



*THE U.S. PEOPLE LIVING WITH HIV
STIGMA INDEX: MICHIGAN
Wave I Findings, 2014 - 2016*

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The PLHIV Stigma Index Partners



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EXECUTIVE SUMMARY

On World AIDS Day in December 2013, the Global Network of People Living with HIV, North America (GNP+NA) announced the launch of *The United States People Living with HIV Stigma Index Project* in Michigan. The **MI PLHIV Stigma Index (MI-SI) Project** seeks to explore and address trends in stigma and discrimination experienced by people living with HIV in southeastern Michigan.¹

“

PROJECT GOALS

The MI-SI project is informed and designed by persons living with HIV (PLHIV) with two primary goals:

1. To document experiences of internalized, social, and institutional stigmas and discriminations among PLHIV in the state, and
2. To increase the capacity of PLHIV and their allies to effectively challenge HIV stigmas and discriminations.

NUMBERS AND NARRATIVES

The MI-SI Project relies on multiple sources of information to support documentation of stigma experiences. These include community survey and questionnaire data; local and state census, surveillance and administrative data; interviews with PLHIV and other stakeholders; and narratives such as stories, photos and videos, and other multimedia presentations of PLHIV life experiences.

In the present report we highlight findings from the first wave of data collected through the MI-SI Project's *PLHIV Stigma Index Questionnaire*. The PLHIV Stigma Index (SI) questionnaire has been administered in over 50 countries, translated to 54 languages, and administered to over 50,000 PLHIV.² During Wave 1 of the Michigan SI Questionnaire the Project adapted and piloted the SI questionnaire to 70 diverse PLHIV in metro Detroit from September-December 2014.

COMMUNITY INITIATIVES

In addition to data documentation, the PLHIV Stigma Index Project implements various initiatives to promote effective responses to HIV stigmas and discriminations in the state. Currently, the MI-SI Project has 5 priority initiative areas: Faith-Based, HIV Criminalization, Internalized Stigma, Transgender Justice, and Youth Justice. Each of these priority areas entails various strategic approaches including:

¹ www.miunified.org See <http://www.stigmaindex.org/> for information on the PLHIV Stigma Index Project globally..

² For more information on global projects using the questionnaire see <http://www.stigmaindex.org/>

- **Awareness-raising:** generating and disseminating informational, educational, and promotional materials about HIV, people living with HIV, and HIV-related stigma to the public.
- **Rights advocacy and defense:** supporting legal and political advocacy among people living with HIV and their allies to support changes to legislation, policies and programs that maintain or perpetuate PLHIV stigma and discrimination, and; improving access to and quality of effective legal remedies to address HIV-related stigmas and discriminations faced by people living with HIV statewide, particularly among marginalized populations.
- **Capacity-building:** supporting individuals, social networks, groups, and communities to provide and access appropriate social and material supports. These include emotional supports, physical supports, and referrals that promote effective coping with HIV-related stigmas/discriminations, and enhance and maintain general well-being among people living with HIV.
- **Equity promotion:** improving the benefits of stigma-reduction efforts for *all* people living with HIV by addressing social and structural traits (e.g., poverty, homelessness, and trauma) that shape experiences and outcomes of HIV-related stigma.

We draw on data from Wave 1 of the SI Questionnaire to explore potential opportunities and challenges for each of these four strategic approaches.

WHAT FORMS OF STIGMA AND DISCRIMINATION DO PEOPLE LIVING WITH HIV FACE IN MICHIGAN ?

Among the 70 SI Questionnaire participants, during the prior year:

- 80% experienced **negative feelings** of self-blame and guilt about being HIV-positive.
- 73% experienced at least one form of **social discrimination**, most commonly hearing gossip about their HIV status and being sexually rejected by potential partners.
- 20% experienced at least one form of **institutional discrimination**, predominately related to healthcare, housing, and insurance access.
- 20% felt that their **rights** as a person living with HIV had been violated or abused.

HOW DOES STIGMA AND DISCRIMINATION IMPACT THE WELL-BEING OF PEOPLE LIVING WITH HIV IN MICHIGAN?

Experiences of stigma and discrimination were associated with several recent (12-month) negative behavioral and psychological responses among SI Questionnaire participants.

- 90% engaged in at least one form of **social avoidance**, the most common behavioral responses consisting of isolating oneself from family and friends, avoiding status disclosure in social support networks, avoiding social gatherings, avoiding sex, and avoiding social media (e.g. Facebook, Twitter).
- 89% **worry about experiencing stigmatizing events**, notably sexual rejection, gossip, having their HIV-status shared without consent through social media, and receiving verbal threats.
- 79% experienced **reductions in psychosocial, physical, and material well-being**, particularly with respect to depression and anxiety, social engagement and support, and physical self-care (e.g., sleep, physical activity).

HOW DO STIGMATIZING AND DISCRIMINATORY EXPERIENCES & IMPACTS DIFFER AMONG PEOPLE LIVING WITH HIV IN MICHIGAN?

Among SI Questionnaire participants, differences in the experiences and consequences of HIV-related stigmas and discriminations varied most notably by the socioeconomic and marginalized statuses of individuals.

- **Age:** People living with HIV over the age of 39 reported fewer recent experiences of social discrimination, and fewer worries about encountering stigmatizing events. They were also less likely than younger participants to engage in social avoidance and to report negative impacts of discrimination on their psychosocial, physical, and material well-being.
- **Race:** There were few racial differences in experiences and consequences of HIV-related discrimination. However, black participants reported slightly less worry about experiencing stigma and discrimination, and slightly fewer negative well-being (psychosocial, physical, or material) consequences as a result of discriminatory experiences.
- **Gender and Sexual Identities:** There were no substantial differences in experiences and impacts of discrimination by gender (female, trans, and male) and sexual (gay/homosexual, bisexual, and heterosexual) identities.
- **Socioeconomic Status:** Overwhelmingly, experiences and consequences of HIV-related stigmas and discriminations were strongly associated with recent or long-term exposure to economic hardships (e.g., food insufficiency and housing instability). Compared to others, people living with HIV who were exposed to acute or chronic economic hardships reported substantially higher internalized negative

feelings about being HIV-positive, more episodes of social discrimination, higher rates of social avoidance, more worries about encountering stigmatizing events, and more negative consequences to well-being (psychosocial, physical, and material) as a result of stigmatizing and discriminatory experiences.

- **Marginalization:** Experiences and consequences of HIV-related stigmas and discriminations were more pronounced among marginalized people living with HIV who had a history of sex work and/or incarceration. Compared to others, marginalized participants reported more negative internalized feeling about being HIV-positive, higher rates of social avoidance, and more worries about encountering stigmatizing events.

WHAT SUPPORTS DO PEOPLE LIVING WITH HIV USE OR NEED WHEN ADDRESSING STIGMAS AND DISCRIMINATIONS?

Despite the high rates of experiences and negative consequences of HIV-related discriminations and stigmas, most participants had access to social and institutional resources to foster positive coping and support efforts to address stigma/discrimination.

- 80% of SI Questionnaire participants reported access to **social supports** (e.g., emotional support, informational support). PLHIV with more positive social supports reported fewer experiences and negative consequences of HIV-related stigmas and discriminations. Access to social supports differed little across participants. PLHIV over the age of 39 reported higher levels of social support compared to others. PLHIV exposed to economic hardships and/or marginalized (e.g., history of sex work, incarceration) reported lower levels of social support relative to others.
- 50% of participants felt that **friends and family** with whom they disclosed their HIV status were supportive.
- 80% of participants felt that they received supportive responses from **healthcare providers, caseworkers, and PLHIV groups and organizations** following HIV disclosure.
- 75% of participants were **aware of organizations or groups** to which they could turn when addressing experiences of HIV-related stigma and discrimination. Awareness was lowest among younger, female, trans, and black PLHIV.
- 53% of participants were **members of a PLHIV social group, support group, or activist network**. Membership rates were lowest among younger and heterosexual/bisexual participants.

- 50-60% of participants had **confronted, challenged, or educated someone** who was stigmatizing or discriminating against themselves or another PLHIV in the past year. These rates were highest among participants who aware of or members of PLHIV-supportive groups and organizations.
- 60% of participants felt confident that they could **influence decision-making in local policies and programs** that affect or perpetuate HIV-related stigma and discrimination. PLHIV who were aware of or members of PLHIV-supportive groups and organizations demonstrated much more positive perceptions about their potential to influence decision-making.
- 74% provided some form of emotional, referral, or another **social support to other PLHIV**, and was greatest among participants who were aware of or members of PLHIV-supportive groups and organizations.

IMPLICATIONS FOR STRATEGIC DIRECTIONS

Experiences of stigma and discrimination were prevalent among respondents to Wave 1 of the SI Questionnaire. Although the small size of our sample is cause for caution against over-generalization, the findings do highlight important considerations in implementing the MI-SI Project strategic directions.

- **Awareness-raising:** Many PLHIV engage in some form of awareness-raising or education about HIV and persons living with HIV when confronted with stigmatizing or discriminatory experiences. Networks of people living with HIV, support groups, agencies, and organizations are important resources to support and expand these efforts. The MI-SI Project should explore ways to expand opportunities for PLHIVs to identify and engage with appropriate agencies and groups that can support individual and collective efforts to raise awareness.
- **Rights advocacy and defense:** A substantial portion of PLHIVs do not feel prepared to influence policy, programmatic, or legal decisions related to HIV. However, awareness of or membership in PLHIV-supportive agencies, groups, and networks can greatly enhance perceptions of capacity to affect changes at the programmatic, policy, and legal levels. The MI-SI Project should explore ways to expand opportunities for PLHIVs to identify and engage with appropriate agencies and groups that can support individual and collective efforts to promote rights approaches, advocacy, and defense.
- **Capacity-building:** PLHIVs have access to a number of important social supports, and provide support to other PLHIVs. Importantly, agencies rather than friends/family were viewed as the most supportive resources with respect to HIV status. The MI-SI Project should explore ways to improve the capacity of PLHIVs

to draw on these natural support resources in order to improve responses to experiences of discrimination.

- **Equity promotion:** Social marginalization (e.g., history of sex work, incarceration) and exposure to economic hardships were stronger predictors of differences in stigma and discrimination than were demographic traits (e.g., race, sexual identity, gender identity). The MI-SI Project should devote particular attention to the unique circumstances, opportunities, and challenges facing marginalized or economically disadvantaged people living with HIV with respect to stigma and discrimination.

INTRODUCTION

Disentangling stigma and discrimination from HIV is the greatest challenge of our time. Stigma is the negative attitude that members of a society have towards people living with HIV, and it can become internalized in those of us living with HIV. Discrimination is the unfair treatment that members of a society inflict upon people living with HIV. In spite of the fact that HIV therapy has grown by leaps and bounds over the past thirty years, the social, political and cultural attitudes of HIV infection have barely changed at all. We are now living longer, healthier lives thanks to, Pre exposure prophylaxis, anti-retroviral therapy, and treatment as prevention, and yet people are missing out on this therapy because of the fear of stigma and discrimination associated with HIV/AIDS.

A social determinant to health, like stigma and discrimination, only exacerbates an HIV diagnosis and helps to marginalize those already highly vulnerable members of our society, like young MSM, sex workers, Trans, and drug users. Stigma also fuels the HIV criminalization laws that are in most cases outdated, and puts a cumbersome burden on people living with HIV not to disclose their status, out of fear of future prosecution. A significant number of the respondents to our questionnaire didn't trust Michigan courts to give them a fair trial, if they were accused of non-disclosure. They cited the, "New Jim Crow" which often leads to discretionary adjudication, causing disparities along racial lines, and dissuades many of those at risk from getting tested, because, what they don't know won't hurt them.

Our data shows that the negative effects of HIV related stigma and discrimination, on people living with HIV, manifests into episodes of depression, anxiety, loss of income, isolation, and suicidal ideations or attempts. Many of us withdraw from family and avoid healthcare. Perceived stigma prevent a lot of us from seeking spiritual support from faith based organizations, while increased drug and alcohol use feeds the flames of internalized stigma, and missed days at work and job loss, inevitably lay an unnecessary financial burden on the rest of society. The family, advocates, and providers of HIV services, have always been aware of the debilitating effects of HIV related stigma and discrimination, against their loved ones, friends and clients. But now we have the Stigma Index, a tool to quantify those effects, and a means to identify ways to affect change.

To that end, based on the data that we gathered from the Stigma Index Questionnaire, the Detroit Stigma Index Leadership Council has chosen four priority areas to focus on: Internalized Stigma, HIV related stigma in the Faith Based Community, HIV Criminalization, and Youth Education and Advocacy. Our strategy to positively impact these priorities is inspired by the concept of GIPA (Greater involvement of people living with HIV), as outlined in the Denver Principles. We plan to encourage proactive leadership in people living with HIV, through education, self-empowerment workshops, advocacy training, and power point presentations based on our data. We believe that an HIV positive persons best advocate is themselves, and that this affirmation of power, is the most effective way for us to tackle the daunting problem of, internal and external, HIV related Stigma and discrimination in the Metropolitan Detroit area.

- The Metro Detroit Leadership Council

SECTION A

HEALTH & BACKGROUND CHARACTERISTICS

In the following section we overview key demographic, health, and other characteristics of persons living with HIV (PLHIVs) who completed the survey. Where available, we compare the distribution of characteristics in the sample to the HIV distribution estimates reported in the “2014 Epidemiologic Profile of HIV in Michigan” (HIV, Body Art, Tuberculosis, Viral Hepatitis Section; Bureau of Disease Control, Prevention and Epidemiology; Michigan Department of Community Health; www.michigan.gov/hivstd)

Key Takeaways

- PLHIVs under 30 years old are overrepresented in the sample compared to their distribution among HIV-positive persons statewide.
- Gay and other men who have sex with men are underrepresented in the sample relative to statewide representation.
- Women and transgender individuals are overrepresented relative to statewide distributions of PLHIVs.
- Participants predominately had educational backgrounds consisting of a high school degree, vocational training, or some exposure to college.
- Over a quarter of participants were unemployed.
- Roughly half of participants experienced some homelessness during their lifetimes.
- Rates of undetectable viral suppression (viral loads <50 copies/mL) were nearly 3-times greater among participants relative to PLHIVs statewide.
- Four in five participants rated their overall health as good, very good, or excellent.

A.1. HIV HISTORY & CARE

Over half (52%) of participants received their first HIV diagnosis 5 or more years ago. Thirteen percent of participants were diagnosed within the 12 months prior to survey administration.

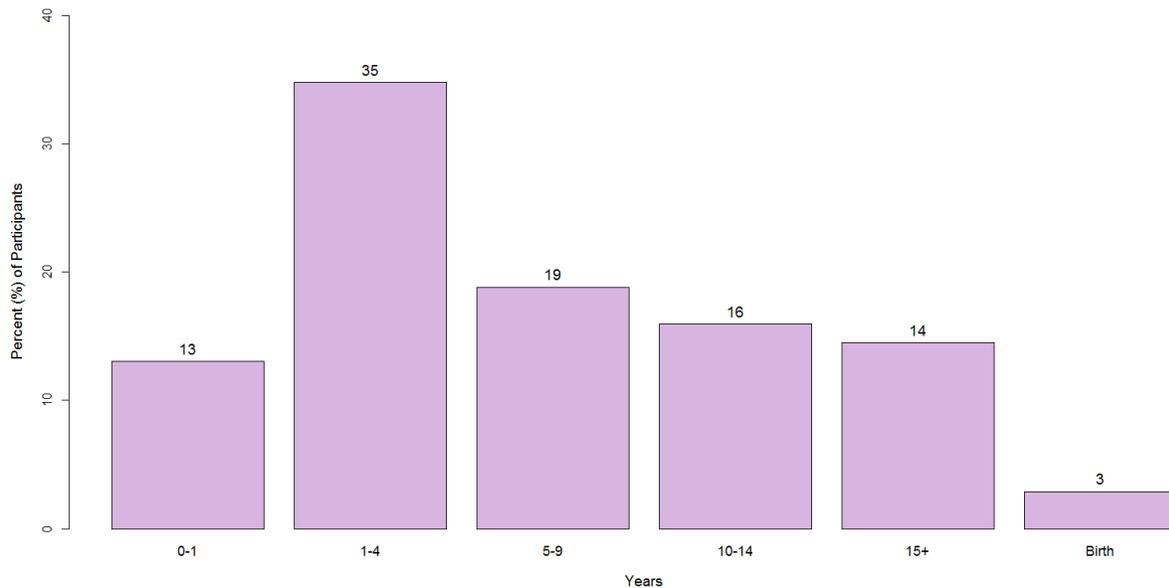


Figure 1. Time in Years since HIV-Positive Diagnosis among Survey Participants

All participants reported current engagement in care, with over 90% accessing care in the prior 6 months. Specifically, 71% had last office visit within last 3 months, 20% within the last 6 months. Only 4% had accessed care over 12 months prior. All reported having had at least one test for CD4 and viral load: 66% had completed bloodwork in the prior 3 months, and 24% between 4-6 months prior.

Nearly all participants (90%) reported current use of antiretroviral therapy (ART) medications.

A.2. DEMOGRAPHIC & SOCIOECONOMIC REPRESENTATION

Most participants (66%) were sexually active at the time of the survey. Slightly more than half (56%) of the sample stated they were single, 16% were partnered but unmarried, and 26% were married.

In Figure 2, we present the distributions of age, and self-reported gender and racial/ethnic identities. The sample reflected a range of ages. Nearly 30% of the sample was under the age of 25, 38% were 25-39, and 34% were aged 40 or older. By comparison, according to statewide estimates,³ 1% of PLHIVs are under the age of 20, 5% are 20-24 years old, 7% are 25-29, 18% are 30-39, 34% are 40-49, and 34% are 50 years of age or older.

