski et al., 2015).

(2016 Ryan White Consumer Survey, Introduction)

It is important to not only have awareness of the existence of social determinants of health but also have a framework for developing a comprehensive plan that identifies actionable steps to move towards greater health equity. The HIV Care Continuum, also explicated in the introduction of this report, presents an analytic framework around the necessary stages of involvement of a person living with HIV/AIDS with their healthcare system and treatment. But it does not summarize the social and economic factors that cause disenfranchisement and poor health outcomes. Fortunately,

‘social determinants of health’ provides a strong foundation to develop a specific framework for identifying intervention points.

This report presents “A Framework for Achieving Health Equity” as the means to identify specific points of intervention that are relevant to this survey effort’s results around social determinants of health. This framework was adapted from the Bay Regional Health Initiative’s Framework for Achieving Health Equity. It is a compilation of both a socio-ecological model and a medical model.



Adapted from Bay Area Regional Health Initiative's Framework for Achieving Health Equity

The sociological model emphasizes how social and physical realities can strongly shape patterns of disease, injury, and treatment throughout an individual’s life (Fielding, Teutsch, & Breslow, 2010). Inherent characteristics of a person, like class, race, ethnicity, immigration status, gender, and sexual orientation, are attributed social meaning through institutional power structures, conferring discrimination on minority groups. Institutions include business, government agencies, schools, systems of law and regulation, and social service organizations. They can diminish individual agency through overt discrimination (racism, classism, etc.) or simply because their systems have been designed for use by the dominant population without sufficient thought to the needs of minorities. Education systems are particularly central as an individual’s education supports their employment and ability to understand health-related needs.



As a result of discrimination and less access to opportunity, minority groups are more likely to be exposed to inferior living conditions. This could include inadequate access to public transportation, poor quality housing, residential segregation (leaving individuals further from needed services), and increased likelihood of exposure to environmental toxins. Beyond the physical environment, individuals may also face a hostile social environment, complete with class-based, race-based, and gender-based violence. This could take the form of overt discriminatory statements or actions against a minority or the presence of pop culture, advertisements, and media that depict minorities in a negative manner. In the work environment, these forces, including prior limited access to educational opportunities, could manifest in fewer employment opportunities, less income, and additional occupation hazards.

The socio-ecological model highlights upstream points of intervention that can take place before an individual becomes sick or injured. Policy changes can make institutional systems more effective for minority groups and promote the work of social service organizations to mitigate the consequences of poor living conditions through outreach programs, affordable housing, and other support services. However to address the source of discrimination at its root, advocacy and social action are needed. They work to improve society's prevailing attitude towards minority populations.

In contrast to the socio-ecological model, the medical model focuses primarily on risk behaviors, clinical diagnosis, and medical intervention in the treatment of disease. Individuals who engage in risk behaviors such as smoking, poor nutrition, low physical activity, violence, alcohol & other drugs, and unsafe sex are more likely to be diagnosed with disease and have poor health outcomes (Institute of Medicine (US) Committee on Health and Behavior: Research, Practice, and Policy 2001). It is here that the medical model interfaces with the socio-ecological model. The individuals most at risk for risk behaviors are those who are disenfranchised through social inequities, institutional power structures, and inferior living conditions.

Within the medical model, there are several intervention points. The first is health education to reduce risk behaviors and promote healthy lifestyles. When individuals do become sick or injured, the healthcare system—made up of networks of doctors, nurses, therapists, administrative staff, and many others—works to treat the disease or heal the injury. But 'healthcare' is a type of institution itself, and thus risks conferring discrimination or not being structured for ease-of-use by minority populations. Case managers can mitigate this by helping patients navigate the complex system of care. They also can help address some of the underlying living condition problems by connecting their clients to support services.

Stigma from HIV status may be experienced across all points of this framework, adding to an individual's existing social, economic, and medical challenges. The experience of stigma is multilayered and complex. It may manifest externally (e.g. a disparaging comment by a health provider, peer, or family member) or internally (e.g. a feeling of failure) and may be a result of existing cultural norms in a given population. Stigma from HIV may also compound the experience of racial or ethnic discrimination in minority populations.



While this framework is presented in a linear fashion, it is also cyclic and recursive. Sick, infirmed, and injured people have to overcome significant challenges to be productive, employed, and self-sustaining. As a result, they may be less likely to have the income required to maintain healthy living conditions and health-promoting behaviors. For some, these factors and forces may trap them in a vicious ‘snowball-effect’ cycle of poverty, unemployment, and disease. For these individuals, it is incredibly important that they receive multiple interventions at all possible points in their trajectory: social service, health education, case management, and healthcare.