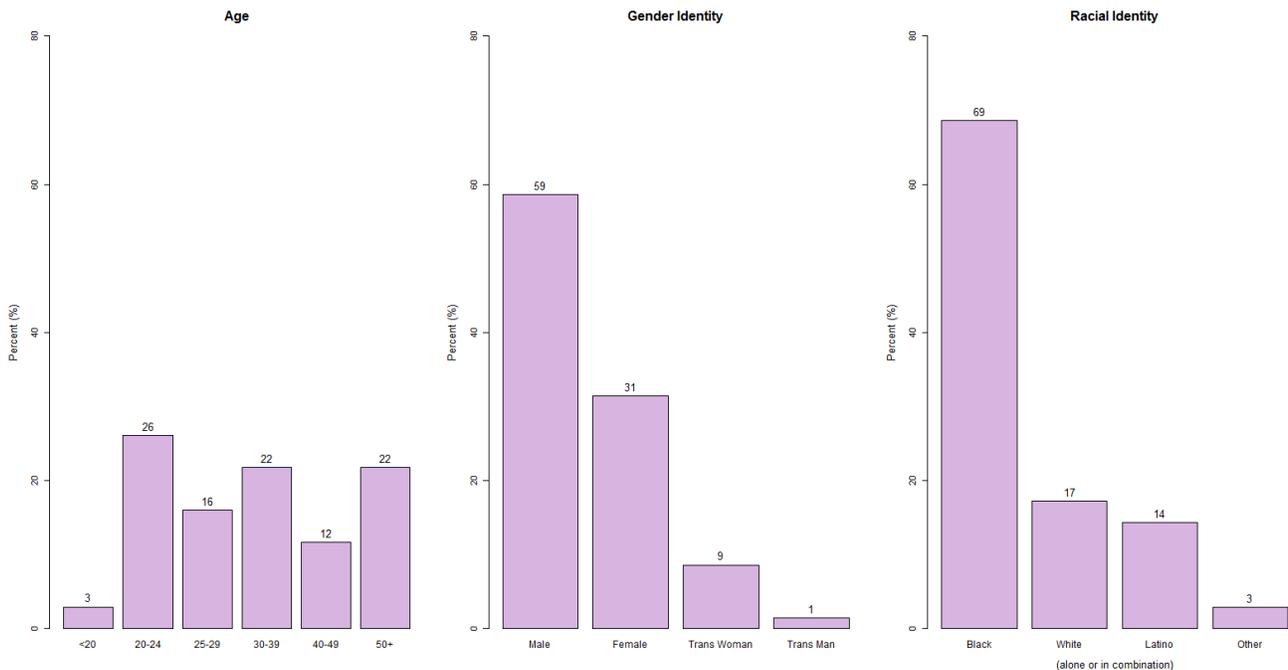


Figure 2. Age, Gender, and Race/Ethnicity among Survey Participants

Most (59%) participants identified as male. Female-identified participants accounted for 31% of the sample. An additional 10% of participants identified as transgender, with all but one of these individuals identifying as transwomen. We note that our classification of “trans” individuals is based on self-described identity. Some trans individuals may have preferred to identify as “male” or “female” as opposed to “transgender”. Statewide, 77% of PLHIVs are designated as male, 23% as female, and roughly 1% as transgender.

³ “2014 Epidemiologic Profile of HIV in Michigan”.

A majority of the sample (69%) identified as black. Whites (17%) and Latinos (14%) were the other most common racial/ethnic identities reported. By comparison, in 2014 56% of PLHIVs statewide identified as black, 34% as white, 5% as Latino, and 6% identified with another racial/ethnic group or mixed race.

At the time of the survey only 42% of participants were employed full-time (26%) or part-time (16%). Over one-quarter (26%) were unemployed, 16% were looking for work, and 10% were on disability.

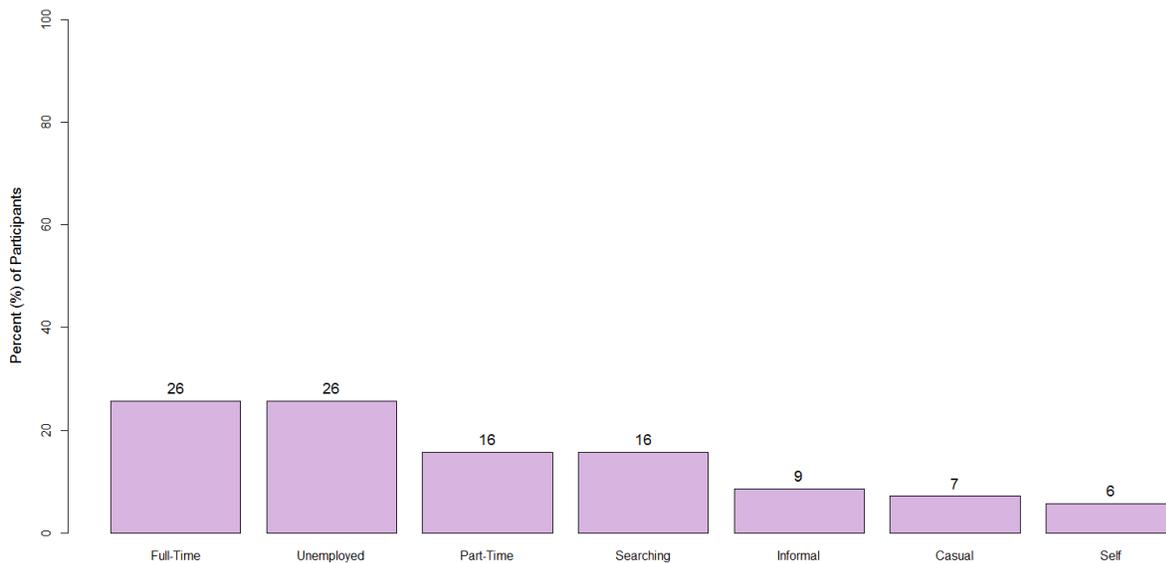


Figure 3. Participants' Employment Status

"Which one of these statements best describes your current employment status?" (check all)

Full-Time	In full-time employment (as an employee)
Unemployed	Unemployed and not working at all
Part-Time	In part-time employment (as an employee)
Searching	Looking for work/employment
Informal	Working under the table/making money informally
Casual	Doing casual or part-time work (self-employed)
Self	Working full-time but not as an employee (self-employed)

Rates of full-time employment differed most by gender (males reported higher rates than female and trans participants), and race (blacks reported higher lower rates than others). Conversely, unemployment rates increased with age, were higher among female and trans participants compared to men, and were higher among black participants relative to others.

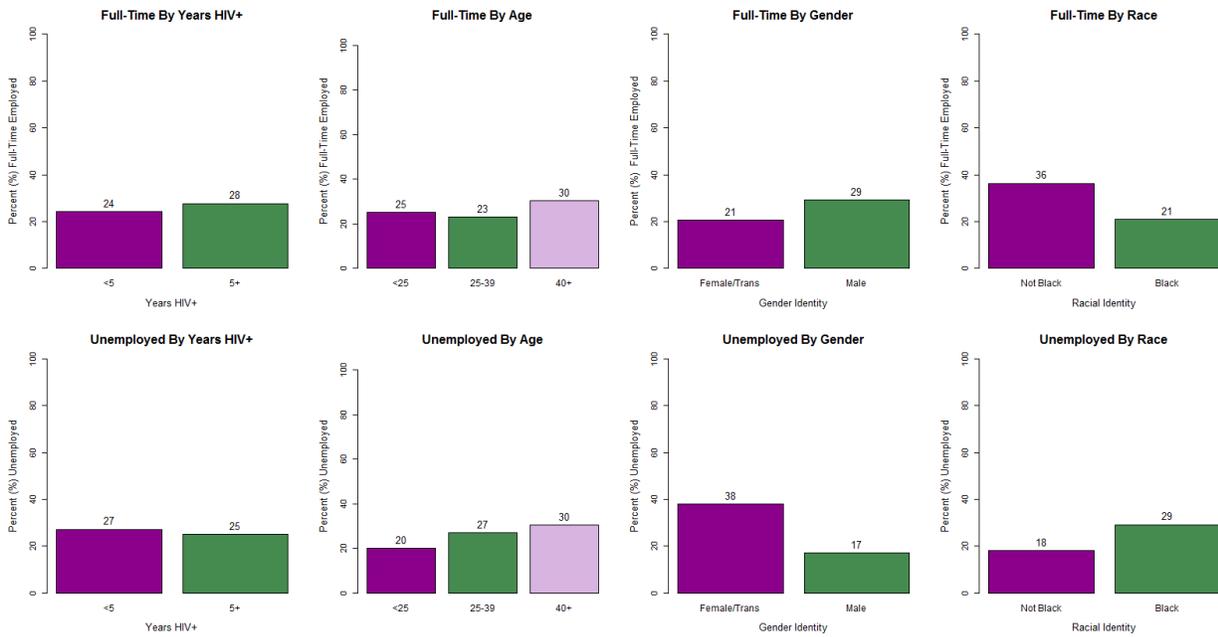


Figure 4. Full-Time & Unemployed Statuses by Participant Demographics

Educational attainment was limited among the sample. Half of the sample reported education as high school (secondary) or less. Although 33% reported having attained some college education, only 17% had a college degree or higher.

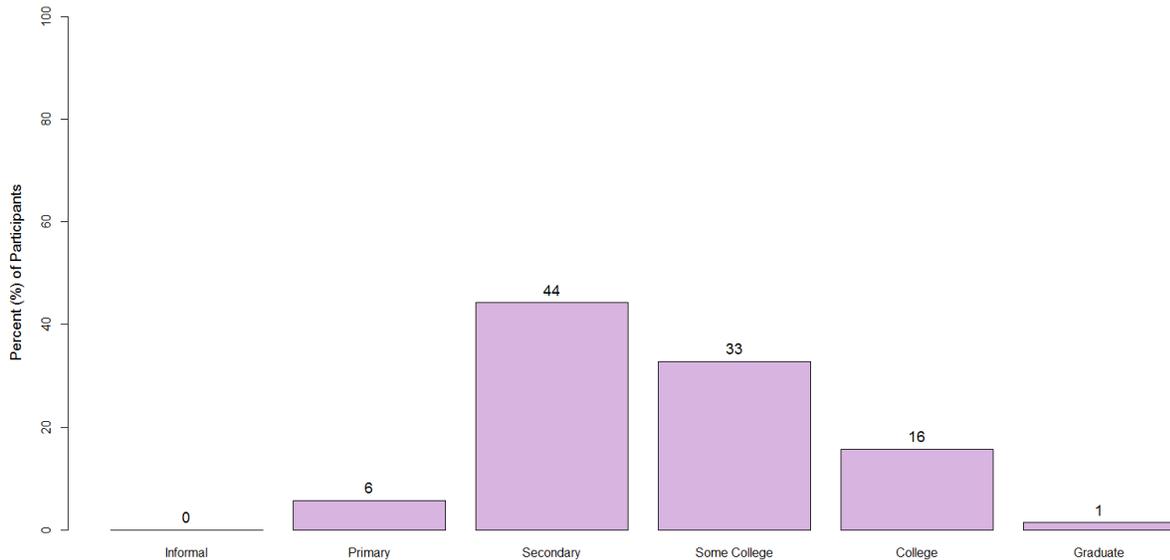


Figure 5. Educational Attainment among Participants

"What is the highest level of formal education you have completed?"

Informal

No formal education

Primary	Primary school (grades K-8)
Secondary	Secondary school (grades 9-12)
Some College	Some college/university
College	Graduated from college/university
Graduate	Post-graduate degree (Master's or PhD)

Rates of post-secondary exposure (some college, college degree, or graduate studies) were lowest among those diagnosed in the last 4 years and participants under the age of 40. Female and trans participants had slightly higher rates of post-secondary exposure compared to men, as did black and full-time employed, and *unemployed* participants relative to others. The higher rates of college exposure among the unemployed may reflect disability or retirement associated with HIV and/or age.

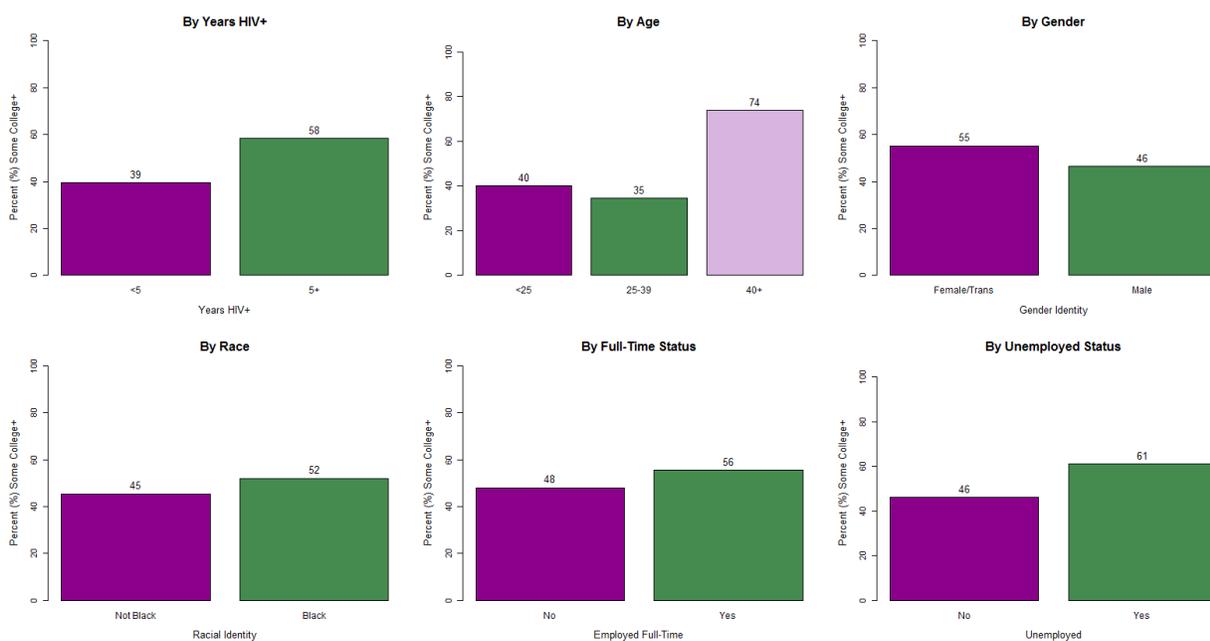


Figure 6. Post-Secondary Exposure (Some College or More) by Demographic and Employment Characteristics

Homelessness was pervasive, with 10% stating that they were currently homeless, and an additional 40% stating that they were previously homeless. Food insufficiency was measured with the item "In the last month, how many days has any member of your household not had enough food to eat?" Over one-fourth (26%) of the sample had experienced at least one day of food insufficiency: 13% reported fewer than 7 days, and an additional 13% reported food insufficiency of 7 days or more in the past month. The two highest reports of food insufficient were 14 days (one respondent) and 30 days (one respondent). We developed an indicator of economic hardship. Persons are considered

vulnerable to economic hardship if he or she reported either ever experiencing homelessness or experiencing at least 1 day of food insufficiency in the prior month. Overall, 56% of participants were classified as vulnerable to economic hardship based on our criteria. Hardship rates were highest among those diagnosed 5 or more years prior, female and trans participants, those lacking full-time employment, and, interestingly, persons with higher education levels. There were no differences by age (not shown).

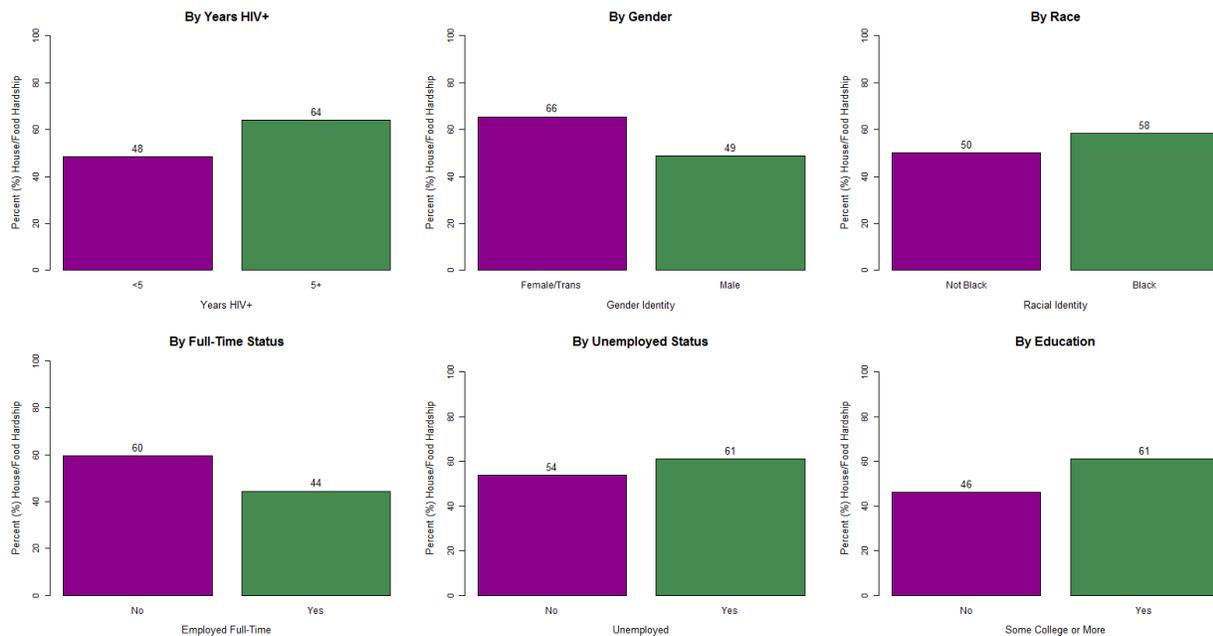


Figure 7. Economic Hardship by Demographic and Socioeconomic Characteristics

A.3. PRIORITY POPULATION REPRESENTATION

Participants were also asked to report whether they identify each of several important priority populations most affected by HIV in the US. Specifically, we asked “do you now, or did you ever, belong to any of the following categories?” Participants selected all categories with which they identified. Roughly half (53%) identified as heterosexual, and 47% identified as gay, lesbian, or a man who has sex with men (MSM). About 20% of the sample had ever been ‘incarcerated’—i.e., had a history of detention in prisons, jails, or Immigrations and Customs Enforcement Detention facilities. One in ten (10%) participants had been incarcerated in a jail or prison in the 12 months prior to completing the survey. Ten to fifteen percent of participants had ever engaged in sex work, identified as bisexual, or were ever injection drug users.

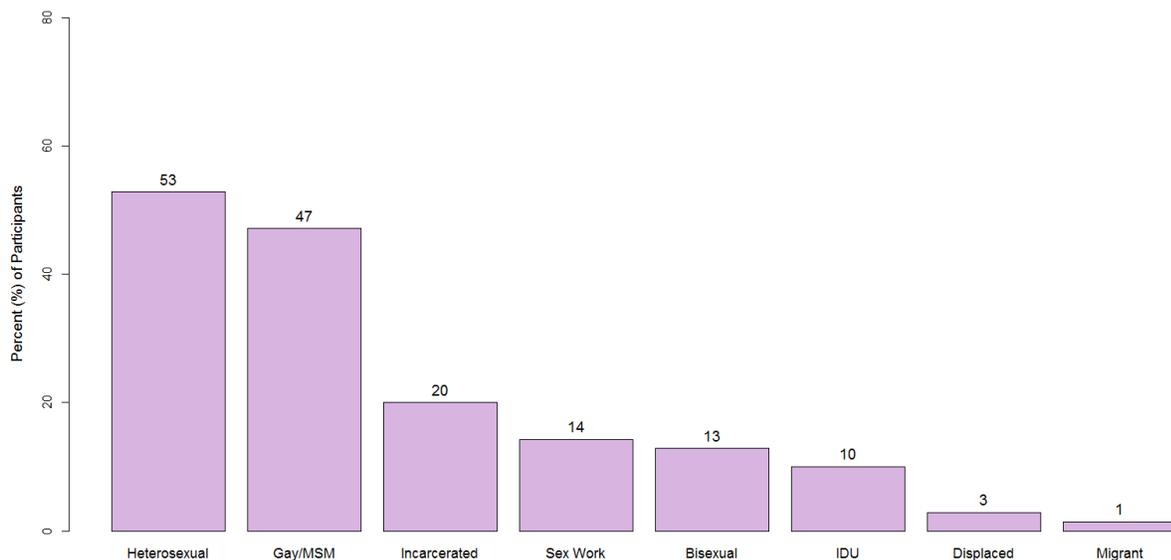


Figure 8. Representation of Priority Populations among Survey Participants

“Do you now, or did you ever, belong to any of the following categories?”

Heterosexual	Heterosexual
Gay/MSM	Gay or lesbian, or man who has sex with men (MSM)
Incarcerated	A person incarcerated, detained, or confined in prison, jail, or Immigrations and Customs Enforcement detention facility
Sex Work	Sex worker
Bisexual	Bisexual
IDU	A person who injects drugs
Displaced	Internally displaced person
Migrant	Migrant worker

In 2014, the statewide estimates⁴ of the distribution of HIV by “exposure category” were reported as 47% heterosexual, 71% gay/MSM, 25% bisexual, and 12% as IDU. Note that these “exposure category” designations differ conceptually from the self-reported “identity” classifications reported here.

Gay, lesbian, and MSM-identified participants had higher rates of representation among men, younger participants or those more recently diagnosed, the unemployed, and those with educational attainment below college.

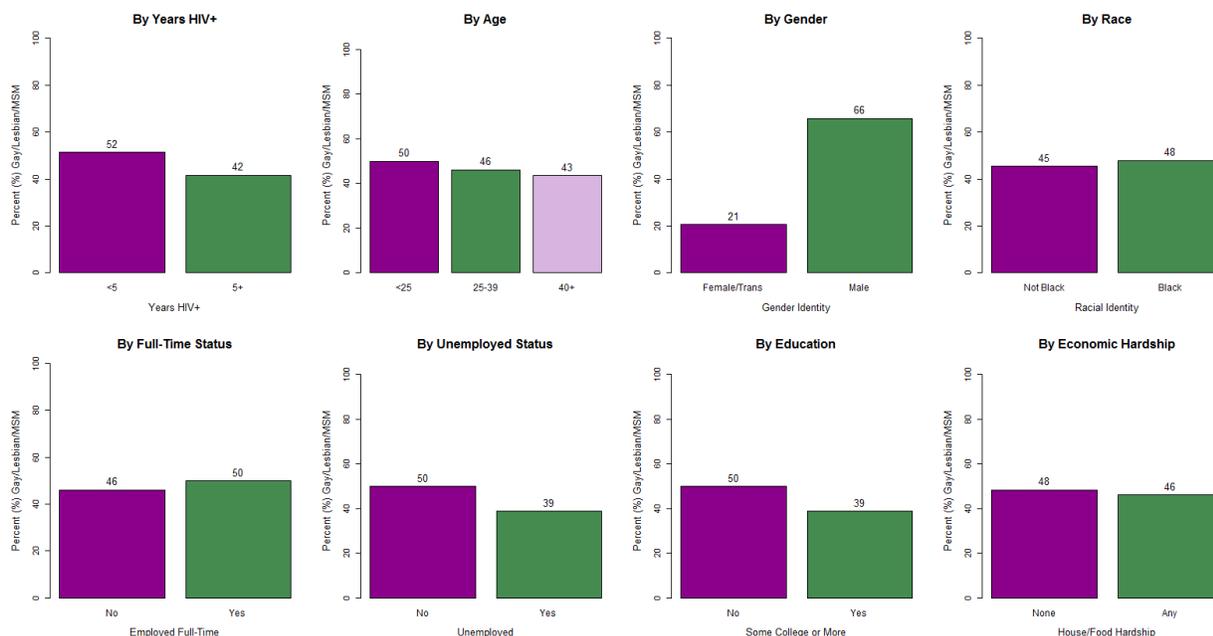


Figure 9. Gay, Lesbian, or MSM Identity by Select Characteristics

History of incarceration was greater among young participants (<25 years old), female and trans-identified participants (note that only one-third of trans participants reported a history of incarceration), persons who did not report being unemployed, participants with a high school education or lower, and persons experiencing economic hardships.

⁴ “2014 Epidemiologic Profile of HIV in Michigan”.

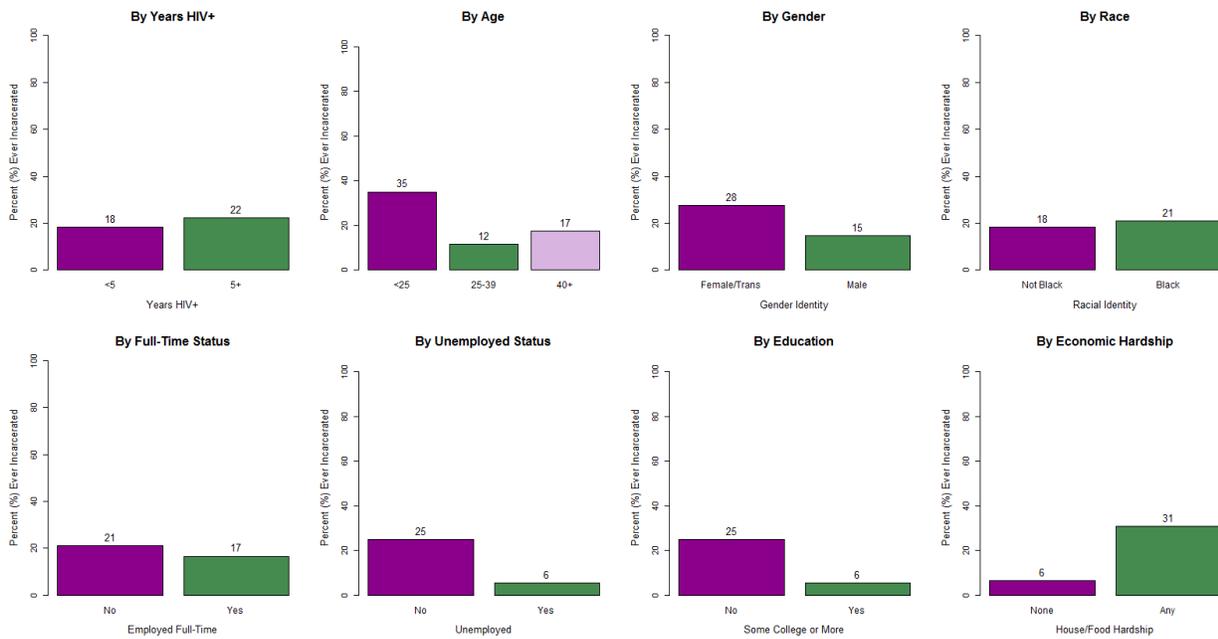


Figure 10. History of Incarceration by Select Characteristics

The percent of participants reporting currently or ever identifying as a sex worker, was highest for young participants (<25 years old), female and trans participants (note that only one-third of trans participants had history of sex work), blacks, persons with a high school education or lower, and participants reporting economic hardships. Persons who stated they were unemployed had lower rates of sex worker identification than others, however, there was little difference in these rates when comparing full-time employment status. Interestingly, sex work rates were somewhat higher among those who were employed full-time compared to those who were unemployed.

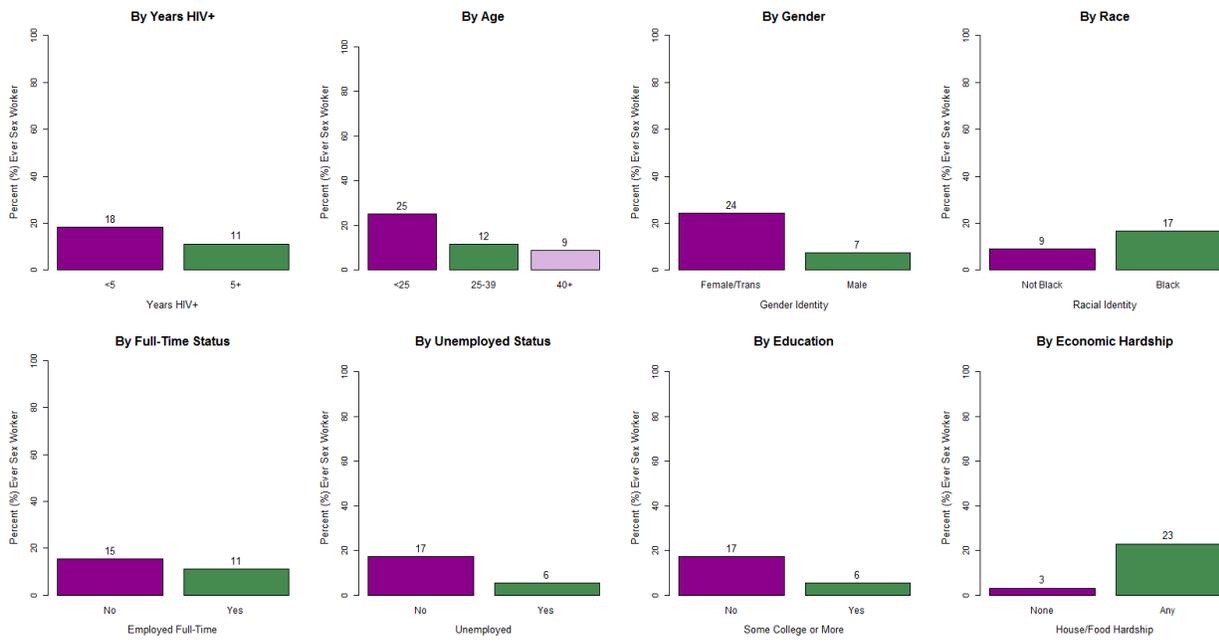


Figure 11. Sex Worker Status by Select Characteristics

A.4. HEALTH

As mentioned above all participants had at least one diagnostic assessment of viral load and CD4, with 90% receiving laboratory results in the prior 6 months. Participants generally had healthy HIV diagnostic traits. Among the sample, 64% reported 'undetectable' viral loads (<50 copies), and 50% reported CD4 counts of 500 or greater. Statewide, 23% of PLHIVs are estimated to have undetectable viral loads.⁵ Nevertheless, 22% and 24% of participants could not recall their last viral load or CD4 status, respectively. In Figure 8 we compare self-reported viral suppression by HIV history and demographics. Compared to others in the sample, those with recent diagnoses (<5 years), younger age, and male- or black-identified reported lower suppression rates.

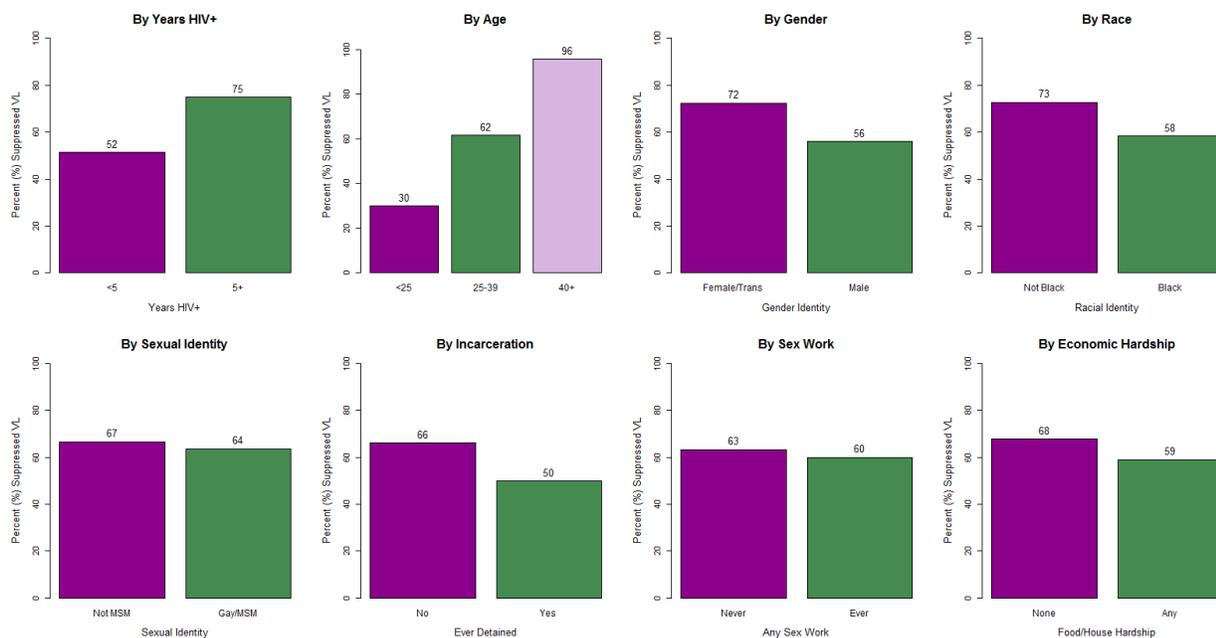


Figure 12. Rates of Viral Suppression by HIV History and Demographics

Other HIV health traits include:

- Hepatitis C co-infection: 3% were currently, and 4% were formerly infected.
- Opportunistic infections: 20% were currently taking OI medication. However, 17% of participants stated that they lack access to OIs if they needed it.

Slightly less than a third (30%) of participants reported having a physical disability. The disabilities most frequently cited included asthma, arthritis, back problems, cancer, diabetes, and lung disease. One third (33%) of participants reported having a mental

⁵ "2014 Epidemiologic Profile of HIV in Michigan".

disability; with nearly half of these described as depression. Mental health issues reported less frequently included agoraphobia, anxiety, bi-polar, PTSD, and ADHD.

At the time of the survey most participants described their health as good (34%) or very good/excellent (46%). Twenty percent of the sample reported having poor/fair health. We compare the rates of good and excellent health reports by HIV history, viral health, and demographic traits (Figure 9).

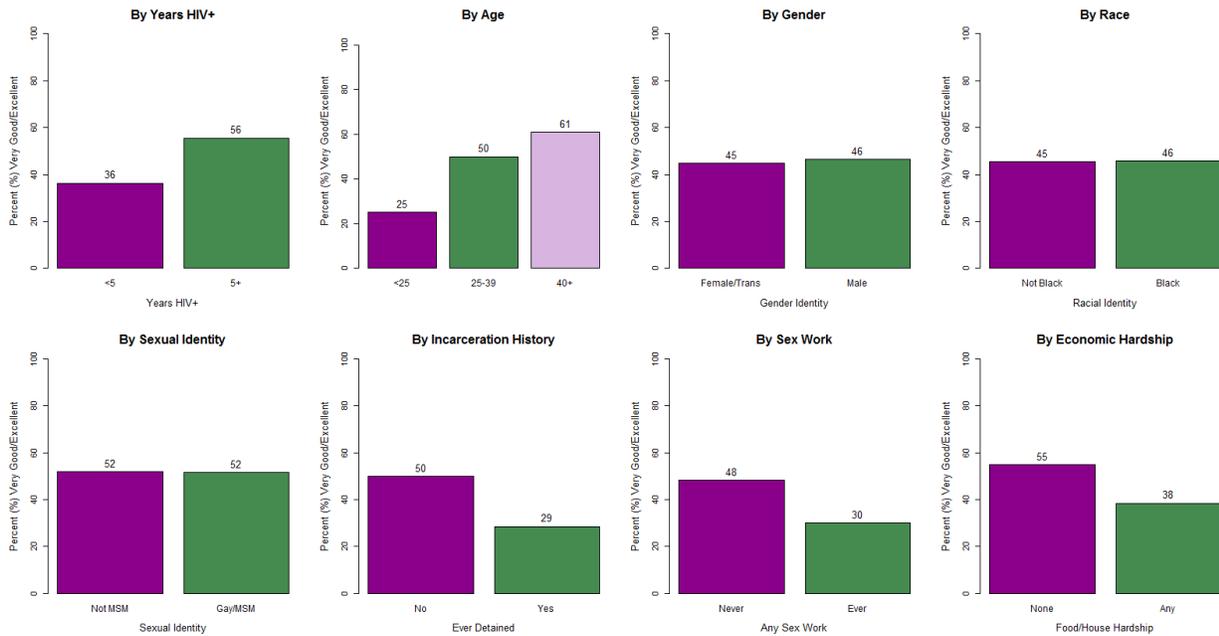


Figure 13. Self-Reported Health by HIV History, Viral Load, and Demographics

SECTION B

ATTITUDES ABOUT HIV-POSITIVE STATUS

Although the negative aspects of HIV infection on health and social relations are frequently discussed, resilient PLHIVs are likely to maintain or develop positive attitudes about the future, and draw on the experience for positive personal growth. These positive attitudes can serve as important resources for coping with social stigmas and discriminatory experiences. Nevertheless, negative attitudes such as internalized stigmas about being HIV-positive may challenge an individual's capacity to positively cope with negative interactions (e.g., discrimination) related to his or her HIV status. In this section we highlight participant perspectives and general attitudes about being HIV-positive.

Key Takeaways

- Participants held overwhelmingly positive views about the future and reported a number of ways in which they have experienced positive personal growth since being diagnosed with HIV.
- Nevertheless, numerous participants reported several negative feelings and attitudes about *being* HIV infected.
- Economic hardship and socioeconomic marginalization (e.g., history of incarceration) were associated with lower overall optimism and heightened status-negativity among participants.
- Recent HIV prevention campaigns in Michigan and nationally were viewed positively, and were typically not viewed as a source of stigma for the HIV-positive participants.

B.1. FUTURE

Participants were asked, “Looking ahead 3 years from now, do you think you will be overall better off, the same, or worse off?” Most (60%) participants stated that they would be better off, 30% assumed that they would fare the same 3 years from now, 4% stated that they would be worse off, and 6% did not respond to this item. In Figure 10 we compare the proportion reporting optimistic outlooks (“better off”) by HIV history and health, demographics, and population. Compared to other participants, those with recent diagnoses, those who identify as black, and those who have never experienced material hardship or incarceration were more likely to express optimistic perspectives. It should be noted that perceptions of little change in 3 years (i.e., stay the same) may also reflect optimism among persons who feel very content with their life.