Thoughtful, robust, and effective efforts are needed to address discrimination and structural inequities in minority populations of PLWHA. Thankfully, the federal government has made this a priority for the national HIV/AIDS system of care. The *National HIV/AIDS Strategy: Updated to 2020*, released in July 2015, notes that addressing living conditions, discrimination, and stigma is critical in achieving health equity:

To address disparities requires focusing on disproportionately affected communities and populations; implementing structural approaches to HIV prevention and care that address conditions such as housing, education, employment, and food security; and reducing stigma and eliminating discrimination associated with HIV infection.

(White House Office of National AIDS Policy, 2015)

Likewise, addressing living conditions, discrimination, and stigma to reduce health disparities is a top priority in Rhode Island. As these survey results show, there are clear differences in health processes and outcomes between racial, ethnic, and socioeconomic groups. Recognizing these differences and understanding their origin allows efforts to not only focus on groups with greatest need but also target specific intervention points. Ultimately, the most sustainable solutions will result from addressing the upstream factors that drive health inequalities.

Lastly, the framework for achieving health equity provides structural support for the key findings, insights, and recommendations that are presented in the next section.

### *Findings, Insights, & Recommendations*

The following section presents key findings, insights, and recommendations.

#### **Social Determinants of Health: Race, Gender, Income, Education**

Health disparities by racial, social, and economic categories among PLWHA were a strong theme throughout nearly all of the results from the survey.

Individuals who identified as black were more likely than individuals who identified as white to have a household income of less than \$10,000 per year (Figure 7), use Medicaid (Figure 16), not have had a visit to an HIV medical provider within the last 6 months (Figure 29), report not being virally suppressed (Figure 34), and report trusting their provider as a barrier to care (Figure 41).

Individuals who identified as Hispanic or Latino/a were significantly more like than those that identified as not Hispanic or Latino/a to have a household income less than \$10,000 (Figure 8) and report an education level of below high school (Figure 9).

Individuals who identified as female were more likely than males to have a household income of less than \$10,000 per year (Figure 7), be disabled or unable to work (Figure 10), use Medicaid (Figure 16), not have had a visit to an HIV medical provider in the last 6 months (Figure 29), and report not being virally suppressed (Figure 35).

Individuals who identified as having a household income of less than \$10,000 per year were more likely than those with a household income of more than \$10,000 per year to report not being virally suppressed (Figure 34), report trusting their provider as a barrier to care (Figure 41), and report depression (Figure 43).

Individuals who identified as having an education level of less than high school were more likely than those with a higher level of education to have a household income of less than \$10,000 per year (Figure 7), be disabled or unable to work (Figure 10), use Medicaid (Figure 16), report needing time to deal with the diagnosis as a reason for delaying visit to an HIV medical provider after diagnosis (Figure 28), report not having a visit to an HIV medical provider in the last 6 months (Figure 29), report not being virally suppressed (Figure 34), report trusting their provider as a barrier to care (Figure 41), and report substance use (Figure 44).

These findings reflect well-documented vulnerabilities associated with individuals living in poverty and challenges related to being a racial or social minority in America. The following example demonstrates how poverty and lack of education can impact health in these populations:

People without a high school education may have fewer work-related skills to present to potential employers or may only qualify for low paying jobs. As a result, they are less likely to find work and be paid above minimum wage. To support themselves and their family, they may need to take on more work hours or additional part-time jobs, leaving less time for self-care and medical appointments. Inconsistent work schedules might make it more

difficult to take medications on schedule and there may be limited time for other health promotion activities such as exercise and eating well. Furthermore, life's sudden disruptions, such as a leaky roof or broken car, may require forfeiting money for medications or planned time-off to see an HIV medical provider. And fluctuations in monthly income might pinball individuals between different levels of eligibility for housing programs and health insurance, requiring constant diligence to maintain access to basic human needs.

Poverty disproportionately impacts minority groups. This survey shows that Black people and Hispanic people living with HIV/AIDS in Rhode Island are more likely to have a household income of less than \$10,000 per year than white and non-Hispanic people (Figure 7). Generations of structural violence—social and institutional systems that prevent certain groups from meeting their basic needs—and racism bear responsibility for this unacceptable social reality.