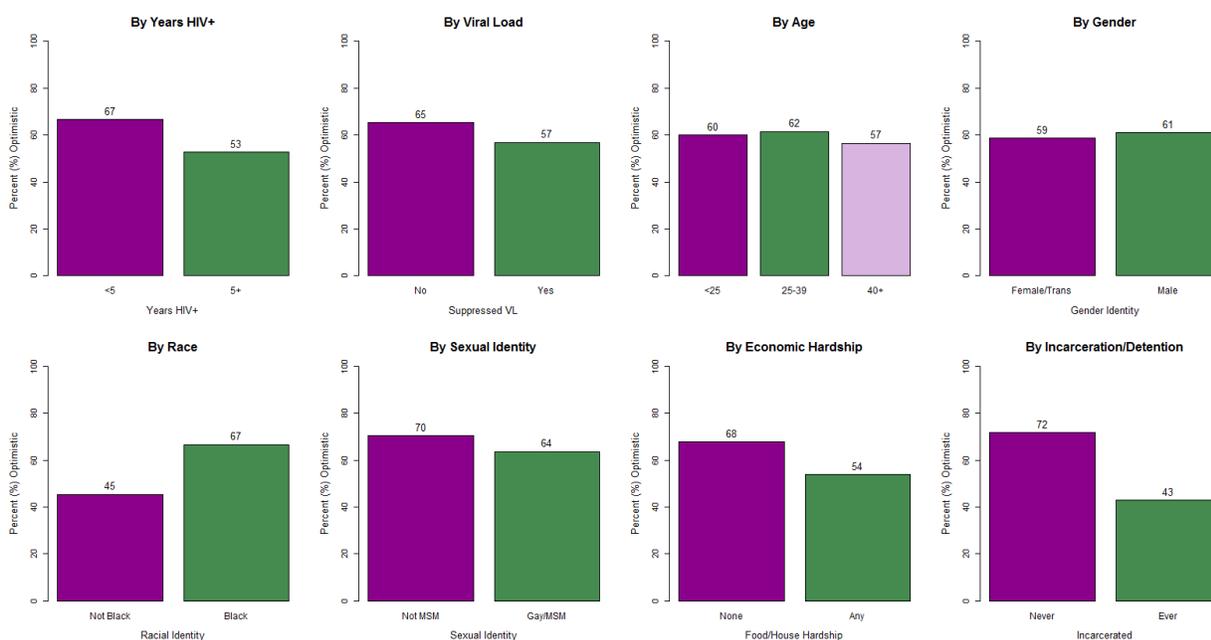


Figure 14. 3-Year Optimism by HIV History, Viral Suppression, Demographics, and Key Population

Survey participants were asked whether they felt they “have grown or developed as a person because of your HIV diagnosis?” Roughly 68% agreed with this statement, 4% somewhat agreed, 16% did not feel they had grown, and 12% had no response. In open-ended responses 6 primary themes of growth were reported.

Table 1. Themes about Personal Growth from Participant Open-Ended Responses

THEME	EXAMPLES
Positive life attitudes, resilience and spirituality	“I feel like a stronger woman today. More educated about HIV than others. More of a

	will to live now. Now that I know I have this, I want to live.”
Advocacy and education	“Definitely I am more active in my community and I take better care of my health”
Improved understanding of sexual, general, and HIV health and self-care	“It has helped me to work on those issues that led to my infection”
Improved relationships with partners	“More open to my wife”
Barriers to growth	<ul style="list-style-type: none"> • Internal shame • Guilt • Depression

Participants were asked to respond to the open-ended question: “What opportunities, if any, do you see for your community resulting from the HIV epidemic?” Although a small number of participants stated that they were unsure how to respond to this item, several stated that the barriers of stigma and discrimination were too large to realistically envision feasible opportunities. In the table we list the primary themes highlighted among those who reported specific opportunities.

Table 2. Themes about HIV Community Growth Opportunities from Participant Open-Ended Responses

OPPORTUNITY THEMES <i>(in no particular order)</i>
Increased education and awareness about HIV in the general population
Greater outreach and access to resources (including support groups) for affected populations; especially women
Increased focus on stigma reduction
Increased positive community building efforts
Getting PLHIVs into positions of leadership and power —in ASOs, other non-profits, and government.
Opportunities from health insurance expansion and research

B.2. RESPONSE TO PREVENTION CAMPAIGNS

HIV prevention campaigns have the potential to reduce incident infections among seronegative individuals. However, the focus on HIV risk and avoidance also has the potential to further stigmatize PLHIVs. We asked participants, “In the last 12 months, have you seen any HIV prevention campaigns (posters, public service announcements, etc.) that were focused on your community?” Roughly 63% of participants reported seeing such campaigns within the prior year. Compared to other participants in the sample, awareness was lowest among younger, and black-, female- and trans-, and non-gay-identified participants. Those with a history of incarceration were also substantially less likely to report awareness of prevention campaigns.

Among the 44 participants who had recently seen an HIV prevention campaign, 64% and 59% found the campaign(s) to be encouraging or empowering, respectively (Figure 12). Overall, 38 (86%) of participants who had seen the campaigns reported positive perspectives on campaigns (i.e. stated that campaigns were encouraging and/or empowering). In general, very few had seen campaigns that they felt were shaming (9%), stigmatizing (4%), or frightening (2%). Because only 6 participants had negative views of campaigns we did not disaggregate by demographic or other traits.

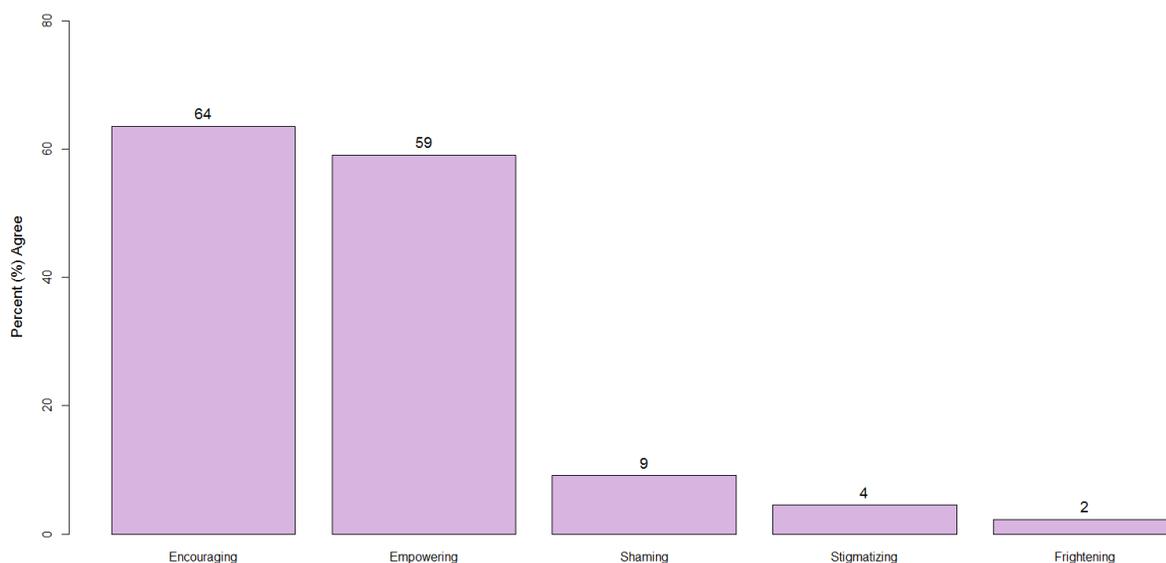


Figure 15. PLHIV Reactions to HIV Prevention Campaigns among Participants who had Recently Seen Campaigns (n=44)

B.3. INTERNALIZED HIV NEGATIVITY

Negative HIV-related feelings among PLHIV are often referred to as ‘internalized stigma’. As highlighted in Section B, several participants viewed internal shame and guilt as important barriers to ongoing positive growth and well-being. We explored the prevalence of negative feelings among the sample. Participants answered the question, “In the last 12 months, have you experienced any of the following because of your HIV status?” Eight negative feelings were listed and are presented in the figure below. Overall, 95% of participants reported feeling at least one of the negative emotions during the prior 12 months; and 74% reported experiencing 3 or more of the 8 emotions. Nearly 80% of participants reported experiencing self-blame and/or guilt in the prior 12 months.

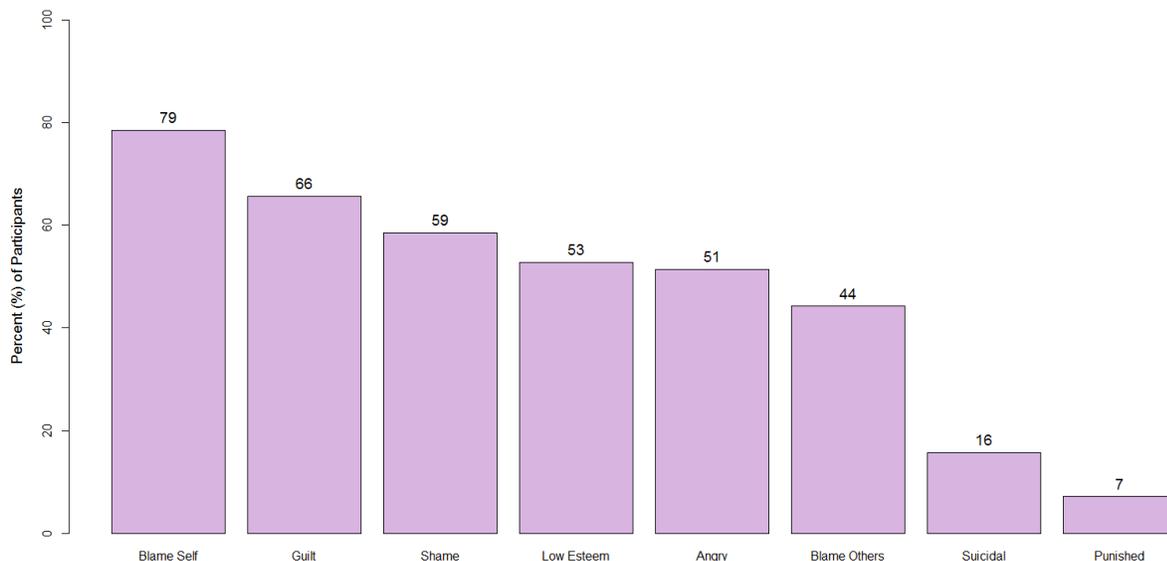


Figure 16. Percent of Participants Reporting Negative Feelings about HIV Status in the Prior 12 Months

Blame Self	I blame myself
Guilt	I feel guilty
Shame	I feel ashamed
Low Esteem	I have low self-esteem
Angry	I feel angry
Blame Others	I blame others
Suicidal	I feel suicidal
Punished	I feel I should be punished

We constructed a summary measure of *internalized stigma* from six (6) of the eight items based on statistical examination of the associations between the items (i.e.,

exploratory factor analysis, and Cronbach’s reliability coefficient estimates). The final variable included the items of: self-blame, guilt, shame, low esteem, anger, and suicidal feelings. Importantly, however, self-blame appeared to reflect both ‘shame/guilt’ concepts which may derive from perceptions of one’s responsibilities; as well as ‘blaming others/deserving punishment’ which may derive from more negative feelings about one’s relation to others in society. On average, participants reported experiencing 3 of the 6 negative feelings ($\alpha=.62$). There were no differences in these scores (internalized stigma) by demographic traits. However, persons who have faced economic hardship have substantially higher levels of internalized stigma compared to others. Other differences that were less pronounced suggest that persons with more recent diagnoses, or a history of incarceration or sex work have slightly higher levels of internal stigma.

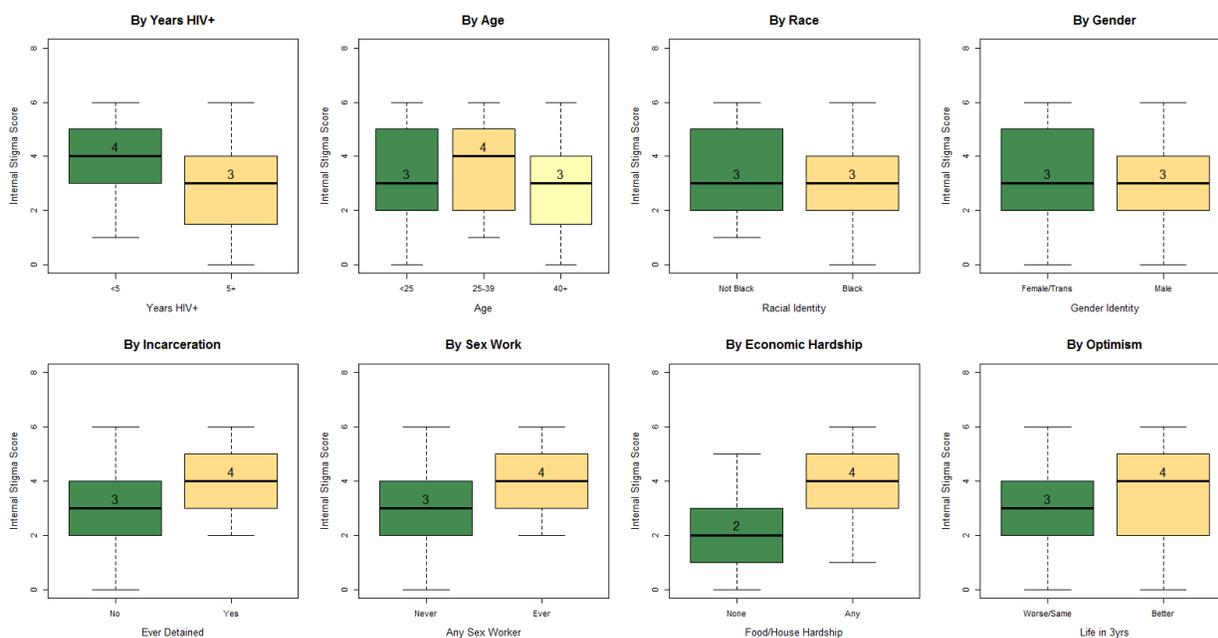


Figure 17. Internalized Stigma Score by Select Characteristics

SECTION C

SOCIAL ENGAGEMENT & SUPPORT

Access to positive social supports and positive engagement with influential others has been shown to improve capacity to positively cope with various experiences of stigma and discrimination. However, fear of rejection, exclusion, or maltreatment due to HIV status may substantially reduce the willingness of PLHIVs to maintain social relationships or foster social support. In this section we explore participants' perceived access to social supports, as well as the perceived facilitators and barriers to social engagement.

Key Takeaways

- Nearly all participants had access to some level of social support at least occasionally, with one in five reporting constant access to social support.
- Almost all participants engaged in at least one form of social avoidance with isolating oneself from family and friends reported among over half of participants.
- Roughly three in ten participants avoided social media (e.g., Facebook) out of fear of inadvertent or non-consensual HIV status disclosure.
- Fears of being rejected sexually, gossiped about, or having status disclosed online was primary concerns for over 70% of participants, and were more common than fears about safety or maltreatment.
- Socioeconomic marginalization (e.g., history of incarceration, and experiences of economic hardships) were associated with lower levels of social support and higher likelihood of anticipating rejection, stigmatization, or maltreatment due to HIV status among participants.

C.1. PERCEIVED SOCIAL SUPPORT

We assessed the presence and frequency of perceived social support access. Participants replied to the question “How often is each of the following types of support available to you if you need it?”

- Advice: “Someone you can count on to listen to you when you need to talk”
- Assistance: “Someone to take you the doctor if you need it”
- Care: “Someone to help you if you were confined to bed”
- Leisure “Someone to have a good time with”
- Affection: “Someone who shows you love and affection”
- Information: “Someone to give you information to help you understand a situation”

Responses included ‘none of the time’, ‘a little’, ‘some of the time’, ‘most of the time’, and ‘always’. In Figure 13 we compare the rate of positive responses (‘some of the time’, ‘most of the time’, and ‘always’) across each of the types of social supports. Overall, roughly 80% or more of the sample had at least occasional (‘sometimes’) access to any type of social support. Informational support ranked highest, and care and assistance (instrumental supports) ranked lowest.

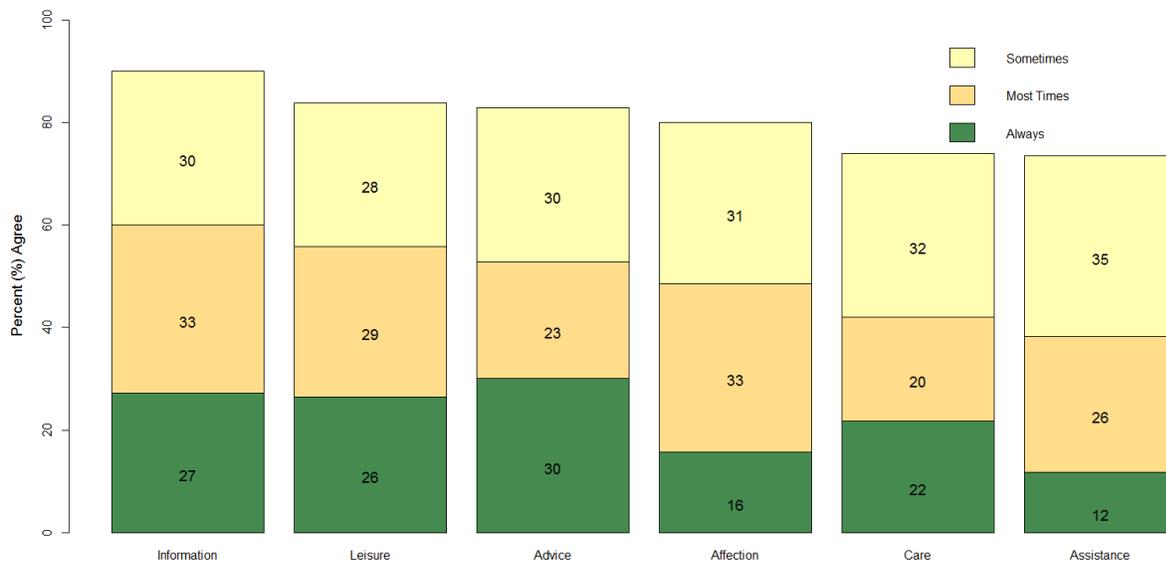


Figure 18. Perceived Access to Social Supports

We developed a summary Social Support Score ($\alpha=.87$) as the average frequency reported across all six support type categories. This score ranged from 1-5, and had a median value of 3.7. In Figure 14 we graph the distribution of the Social Support Scale

by HIV history, demographics, and optimism. These box-and-whisker plots indicate the group median (black horizontal line) and the 25th and 75th percentiles of the distribution (bottom and top of the boxes, respectively). Participants who were younger, vulnerable to economic hardships, and had ever been incarcerated or engaged in sex work had substantially lower scores.