When considering how to improve health outcomes for these populations, it is important to recognize the dual need for both non-medical supportive services and the medical system of care. Non-medical supportive services provide acute assistance to meet basic human needs like housing, food, and employment. Without a safe place to sleep and access to healthy food, active engagement in self-care activities such as medication management becomes even more challenging. A stable home address and phone number make it much easier for HIV clinics to follow-up and ensure that the individual is linked to care.

Both sides, HIV medical and non-medical services, need to be continually evaluated on whether their services are **easy to find, access, and use** by impoverished and minority populations. It is an unfortunate reality that aspects of the system of care in Rhode Island and nationally place great burden on the individual to decipher the available set of social and medical services. Impoverished individuals, especially those with HIV or other chronic health care issues, with low education levels or health literacy are the least likely to have the time and skills necessary to successfully navigate the requisite paperwork, phone calls, eligibility requirements, and appointments. Yet they also are ones in greatest need of overcoming those barriers. The systems in place to support these populations must work to become more user-friendly to the people they serve.

#### Recommendations:

- Inform HIV medical and non-medical providers that these disparities exist in the HIV system of care in Rhode Island.
- Target racial, social, and ethnic minorities in prevention and care outreach activities.
- Continue to emphasize social determinants of health during future quality improvement and monitoring activities.
- Continue to pursue system of care improvement activities that facilitate ease of use for disenfranchised, impoverished, and minority populations.

## Gay Men with HIV

The results of this survey show that, in most areas, gay men (also known as men who have sex with men or MSM) are performing as well or better than straight men in terms of economic social determinants of health, health processes like taking medication and visiting their HIV medical provider, and health outcomes like viral suppression. This speaks to the continued success of prevention, outreach, and care programs that focus specifically on the MSM population. It may also speak to how not-straight respondents, specifically not-straight men, were significantly less likely to report low levels of education (Figure 9).

Gay men with HIV are significantly less likely than straight men, straight women, and gay women to report a household income of less than \$10,000 (Figure 9). They are also significantly less likely to report being disabled or unable to work or report being on Medicaid (Figure 11, Figure 17).

There were not any notable or significant differences between gay and straight men reporting a visit to an HIV medical provider within the last 6 months (Figure 32) or viral suppression from last viral load test (Figure 37). Gay men were less likely than straight men to report always taking their HIV medication as prescribed but the difference was not significant (Figure 34). There was not a notable difference between gay men and straight men reporting that trusting their provider was one of the most difficult aspects about using HIV services (Figure 44).

However, while the difference was not significant, gay men were much more likely than straight men to report depression (Figure 46). This is likely a result of the additional stigma and discrimination that those that identify as not-straight may face in society every day. It is important to recognize that gay men were not any more likely than straight men to report substance use (Figure 47). This may indicate that gay men have appropriate access to healthy forms of coping, like counseling, therapy, support groups, or social networks that support them, and are therefore not any more likely to turn to substance use to cope.

It is possible that certain subpopulations of gay men—such as those in racial or ethnic minorities – may be more likely to report depression and substance use and less likely to report positive health processes and outcomes like visiting the doctor, taking medications as prescribed, and achieving viral suppression. In theory, this could be attributed to the additional stigma and discrimination that those individuals might face in the context of their cultural reality or the greater likelihood that members of those populations are impoverished. However, the sample size of this survey does not allow for accurate stratifications at this level.

## Recommendations

- Continue care, prevention, outreach, and education efforts that target gay men.
- Further explore how health disparities may affect gay men disproportionately in racial and ethnic minority population.

## **Heterosexual Women with HIV**

Heterosexual women with HIV may be an underemphasized subpopulation of PLWHA in RI.

Women respondents were significantly more likely than men to report a household income of less than \$10,000 (Figure 7), an employment status of disabled or unable to work (Figure 10), and an insurance type of Medicaid (Figure 16). They were also significantly less likely to report a visit to an HIV medical provider in the last six months (Figure 29) and less likely to report viral suppression from their last viral load test (Figure 34).

Interestingly, women were equally likely to report below a high school education compared to men (Figure 9). Therefore, the income level and employment disparity between men and women appear to be more a result of workplace discrimination against women than differences in educational achievement.

It is unclear whether gender is a more deterministic factor among white or black populations. From this survey, it appears that black and white women are comparably vulnerable. As they do not report trusting their provider as a barrier to care more than men do (Figure 41), the fundamental issue appears to be that women are more likely to be impoverished than men.