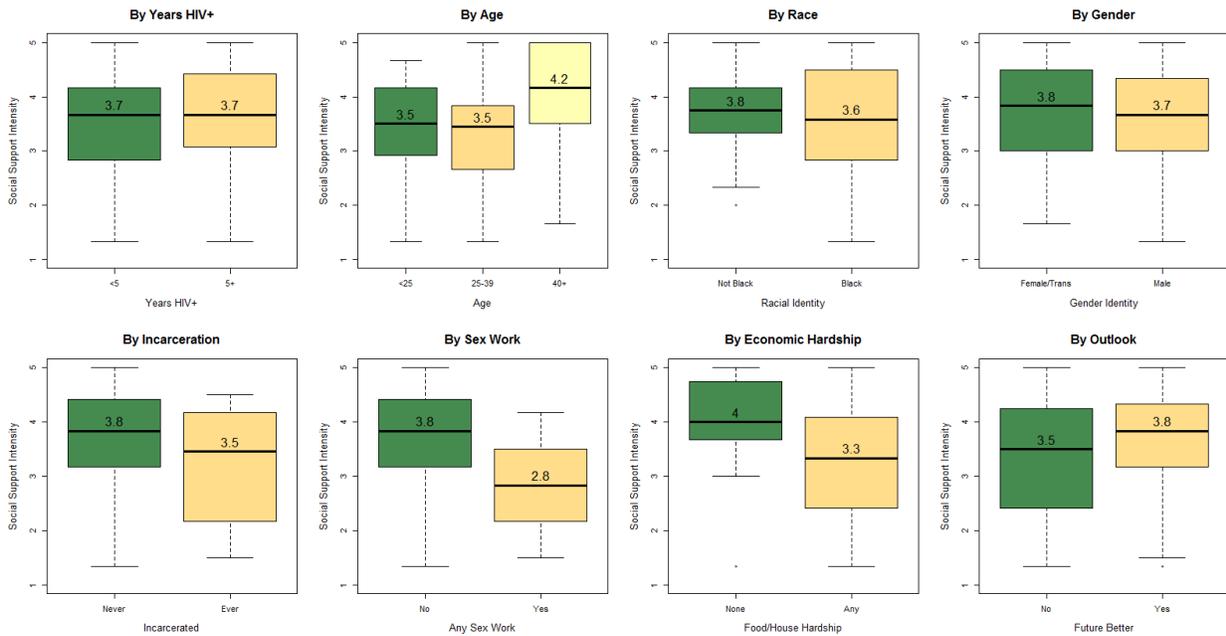


Figure 19. Social Support Score by HIV History, Demographics, and Population

Additionally, among the 33 participants currently in a relationship, 61% felt that their spouse/partner was very supportive, 25% perceived their partner as 'somewhat' supportive, and 13% felt that they received no support from their partner or spouse.

C.2. SOCIAL AVOIDANCE

Participants reported whether or not during the prior 12 months they had engaged in socially avoidant behaviors due to their HIV status. We present the frequency of reporting engagement in each of twelve types of social avoidance behaviors. Overall, rates of avoidance were highest for direct social relationships (avoiding people, events, disclosure, or sex). Institutional avoidance (avoiding clinical, employment, educational, or marital institutions) was substantially less likely among the group. Nearly all (90%) participants reported engaging in at least 1 of the 12 avoidant behaviors, with half of the participants engaging in 3 to 9 (maximum reported number) behaviors.

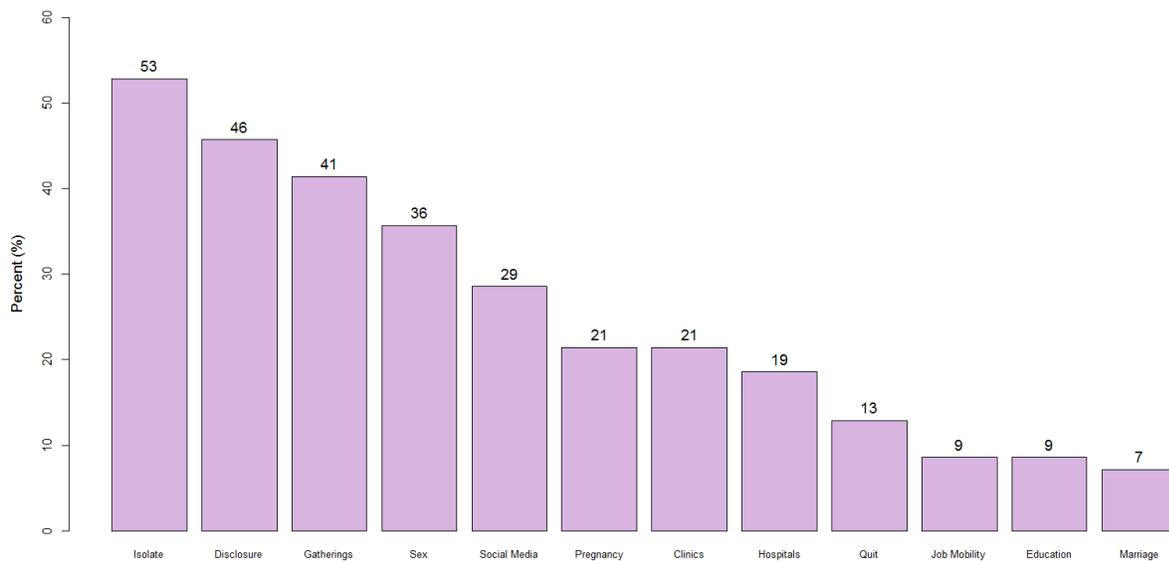


Figure 20. Engagement in Social Avoidance Behaviors

Isolate	I have isolated myself from my family and/or friends
Disclosure	I decided not to share my HIV status with someone who might have provided support to me
Gatherings	I have chosen not to attend social gathering(s)
Sex	I decided not to have sex
Social Media	I decided not to participate in social media (Facebook, Twitter, or other) because I was afraid that my HIV status might be found out
Pregnancy	I decided not to have (more) children
Clinics	I avoided going to a local clinic or doctor when I needed to
Hospitals	I avoided going to a hospital when I needed to
Quit	I made the decision to stop working
Job Mobility	I decided not to apply for a job/work or for a promotion
Education	I withdrew from education/training or did not take an opportunity for education/ training

We developed an overall score ranging from 1 to 12 ($\alpha=.65$), which indicates the number of avoidance behaviors participants report. The median value for this measure was 2.5, indicating relatively limited avoidance engagement. However, items such as decisions to have children will not apply to everyone. Thus, we anticipate lower scores overall. We compare Avoidance Scores by HIV history, demographics, and population in Figure 16. Avoidance scores differed most prominently by gender identity and population. Male-identified participants, those with a history of economic vulnerability, incarceration, or sex work, and those with lower social support had higher avoidance scores.

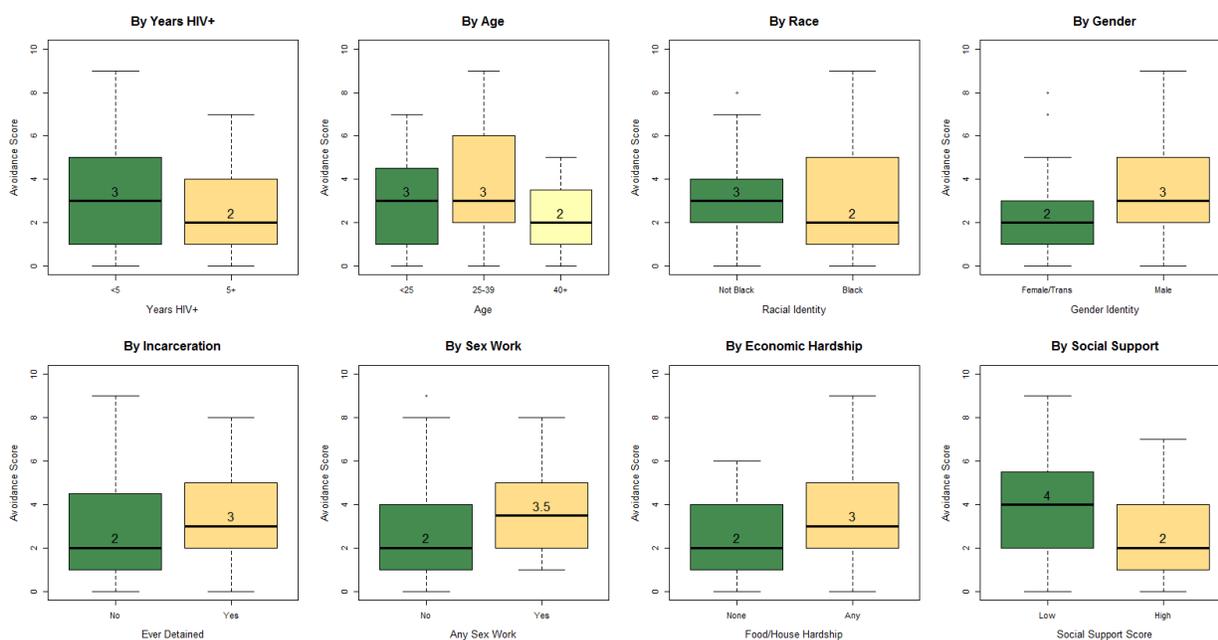


Figure 21. Avoidance Score by HIV, Demographics, and Population

C.3. ANTICIPATED STIGMA

We explored the extent to which participants anticipated being stigmatized, harassed or discriminated against in social interactions. Participants reported on whether during the prior 12 months they had feared any of 7 stigmatizing or discriminatory experiences occurring: “In the last 12 months, have you been fearful of any of the following things happening to you—whether or not they actually have happened to you?” Overall, 89% of participants reported fearing at least one of the 7 stigmatizing events.

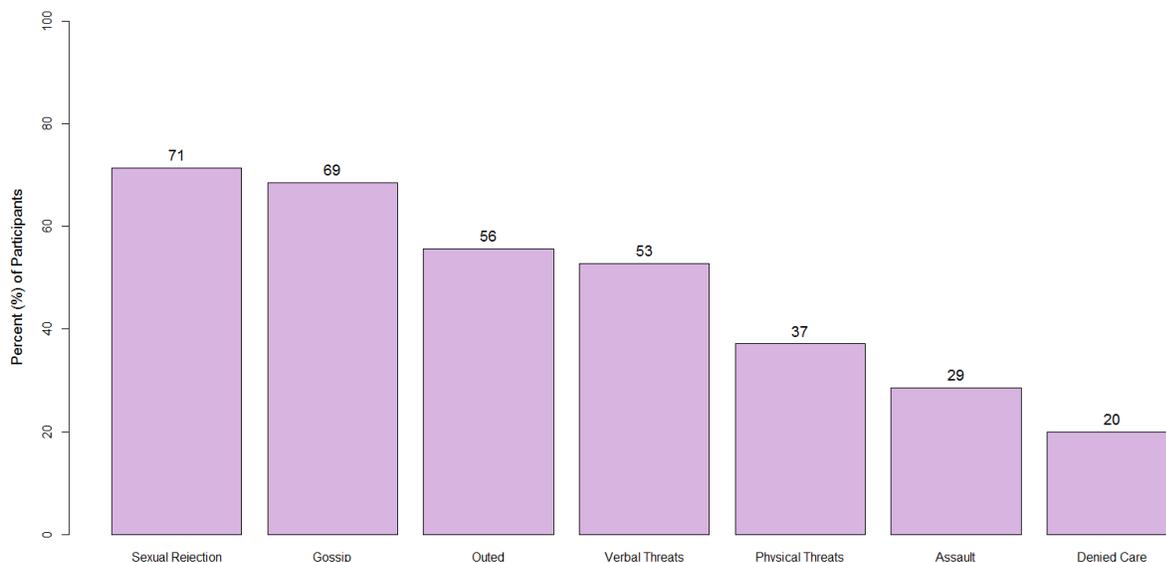


Figure 22. Percent of Participants Reporting Anticipated HIV Stigmas in Prior 12 Months

Sexual Rejection	Been afraid that someone will not want to be sexually intimate with you because of your HIV-positive status
Gossip	Being gossiped about
Outed	Having your HIV status shared without your consent online or through social media
Verbal Threats	Being verbally insulted, harassed and/or threatened
Physical Threats	Being physically harassed and/or threatened
Assault	Being physically assaulted
Denied Care	Being denied health care

We summarized the number of stigmatizing events (out of 7) that individuals anticipated occurring. The median number of anticipated stigmas was 3. Persons who had lived with HIV for 5 or more years, older persons, and Black individuals had lower reported anticipated stigmas compared to others. Persons experiencing economic hardships, or a history of incarceration or sex work demonstrated higher anticipated stigmas relative to others.

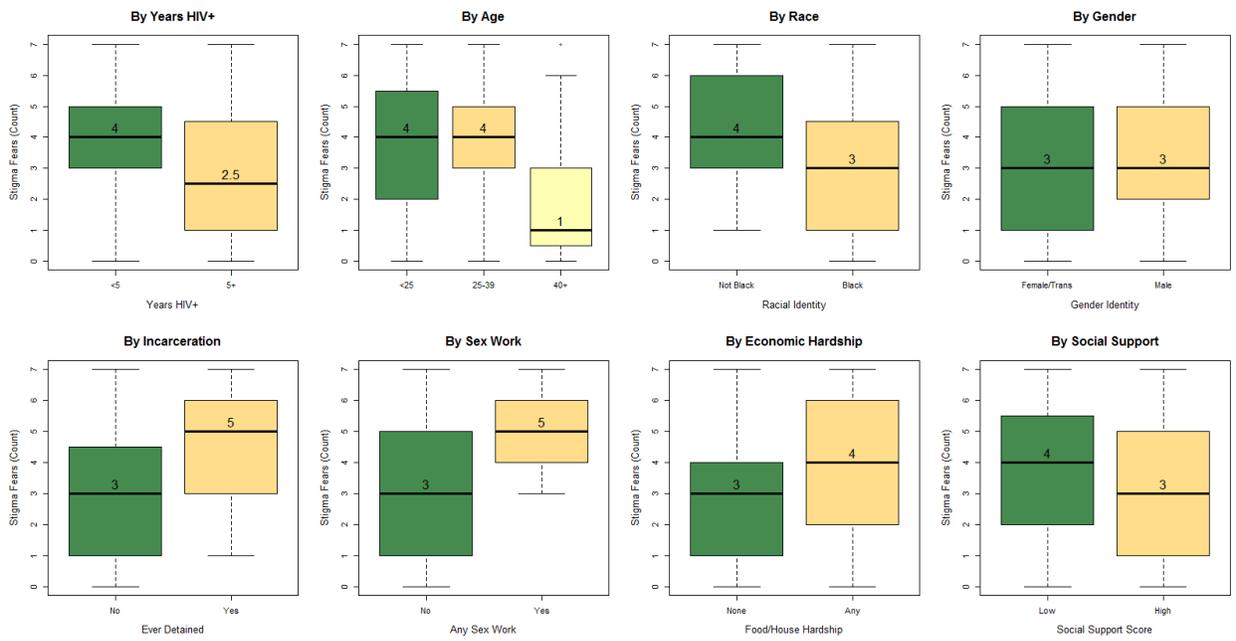


Figure 23. Anticipated Stigma Score by Select Characteristics

SECTION D

EXPERIENCES OF STIGMA & DISCRIMINATION

PLHIVs may experience various forms of social and institutional HIV-related stigmas and discriminations for multiple reasons. Stigmatizing and discriminatory experiences can also negatively impact the psychological (e.g., depression), social (e.g., social avoidance), and behavioral (e.g., health-seeking) well-being of HIV-positive persons. Here we highlight participants' exposure to, experiences of, and perceptions about recent experiences of HIV-related stigma and discrimination.

Key Takeaways

- Most participants reported recent experiences of gossip and sexual rejection as a result of their HIV-positive status.
- Experiences of discrimination were most prevalent among participants reporting economic hardships.
- Participants with higher levels of social support reported less exposure to HIV-related stigmas and discrimination compared to those with lower levels of social support.
- There is a strong positive association between anticipated stigma (i.e., fears of rejection and maltreatment) and actual experiences of stigmatizing and discriminatory interactions.
- Depression, anxiety, and social withdrawal were the most common consequences of experiencing stigma and discrimination reported by participants.
- Social discrimination was substantially more common among participants than institutional discrimination.
- Socioeconomic marginalization (e.g., incarceration, economic hardship) and fears about social rejection and maltreatment were important predictors of attitudes about the fairness of the Michigan criminal justice system in handling cases involving HIV-positive persons.

D.1. SOCIAL STIGMA & DISCRIMINATION

We asked participants to report whether they experienced any of 11 types of stigma, harassment or discrimination in the prior 12 months: “In the last 12 months, to your knowledge, how often (never, once, few times, often) have you been...” Nearly 73% of participants experienced at least 1 of the 11 forms of exclusion, stigma or discrimination. Gossip and sexual rejection were the most common types of stigmatizing experiences reported among participants.