Overwhelmingly, women report getting HIV through heterosexual sexual contact (Figure 20). The quintessential example of this exposure type would be a heterosexual woman getting HIV through unprotected sex with her bisexual husband who did not inform her that he was also engaging in unprotected sex with male partners. However, as this survey did not ask for marriage status, our results are not specific to married women and must be considered relevant to single women as well.

Promoting prevention to married women is an incredibly difficult challenge precisely because they likely do not believe they are at risk. Meeting these women where they are, perhaps at primary care clinics, would be important as they might be less likely to seek HIV prevention and testing services from an STD clinic. Promoting prevention to single women is a relatively easier task. It would require targeting prevention messages to this audience in addition to the more prominent and dominant transmission profile of men who have sex with men (MSM).

Heterosexual women continue to be at high risk and present an opportunity for targeted prevention activities in Rhode Island.

### **Recommendations:**

- Inform primary care providers in Rhode Island of this transmission risk profile and promote more active screening, testing, and education.
- Target heterosexual women (both married and unmarried) in prevention and care outreach activities.

### **Substance Use and HIV Care**

While substance use issues impact a small subset of the overall PLWHA in RI population (Figure 42), those with substance use were significantly less likely to report always taking their medication as prescribed and being virally suppressed (Figure 46). Compared to other services, a relatively high proportion of people who need substance use services (inpatient, outpatient, and needle exchange) reported that they could not get them (Figure 50). Therefore, improving substance use services for PLWHA should be an important new focus in HIV care.

Fortunately, those with substance use were close to as likely as those without to have had a visit to an HIV medical provider in the last six months (Figure 46). This means that there is an opportunity for HIV medical providers to identify substance use in their patients and refer them to the appropriate treatment and recovery centers. Rhode Island is building a strong foundation of peer recovery services that would be helpful to PLWHA.

#### Recommendations:

- Promote coordination between HIV medical providers and substance use treatment centers and recovery clinics, with a particular focus on peer recovery services.
- Promote integration and/or the colocation of behavioral health care services within the primary care environment.
- Ensure that case managers and medical providers routinely screen for substance use.

### **Mental Health and HIV Care**

While the results did not show significant differences in health process and outcomes between people with and without depression (Figure 45), depression and other mental health issues is the most commonly reported medical or personal issue that PLWHA in RI face in addition to HIV (Figure 42). Over half of this survey's respondents reported needing mental health services (Figure 50). The analysis indicates that depression does not impact certain sociodemographic groups more so than others (Figure 43). It is a comorbidity risk inherent in the experience of having a chronic illness. That being said, those with a household income of less than \$10,000 per year and those who identified as a non-straight sexual identity were slightly more likely to report depression. Depression is higher in these groups due to the day-to-day challenges of living in poverty and the stigma and discrimination that those that identify as non-straight may face.

#### Recommendations:

- Better integrate mental health care into HIV medical care by either co-locating mental health services within HIV medical clinics or by ensuring that all patients receive a brief mental health screening with every visit to their HIV medical provider.
- Ensure that case managers and medical providers routinely screen for mental health issues.
- Provide a list of resources to consumers for their mental health needs
- Investigate possible role of peers or support/social groups as a way for consumers to get some of the support they need as well as information on mental health services.

### **Case Manager Quality Improvement**

Case managers represent a great opportunity to help consumers access the medical and support services they need, especially mental health and substance use services. Unfortunately, the results of this survey did not show significant health process and outcomes differences between those respondents that have a case manager and those that do not. This is likely due to inconsistency in quality of case managers across agencies and individuals. Some case managers do have a very positive impact on the health and wellbeing of their clients, but their effect was muted by being statistically included in a group with case managers who do not.

These findings support the need to continue to engage case managers in quality improvement activities.

#### Recommendations:

- Explore ways make case management services more consistent by identifying and promoting best practices and quality management improvements.
- Explore funding a HIV case manager certification program and/or standardized training curriculum.
- Support case managers with regular training opportunities for professional development.
- Provide case managers with robust resources that describe available services from organizations in RI that they can share with clients.