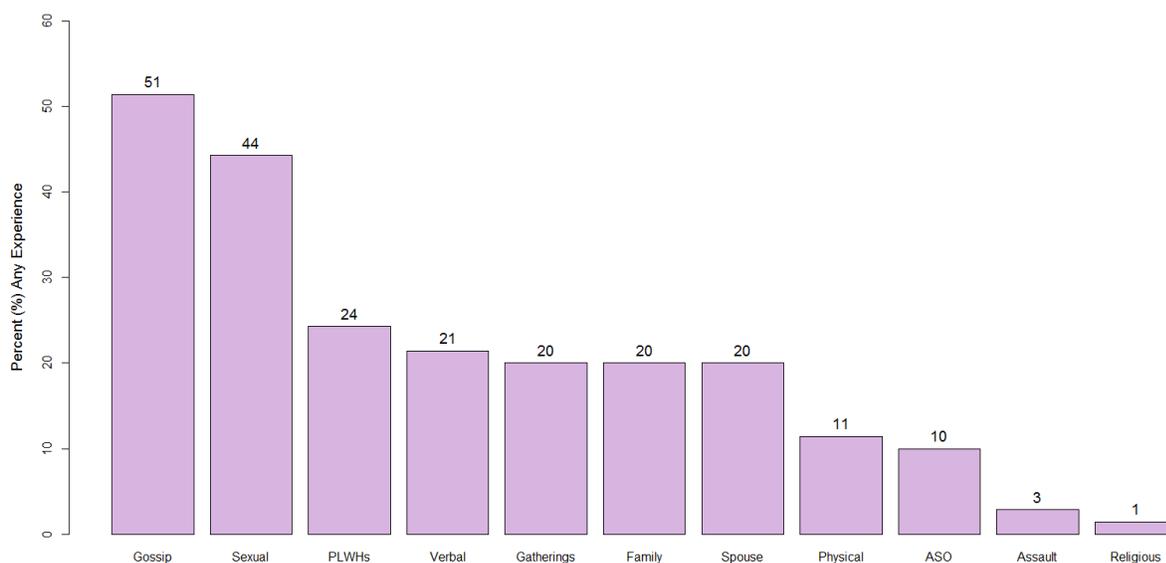


Figure 24. Percent of Participants Reporting Types of Stigmas and Discriminations in Prior 12 Months

Gossip	Aware of being gossiped about
Sexual	Sexually rejected as a result of HIV+ status
PLHIVs	Discriminated against by other people living with HIV
Verbal	Verbally insulted, harassed and/or threatened
Gatherings	Excluded from social gatherings or activities
Family	Excluded from family activities
Spouse	Subjected to psychological pressure or manipulation by your partner in which your HIV+ status was used against you
Physical	Physically harassed and/or threatened
ASO	Discriminated against by someone who works for an HIV/AIDS service organization
Assault	Physically assaulted
Religious	Excluded from religious activities or places of worship

For each of the 11 types of stigma and discrimination, participants were asked how frequent they occurred during the past year: never (0), once (1), a few times (2), or

often (3). We summarized these among 9 of the 11 items. The 9 items were selected based on statistical examination of the items (factor analysis and reliability coefficients). The final summary measure ($\alpha = .72$) excluded items on physical violence and ASO discrimination. The final *intensity* scores in the sample ranged from a low of 0 to a high of 19 (out of a possible maximum of 27 (9 types x highest frequency of 3)).

Demographically, older participants reported lower discrimination intensity relative to others. Notable differences in discrimination intensity were evident for socioeconomic traits, particularly for those experiencing economic hardships. Whereas participants with higher levels of social support reported lower overall discrimination intensity, social avoidance and anticipated and internalized stigmas were associated with higher reported discrimination intensity.

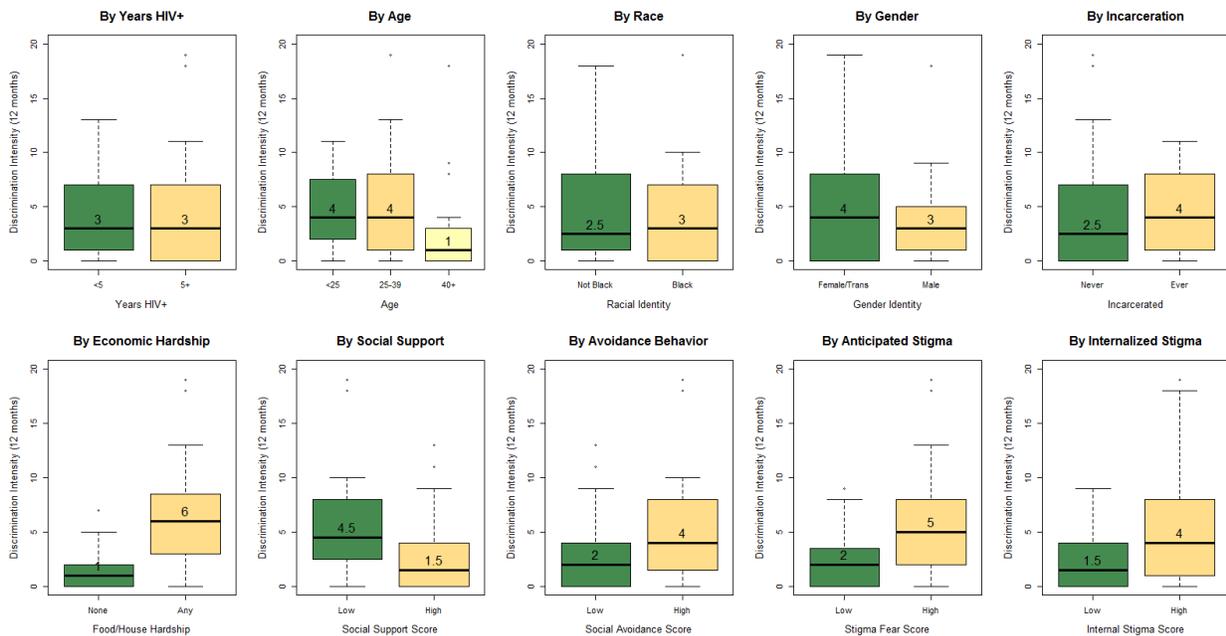


Figure 25. Recent Discrimination Intensity by Select Characteristics

In addition to the intensity of these discriminatory experiences, participants were asked: “If you have experienced some form of HIV-related stigma and/or discrimination in the last 12 months why do you think this is?” Participants could select more than one reason from among a list of 5 possible reasons. The most common replies were that others were afraid or uninformed.

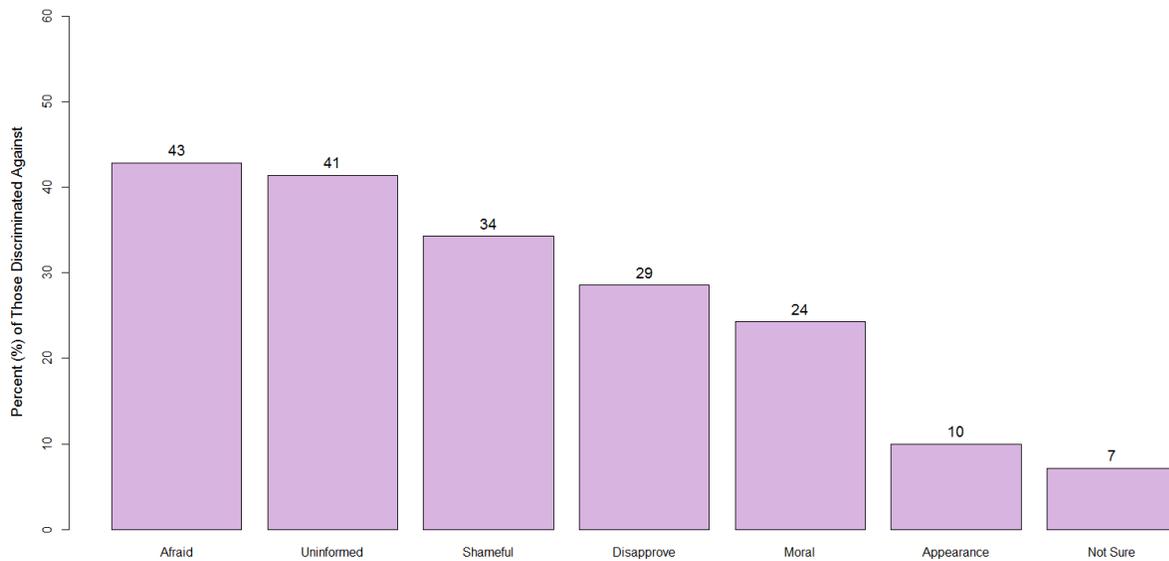


Figure 26. Perceived Reasons for Recent Discrimination

Afraid	People are afraid of getting infected with HIV from me
Uninformed	People don't understand how HIV is transmitted and are afraid I will infect them with HIV through casual contact
Shameful	People think that having HIV is shameful and they should not be associated with me
Disapprove	People disapprove of my lifestyle or behavior
Moral	Religious beliefs and 'moral' judgments
Appearance	I look sick with symptoms associated with HIV
Not Sure	I am not sure of the reason(s)

D.2. IMPACT OF SOCIAL STIGMA & DISCRIMINATION

Participants reported the impact of social stigma and discrimination on their well-being. Participants were asked, whether they experienced any of 11 potential negative consequences as a result of recent experiences of discrimination. Depression and anxiety were most frequently reported followed by familial exclusion.

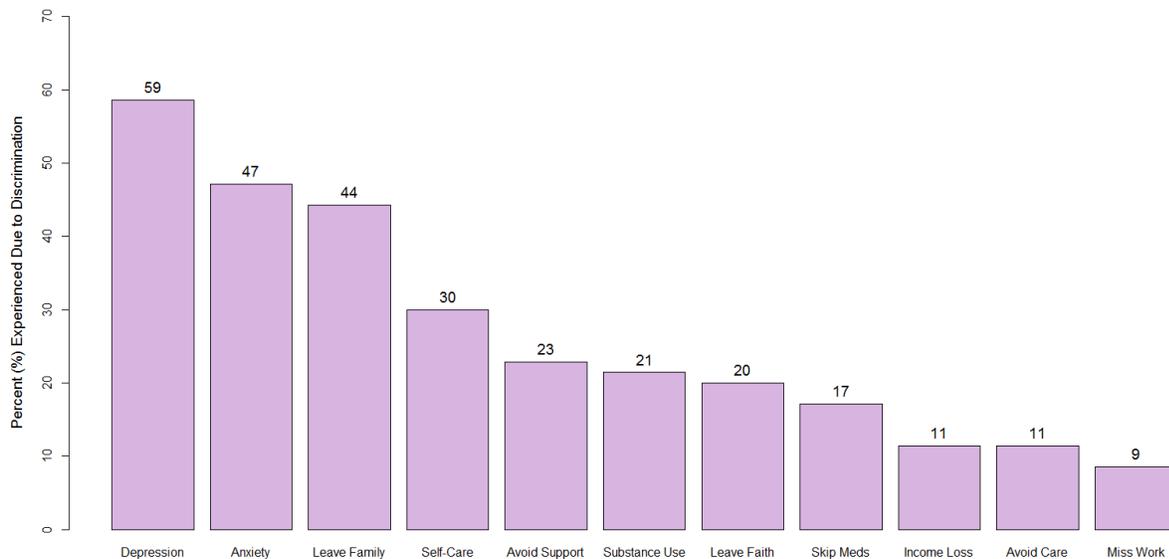


Figure 27. Reported Consequences of Experiences of Discrimination During the Prior 12 Months

Depression	Depression
Anxiety	Anxiety
Leave Family	Withdrawing from family or friends
Self-Care	Reduced exercise, physical activity, or sleep
Avoid Support	Avoiding social support
Substance Use	Increased drug or alcohol intake
Leave Faith	Withdrawing from faith-based or spiritual support
Skip Meds	Skipped doses of medication
Income Loss	Income loss
Avoid Care	Avoiding health care
Miss Work	Missed days at work or school

Among the 70 survey participants 55 (79%) reported experiencing at least one of the 11 listed negative consequences as a result of recent discrimination, with a median of 2 and a maximum of 10 negative consequences. We summed the total number of reported consequences ($\alpha=.81$) The number of negative consequences was higher for persons experiencing economic hardships, having lower levels of social support, reporting higher

social avoidance, reporting higher levels of anticipated and internalized stigmas, and experiencing higher than average intensity of discriminations.

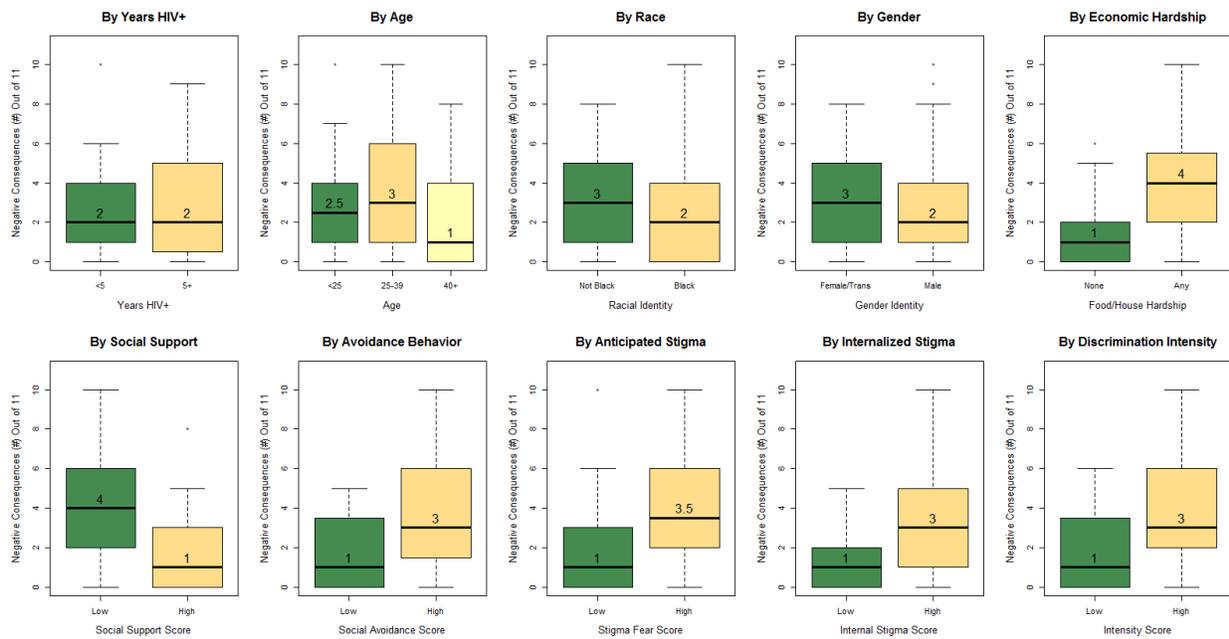


Figure 28. Number of Negative Consequences Due to HIV Discrimination in Prior 12 Months

D.3. INSTITUTIONAL DISCRIMINATION & RIGHTS VIOLATIONS

In addition to experiences of social stigma, we asked participants to report whether they experienced any of 14 forms of discrimination and/or violations of rights in accessing work, housing, health and education services in the prior 12 months as a result of their HIV status. We report the 11 discrimination/violation items reported by at least 1 participant. Among participants nearly 80% reported that they had not experienced structural discriminations or violations of their rights. Nevertheless, 9-11% reported discrimination in health care, housing, and insurance access due to HIV-positive status.

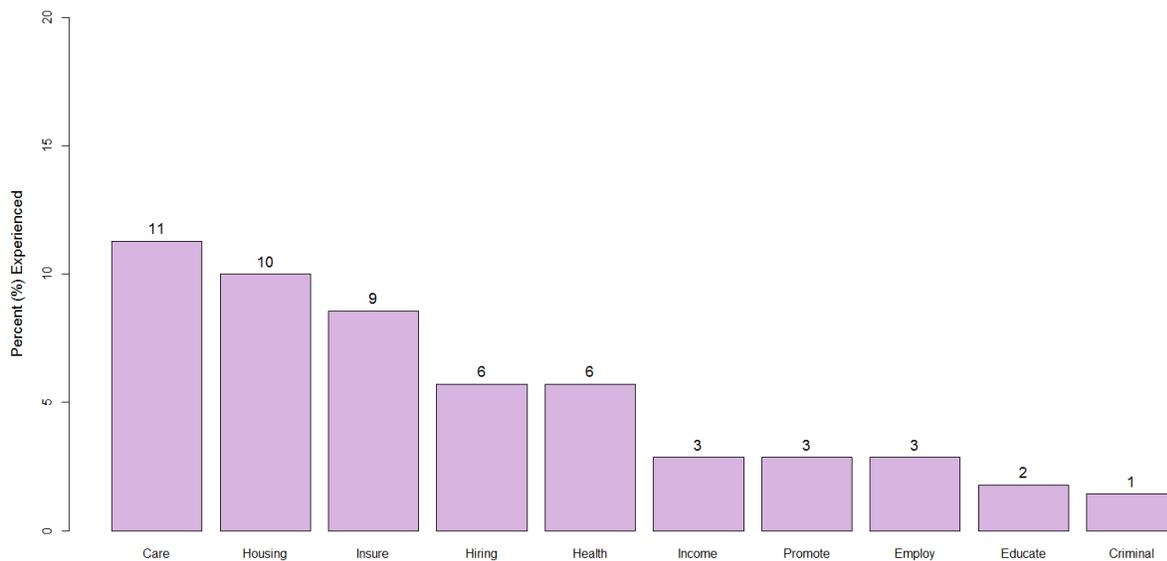


Figure 29. Experiences of Institutional Discrimination or Rights Violations in Prior 12 Months

Care	Denied health care
Housing	Been forced to change your place of residence or unable to rent accommodation
Insure	Denied health or life insurance because of HIV
Hiring	Refused employment or work opportunity
Health	Forced to submit to a medical or health procedure (including HIV testing)
Income	Lost a job or another source of income
Promote	Job change or refused promotion
Employ	Had to disclose HIV as part of a job application
Educate	Dismissed, suspended or prevented from education
Criminal	Investigated, arrested, or taken to court on criminal matter related to HIV

Several participants reported concerns about their legal rights as an HIV-positive person. Roughly 20% agreed that their rights as a person living with HIV had been abused in the prior 12 months. Moreover, 38% agreed that they were worried about being falsely accused for not disclosing their HIV status to a sexual partner.

In response to the question, “If someone were to file charges against you claiming that you were a sexual partner and you did not disclose your HIV status to him or her, do you trust that you would be given a fair hearing in Michigan’s criminal justice system?” nearly 60% stated that they would probably not or definitely not be given a fair hearing. Rates of agreement differed by age, gender, history of incarceration and sex work, experiences of economic hardships, social avoidance, and anticipated stigma.

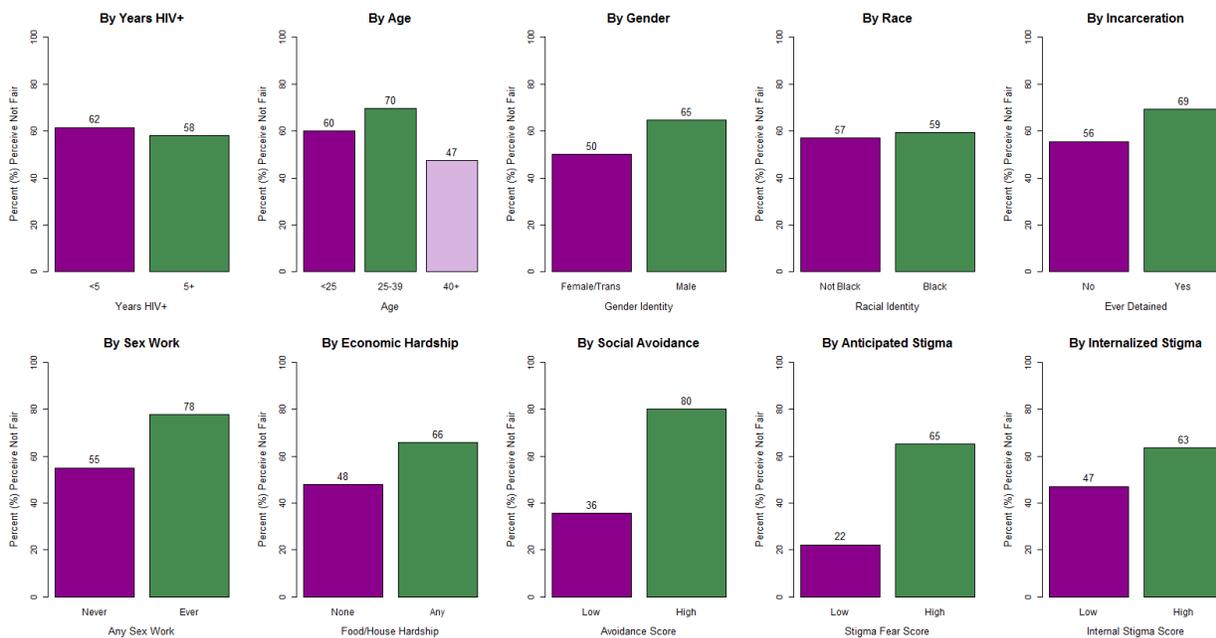


Figure 30. Perceived Criminal Justice System Not Fair to HIV+ by Select Characteristics

SECTION E

TESTING, TREATMENT, & DISCLOSURE

Repeat testing, early testing following HIV exposure, and rapid engagement in care have been shown to greatly increase the long-term health of HIV-positive persons. When combined with accurate disclosure of HIV status, these behaviors can also substantially reduce new infections within the general population. Unfortunately, anticipation of and experiences with HIV stigma and discrimination can serve as barriers to engaging in these health-promoting behaviors. In the following section we explore participants' prior experiences with and perceptions of testing, treatment and disclosure with a particular focus on their relation to fears, stigmas, and discriminatory events among PLHIV participants.

Key Takeaways

- Most participants were repeat testers and engaged in care soon after diagnosis.
- Desire to take care of one's own health was an important facilitator of testing decision-making.
- Perceptions about readiness to deal with HIV were a key feature of care engagement decision-making.
- Fear of being shunned or stigmatized were predominant concerns in decision-making around testing
- Socioeconomic exclusion (e.g., incarceration, economic hardship) was associated with delays in testing and treatment, and heightened the influence of stigma/discrimination fears on testing decision-making.
- The response of family and friends to disclosure was mixed, but generally deemed less supportive than AIDS Service Organizations, clinics, and other groups/organizations.
- Anticipated fears about being stigmatized were associated with declines in perceived supportiveness of family and friends.

E.1. TESTING & DIAGNOSIS

Slightly more than half of the 70 participants surveyed were 'repeat testers': 20% had one test prior to their HIV diagnosis, and 31% reported more than one test prior to testing positive. Fewer than 5% of participants had tested but never received their results, and 44% had not tested prior to diagnosis. Repeat testing (receipt of results for one or more prior HIV tests) was greatest among younger participants, those diagnosed recently, those with a history of incarceration and sex work, those with low levels of current social support, and those with higher levels of anticipated stigma. Repeat testing rates were also somewhat higher among women and trans persons relative to men, among black participants relative to others, and those experiencing economic hardships.

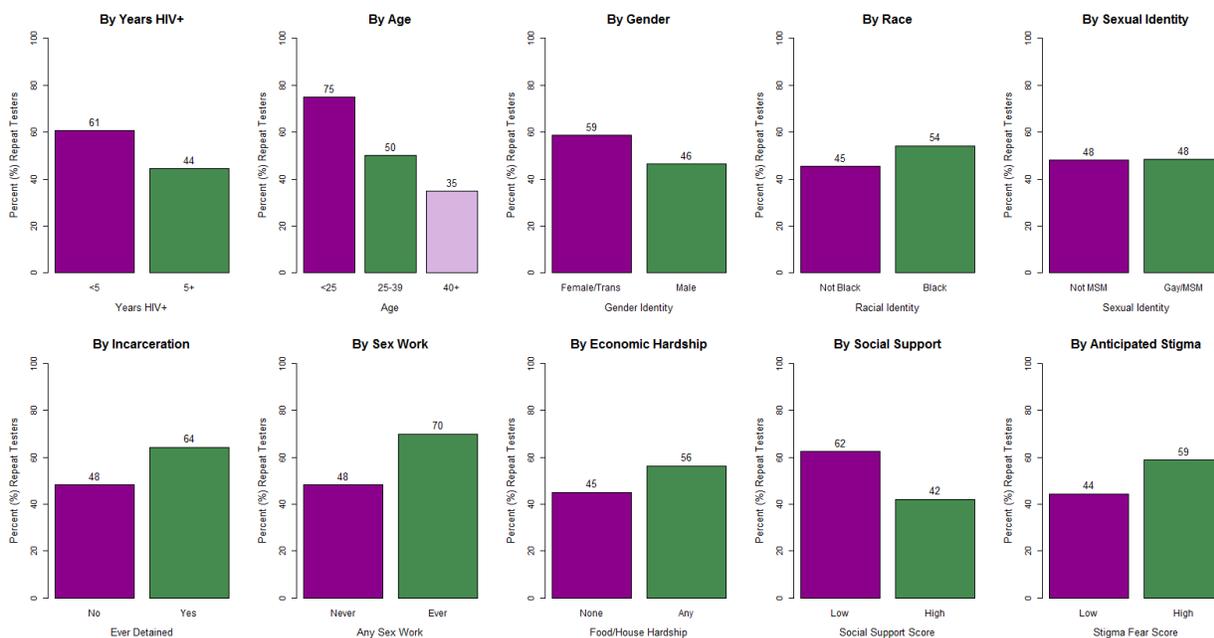


Figure 31. Repeat Testing Prior to HIV Positive Diagnosis by Select Characteristics

Participants were asked to respond to the question “Thinking back to the time that you were diagnosed with HIV, why were you tested?” Participants selected 13 of the 14 possible items (an additional category “other” is excluded here). Among the various reasons for getting tested for HIV the most common response (30%) was testing as a means of self-care or just wanting to know his/her HIV status.

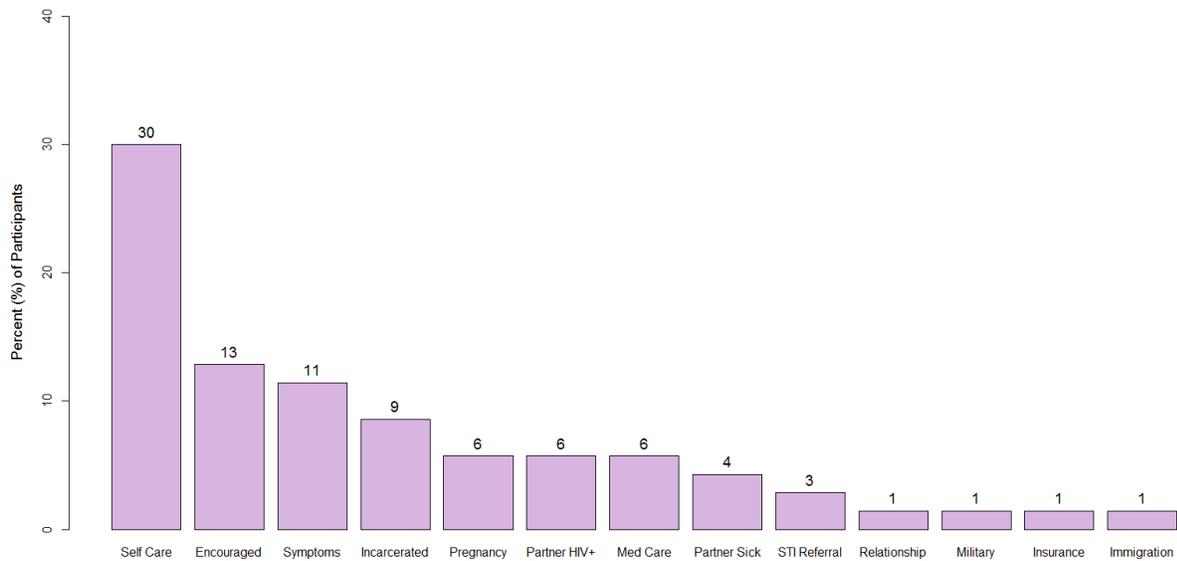


Figure 32. Reasons for Getting Tested

Self Care	I just wanted to know
Encouraged	I was encouraged to test by my partner or a family member or friend
Symptoms	Referred due to suspected HIV-related symptoms (e.g. tuberculosis)
Incarcerated	Beginning, during, or ending a period of incarceration in a jail or prison
Pregnancy	Pregnant or had just delivered a baby
Partner HIV+	Husband/wife/partner/family member tested positive
Med Care	It was ordered by my health care provider as part of a routine checkup or surgical procedure
Partner Sick	Illness or the death of a husband/wife/partner/family member
STI Referral	Referred by a clinic for sexually transmitted infections
Relationship	To prepare for a marriage/sexual relationship
Military	Military induction or military service
Insurance	For health or life insurance coverage
Immigration	Immigration purposes

We asked participants: “Before you took an HIV test, were you afraid that any of the following would occur if you tested positive?” Among the list of 14 items (plus an “other” option, excluded here) being shunned (67%) or being identified with a stigmatized group (44%) were the most common fears.

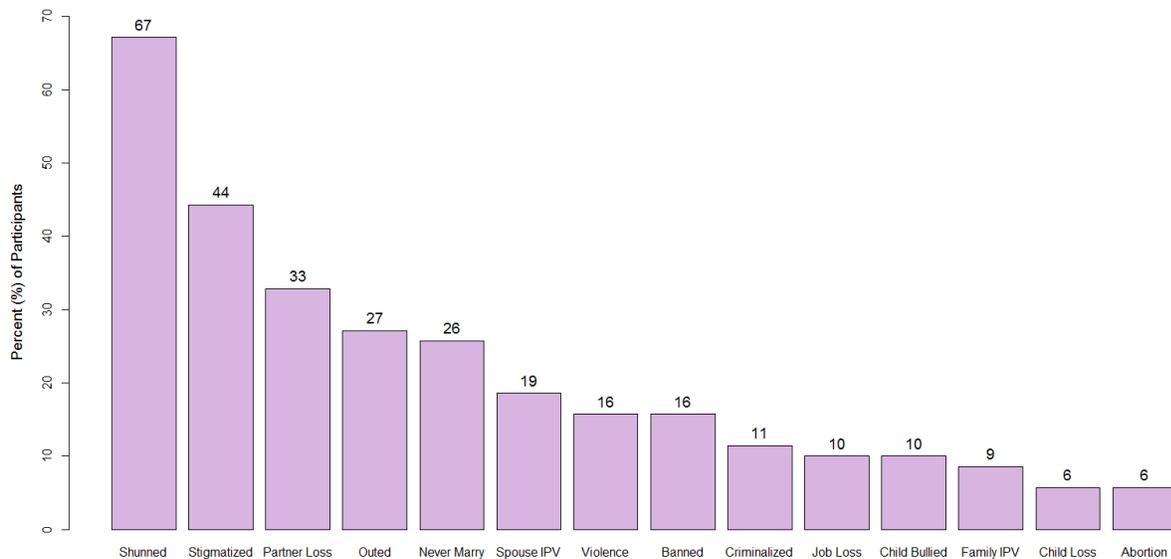


Figure 33. Fears about Testing HIV-Positive prior to HIV Diagnosis

Shunned	I would be shunned by family or friends
Stigmatized	People might think that I am promiscuous, a man who has sex with men, a sex worker, or an IV drug user
Partner Loss	My husband/wife/partner would leave me
Outed	People might find out that I am, or have been, engaged in sexual activity outside of marriage, a man who has sex with men, a sex worker, or an IV drug user
Never Marry	I would not be able to get married
Spouse IPV	My husband/wife/partner would be physically violent with me
Violence	Members of my community would be physically violent with me
Banned	I would be forced to leave my home or community
Criminalized	The police or legal authorities might attempt to bring criminal charges against me
Job Loss	I would lose my job or be removed from my school program
Child Bullied	My children would be treated badly by our family, our community, or their school
Family IPV	Other family members would be physically violent with me
Child Loss	My children would be taken from me
Abortion	I would be forced to terminate a pregnancy

The rate of agreement about fear of being shunned by family or friends (67%) was relatively consistent across time since diagnosis, age group, gender, and sexual identity. There was considerable variation across racial, socioeconomic, and psychosocial characteristics as well as between persons interpersonal and discriminatory experiences since testing HIV-positive.

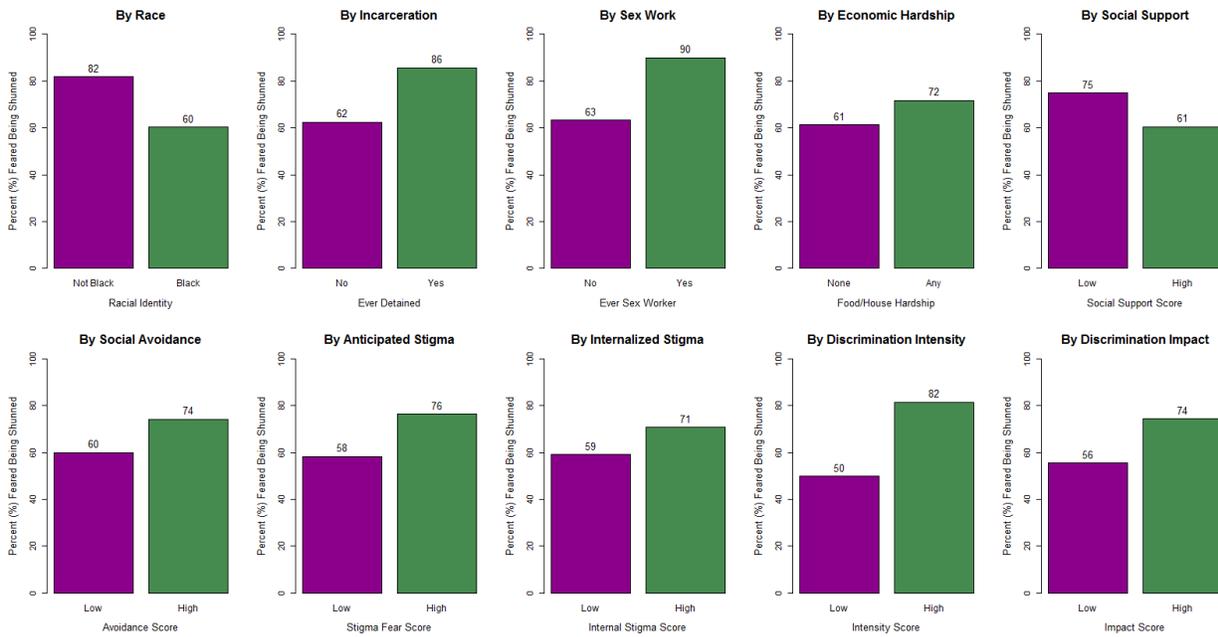


Figure 34. Fear of Being Shunned prior to taking an HIV Test by Select Characteristics

With respect to the test at which they were diagnosed with HIV, most (73%) participants reported that the test was voluntary. Nevertheless, a sizable portion reported being tested without their knowledge (9%) or coerced (6%). Slightly less than 10% reported that the decision to test was taken “under pressure from others”.

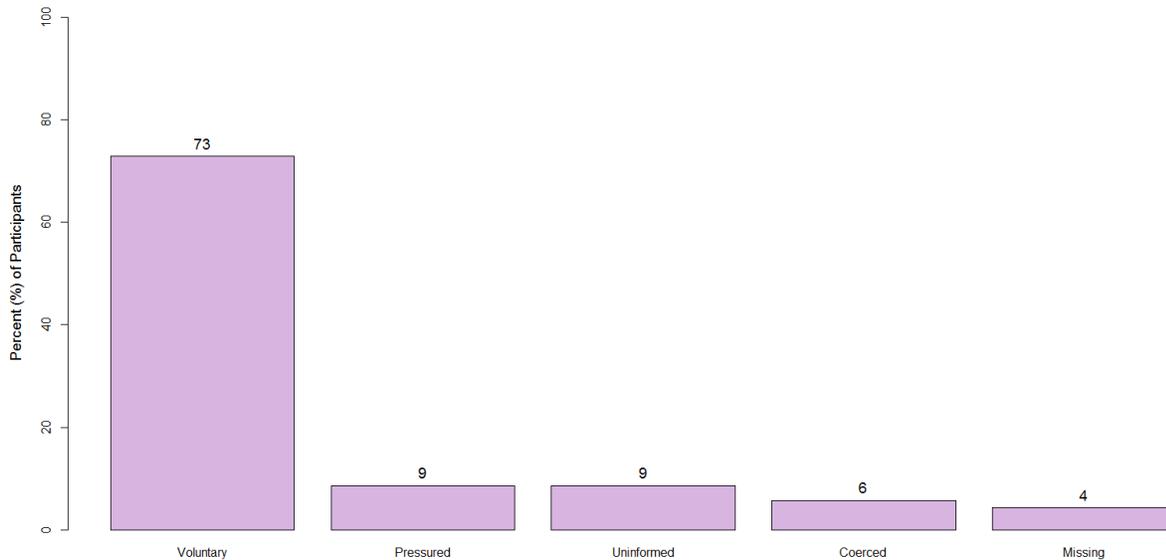


Figure 35. Voluntariness of Testing at Time of HIV Diagnosis

Fewer than half (42%) of participants received no counseling when they tested for HIV. These rates differed by demographic and socioeconomic backgrounds. Participants diagnosed in the prior 4 years and men were more likely than others to report receipt of counseling. Blacks and persons with a history of incarceration or economic hardships were less likely to receive counseling.