### **Age, Adherence, and Viral Suppression**

Young people were less likely to report always taking their medications for HIV/AIDS as prescribed (Figure 31) and were less likely to report being virally suppressed (Figure 34) than older PLWHA. Lack of adherence to medical advice and treatment among young people is not specific to HIV/AIDS. It has been well-documented in youth across nearly all chronic diseases. Additionally, younger people with HIV or at risk for HIV may view HIV as less serious than older peers due to the relatively recent introduction of life-saving HIV drugs that greatly prolong life expectancy.

#### Recommendations:

- Inform medical providers of this self-reported discrepancy in medication adherence between age groups and target efforts (e.g. provider training) to address these disparities.
- Place renewed focus on educating young people with HIV on the consequences of nonadherence or partial adherence.

### **Language Barrier during Diagnosis**

People who listed a language other than English as their primary language were 30% more likely to report needing time to deal with their diagnosis was a reason for delaying a visit to their HIV medical provider after diagnosis (Figure 27). They were also significantly more likely to report an education level below high school (Figure 9).



HIV diagnosis is a critical moment. It is the first time that the HIV system of care has a meaningful interaction with a person who will live with HIV for the rest of their life. It is important that key pieces of information are not only shared with the newly diagnosed but also *heard* and internalized. However, when a language barrier exists between the person delivering the diagnosis and the person receiving the diagnosis, it becomes increasingly likely that these key messages will not be heard. Perhaps the only messages internalized are those associated with surprise and shock and those that have been shaped by common public misconceptions about HIV. These data point clearly to a need to ensure that diagnoses are delivered by professionals who speak the primary language of the individual receiving the diagnosis.

In addition, it is important to recognize that cultural realities that promote stigma and discriminations against people with HIV in populations with language barriers (e.g. the Hispanic-Latino community) may reinforce negative perceptions of living with HIV.

Recommendations:

- Promote the use of translators to deliver diagnoses at STD-testing sites and primary care facilities.
- Ensure culturally and linguistically appropriate services and materials are available at screening, testing, treatment, and support service locations.
- Consider increasing HIV education and awareness targeted to specific communities with language barriers.

### **Satisfaction with Medical Providers and Trust**

Consumers reported generally being very satisfied with their HIV medical providers (Figure 47). However, certain groups were more likely than others to report trusting their provider as a barrier to care—specifically, those who identified as black, those who reported a non-English primary language, those with a household income of less than \$10,000, and those with an education level of below high school (Figure 41).

Recommendations:

- Inform medical and non-medical HIV providers that certain groups are more likely to report trust as a barrier care.
- Explore means of promoting trust in the clinical environment.

### **Using Survey Results in System of Care Planning and Improvement Activities**

These survey results provide robust data to support future Ryan White program care planning, improvement, and evaluation activities. Specifically, these data will be used to support Rhode Island's Integrated HIV Prevention and Care Comprehensive Plan, including the Statewide Coordinated Statement of Need, CY 2017-2021. Survey data combined with additional needs assessment results will also be used to inform ongoing program needs.



Recommendations:

- EOHHS should review and prioritize recommendations to meet Ryan White program needs and HRSA requirements.
- EOHHS should identify recommendations that intersect with the statewide integrated comprehensive plan and develop strategies, objectives, and timeline for implementation, including funding, procurement, and resources.
- EOHHS should identify topic areas for further exploration and research opportunities.

## Conclusion

In conclusion, the results of this survey reveal that certain subpopulations of PLWHA need renewed focus by HIV medical care and support service organizations in Rhode Island to more effectively enfranchise them in the system of care. Race, ethnicity, gender, age, economic resources, and education level should not impact a person's potential for health and wellbeing. Going forward, organizations should seek to deeply embed a health equity lens into all quality management activities. Resolving these unfair disparities will require a thorough understanding of their root causes as well as the best practices to address them. Thoughtful collaborations between medical, non-medical, and behavioral health teams should then be built around these findings.

## Acknowledgements

### Authors

August Oddleifson, BA (JSI)  
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Annie Silvia, MPA (JSI)  
Paul Loberti, MPH (EOHHS)

### Special thanks to...

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The Agape Center  
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## References

- Abbott, L. S., & Williams, C. L. (2015). Influences of Social Determinants of Health on African Americans Living with HIV in the Rural Southeast: A Qualitative Meta-synthesis. *Journal of the Association of Nurses in AIDS Care*, 26(4), 340–56. <http://doi.org/10.1016/j.jana.2015.03.004>
- Centers for Disease Control and Prevention. (2014). *Understanding the HIV Care Continuum*. Retrieved from [http://www.cdc.gov/hiv/pdf/dhap\\_continuum.pdf](http://www.cdc.gov/hiv/pdf/dhap_continuum.pdf)
- Dean, H. D., & Fenton, K. A. (2013). Integrating a Social Determinants of Health Approach into Public Health Practice : A Five-Year Perspective of Actions Implemented by CDC ' s National Center for HIV / AIDS , Viral Hepatitis , STD , and TB Prevention, 128, 5–11.
- Fielding, J., Teutsch, S., & Breslow, L. (2010). A Framework fo Public Health in the United States. *Public Health Reviews*, 32(1), 174–189.
- Howe, C. J., Napravnik, S., Cole, S. R., Kaufman, J. S., Adimora, A. A., Elston, B., ... Mugavero, M. J. (2014). African American race and HIV virological suppression: Beyond disparities in clinic attendance. *American Journal of Epidemiology*, 179(12), 1484–1492. <http://doi.org/10.1093/aje/kwu069>
- Institute of Medicine (US) Committee on Health and Behavior: Research, Practice, and Policy. (2001). Behavioral Risk Factors. In *Health and Behavior: The Interplay of Biological, Behavioral, and Societal Influences*. Washington (DC): National Academies Press (US).
- Mugavero, M. J., Lin, H., Allison, J. J., Thomas, P., Willig, J. H., Raper, J. L., ... Saag, M. S. (2009). Racial Disparities in HIV Virologic Failure: Do Missed Visits Matter? *Journal of Acquired Immune Deficiency Syndromes*, 50(1), 100–108. <http://doi.org/10.1097/QAI.0b013e31818d5c37>.Racial
- Oster, A. M., Russell, K., Wiegand, R. E., Valverde, E., Forrest, D. W., Cribbin, M., ... Paz-Bailey, G. (2013). HIV Infection and Testing among Latino Men Who Have Sex with Men in the United States: The Role of Location of Birth and Other Social Determinants. *PLoS ONE*, 8(9). <http://doi.org/10.1371/journal.pone.0073779>
- White House Office of National AIDS Policy. (2015). *National HIV/AIDS Strategy*. Washington (DC). Retrieved from [www.AIDS.gov/2020](http://www.AIDS.gov/2020)
- Zinski, A., Westfall, A. O., Gardner, L. I., Giordano, T. P., Wilson, T. E., Drainoni, M. L., ... Mugavero, M. J. (2015). The contribution of missed clinic visits to disparities in HIV viral load outcomes. *American Journal of Public Health*, 105(10), 2068–2075. <http://doi.org/10.2105/AJPH.2015.302695>

## Appendix A: IRB Approval



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November 11, 2015

Anne Marie Silvia  
Project Director  
JSI Providence

**STUDY TITLE: "RI HIV Care and Services Consumer Survey"**

IRB REFERENCE: IRB #15-023

**ACTION: APPROVED**

APPROVAL DATE: November 11, 2015

EXPIRATION DATE: November 10, 2016

REVIEW TYPE: Expedited

REVIEW CATEGORY: Expedited review category #7; informed consent documentation waived/altered

Dear Ms. Silvia:

Thank you for your submission of New Project materials for this research study (protocol, survey and attachments dated 11/11/15). The JSI Institutional Review Board (IRB) has **APPROVED** your submission. This submission has received Expedited Review based on the applicable federal regulation. Federal regulations require that all research be reviewed at least annually. Based on the level of risk, this project requires continuing review on an annual basis.

The IRB specifically considered (i) the risks and anticipated benefits, if any, to subjects; (ii) the selection of subjects; (iii) the procedures for securing and documenting informed consent; (iv) the safety of subjects; and (v) the privacy of subjects and confidentiality of the data. All research must be conducted in accordance with this approved submission. The IRB has determined that you have met the regulatory requirements necessary in order to waive documentation of informed consent.

Please retain this letter with your project's research records. Research records include all IRB submissions and responses and must be kept in the project director/principal investigator's file for a minimum of three (3) years after completion of the study. If you have questions, please contact Andy Buckley at 617 385-3616 or email [IRB@jsi.com](mailto:IRB@jsi.com).

Sincerely,

A handwritten signature in black ink that reads "Lauren Kunches".

Lauren Kunches, Ph.D.  
JSI IRB Chair and Research Protections Specialist  
OHRP IRB00009069 John Snow, Inc.