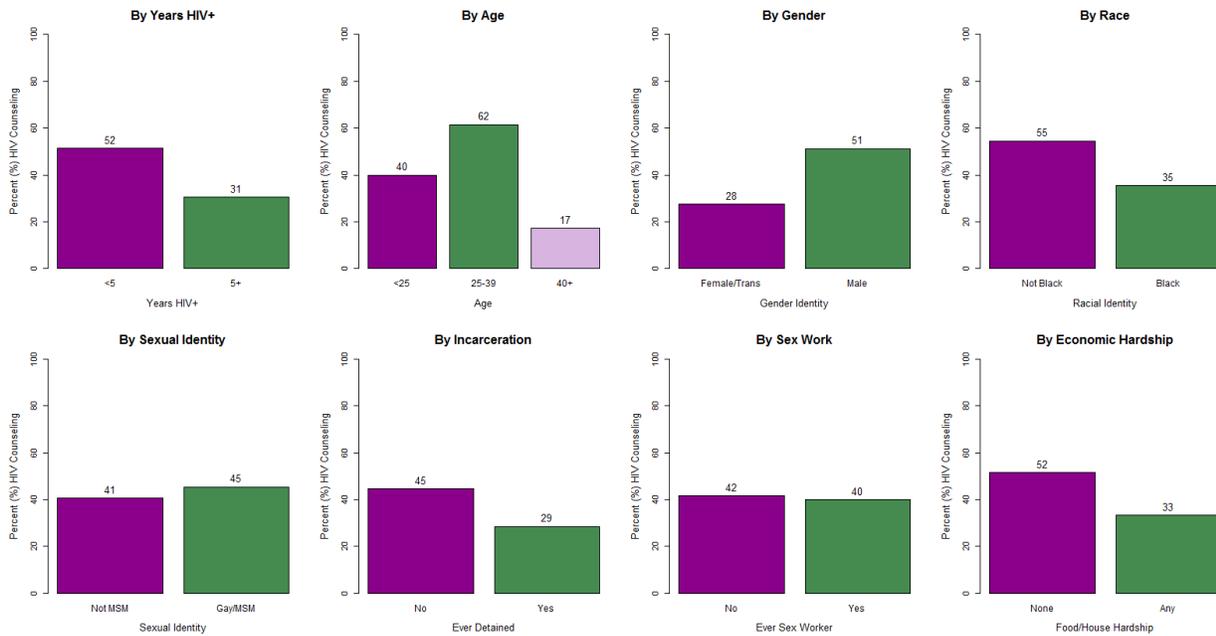


Figure 36. Percent of Participants Who Received Counseling during HIV Test by Select Characteristics

In order to assess general attitudes and norms about testing, participants were presented with the following scenario: “A person, who is otherwise feeling healthy, states he or she does not want to take an HIV test out of fear of being prosecuted if the HIV test comes back positive.” Participants were asked how reasonable they felt it was for this individual to not get tested for HIV. Most reported that it was very reasonable (38%) or somewhat reasonable (43%) for the person to not get tested. Differences in perceptions of the reasonableness of not testing were evident by race, sexual identity, and perceptions about the fairness of the criminal justice system for HIV-positive persons.

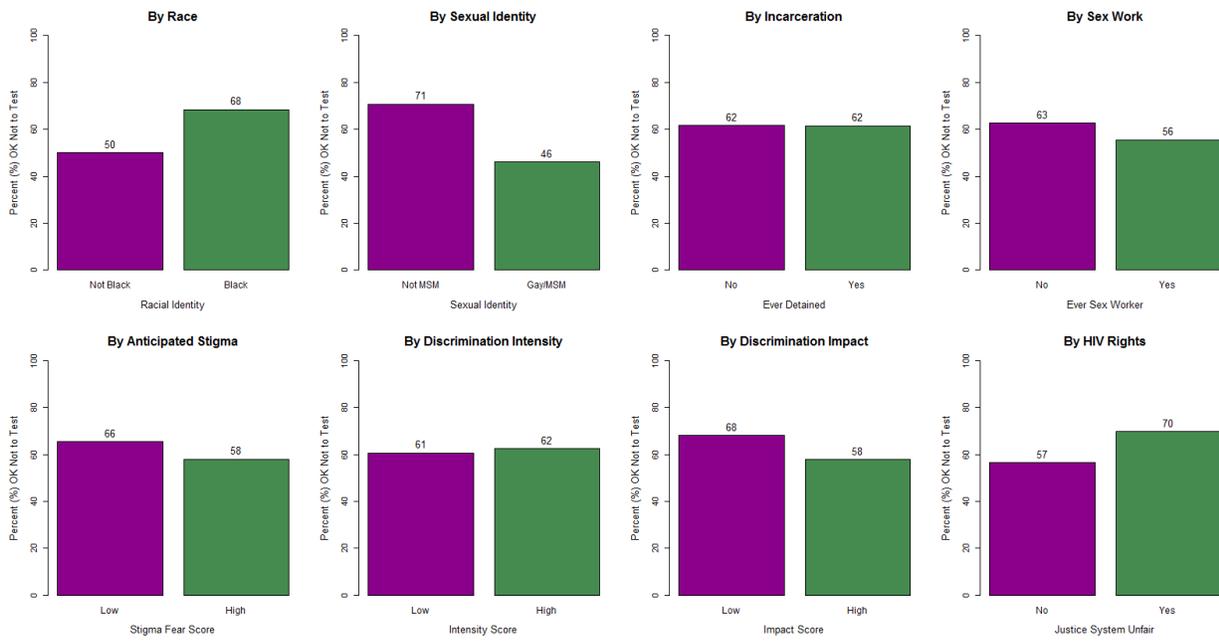


Figure 37. Reasonable to Avoid Testing for Fear of Prosecution by Select Characteristics

E.2. TREATMENT

All (100%) participants stated that they had seen a health professional for care related to their HIV diagnosis. Participants overwhelmingly reported positive interactions with their current health care providers: 86% stated that they felt supported by providers to make their own health care decisions. Nevertheless, 14% said that they felt coerced into taking HIV medications (for their own health or to reduce transmission) at some point during receipt of care.

Among the 70 participants, 68 reported their current health insurance coverage. Public insurance was the primary means of financial support for health care among participants. At the time of the survey, 60% were using Medicaid, 15% reported access to Medicare, 15% reported access to ADAP, 4% were on private insurance supplemented by ADAP, and 3% accessed some other form of public insurance. Overall, 77% reported access to at least one of these forms of public insurance support. However, 9% of participants were uninsured at the time of the survey.

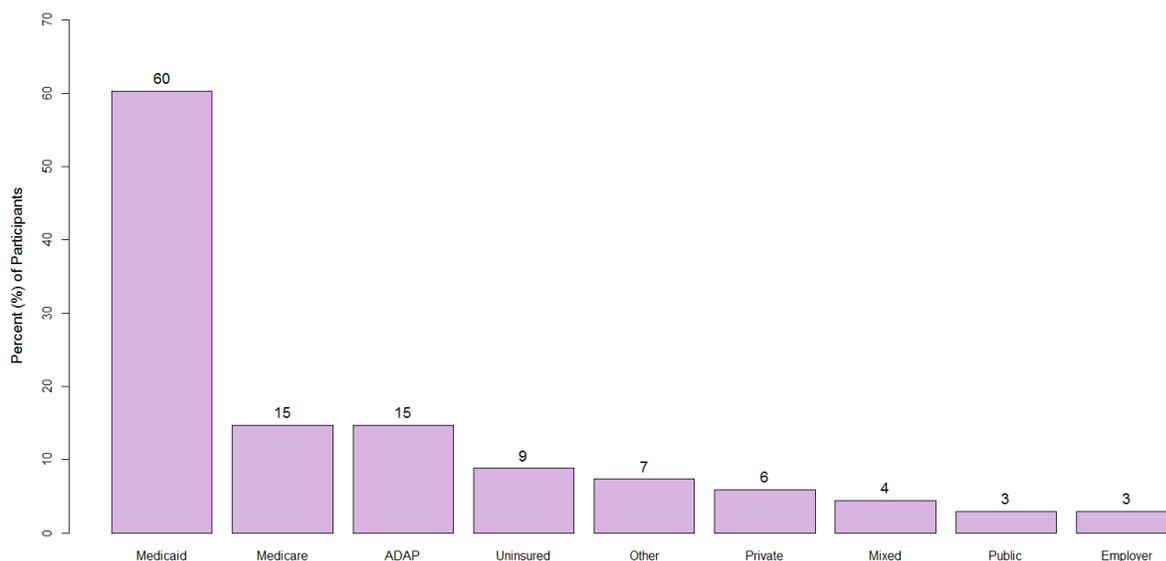


Figure 38. Current Insurance Coverage among 68 Participants Reporting

Medicaid	On Medicaid/Healthy Michigan
Medicare	On Medicare
ADAP	On Ryan White/ADAP/MIDAP
Uninsured	Uninsured
Other	Other insurance (not specified)
Private	On private insurance (not through an employer, Medicaid, or Medicare)

Mixed	On private insurance, but with premiums covered by Ryan White/ADAP/MIDAP
Public	On another public insurance plan (such as a county plan)
Employer	On insurance from my or my spouse/partner's employer

Implementation of the Affordable Care Act (ACA) resulted in changes to insurance for 27% of participants. Among the various insurance effects of ACA for these 19 individuals, 26% were in Medicaid from a previously uninsured status (not counting Ryan White/ADAP), 21% reported gaining access to private insurance from a previously uninsured status (not counting Ryan White/ADAP), 10% gained private insurance where they previously were covered through the pre-existing insurance pool (PCIP), and 15% reported a change in their private insurance provider.

Most participants (69%) began receiving care for HIV infection—i.e., started seeing a health professional with or without treatment initiation—within 3 months of their initial diagnosis.

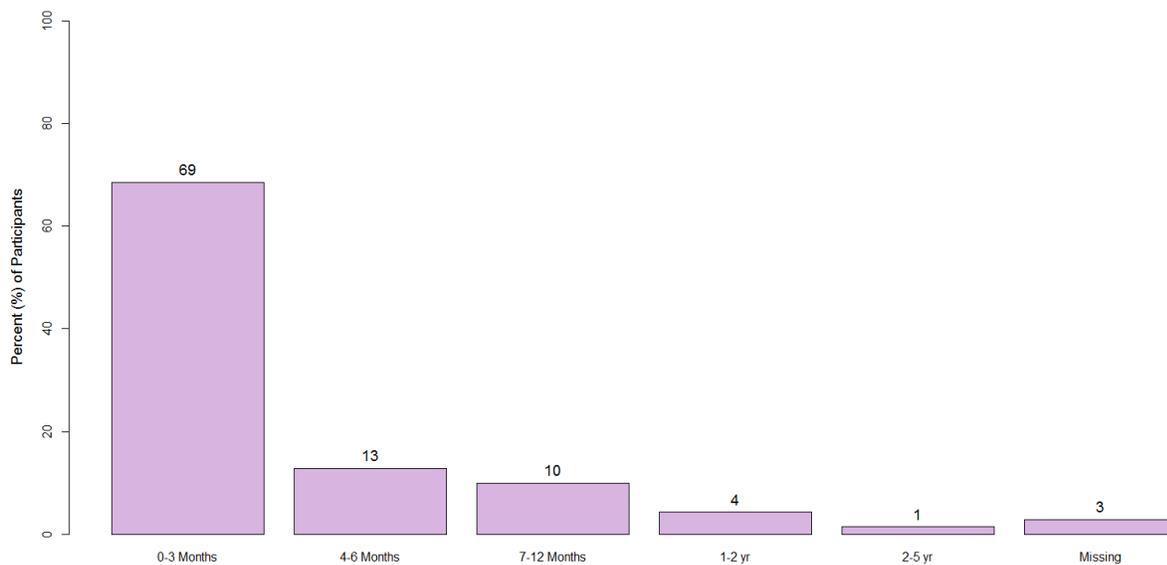


Figure 39. Time from Diagnosis to Seeking Care (Care Engagement)

There were little to no differences in the rate of rapid care engagement (within 3 months of diagnosis) by age (65-70%), gender (68-69%), economic hardship (67-71%), or social support (68-69%). Among the 70 participants, however, blacks, gays, those diagnosed within the last 4 years, and those who did not receive HIV counseling reported higher rates of rapid care engagement. Persons with a history of incarceration

or sex work, and those who were worried about being shunned if they received a positive test result were more likely than others to report delays in seeking care.

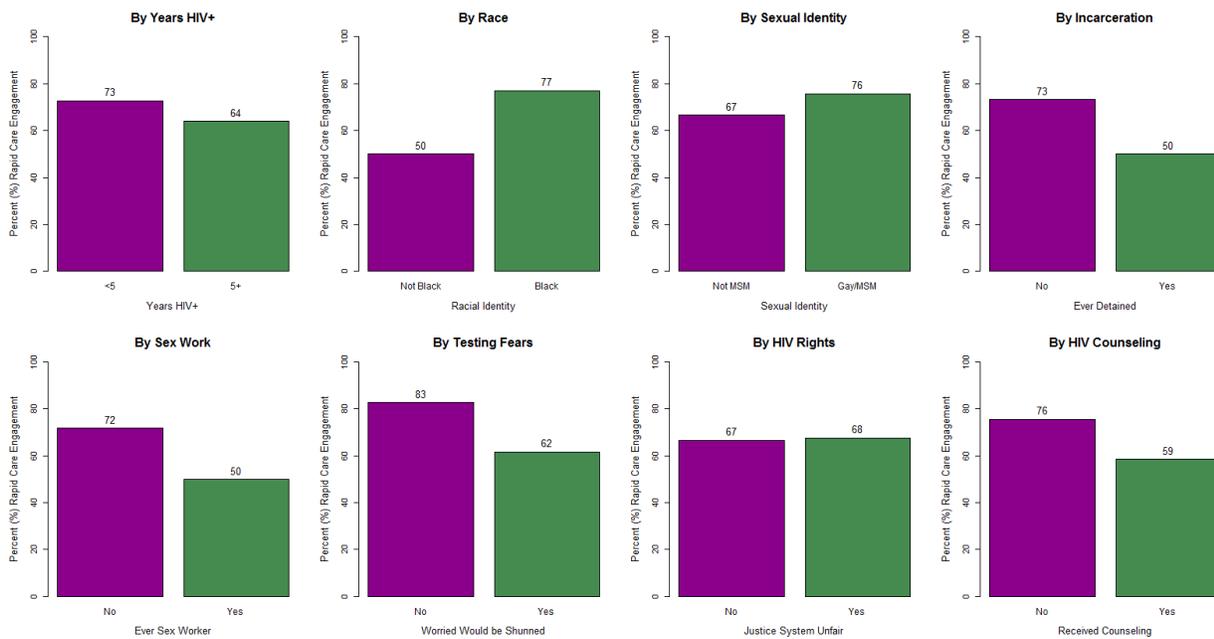


Figure 40. Rate of Rapid Care Engagement (within 3 Months of Diagnosis) by Select Characteristics

Participants were asked “If there was a gap in time between your HIV positive test and the time you started care, indicate the reason(s) for the delay” out of 15. Thirty (43%) of the 70 participants reported at least one reason for delay in care. Among this subset of participants, the most commonly cited reason (50%) for delay in care was not feeling ready to deal with HIV infection. Privacy concerns, fear of stigmatizing or discriminatory responses from health care staff and others, and awareness and cost of care resources were also frequently provided as reasons for delayed engagement in care. Structural barriers (e.g., legal concerns, and transportation or employment issues) were less frequently cited.

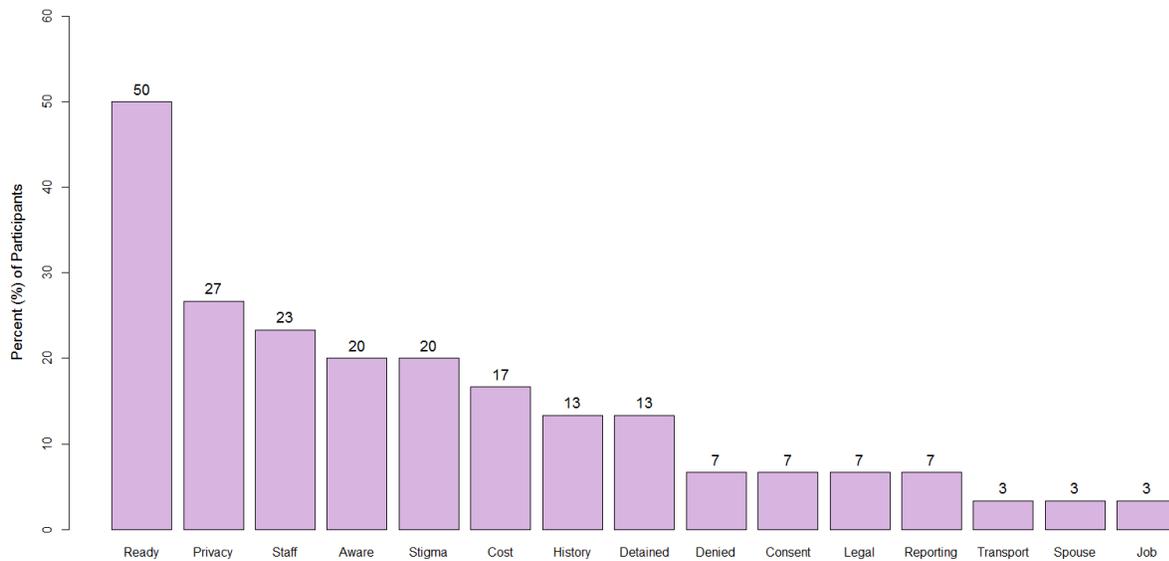


Figure 41. Reasons for Delay in Care Engagement following HIV Diagnosis (n=30)

Ready	I was not ready to deal with my HIV infection
Privacy	I was afraid that someone I knew would see me there
Staff	I was afraid that the health care workers (doctors, nurses, staff) would treat me badly
Aware	I did not receive a referral or did not know where to go to get HIV care
Stigma	I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with men
Cost	I could not afford health care
History	I had a bad experience with a health care worker previously
Detained	I was incarcerated, detained, or otherwise confined and was not able to access HIV care
Denied	I was refused care
Consent	I was afraid that the health care workers would disclose my status without my consent
Legal	I lack legal status or documentation
Reporting	I was worried that the health care workers would give my name to the police or immigration authorities
Transport	It was difficult to arrange transportation to the clinic or hospital
Spouse	I would have had to tell my husband/wife/partner if I started getting care
Job	I could not receive care during work hours without disclosing my HIV status to my employer

Participants were asked their perceptions of the importance of HIV criminalization to persons' decisions to engage in care. Specifically, they were asked how reasonable they perceived the following scenario: "A person, who is otherwise feeling healthy, avoids getting treatment for HIV out of fear that people might find out he or she is HIV positive

and press charges against him.” Overall, 49% stated that it was not reasonable to delay care out of concern of prosecution, whereas 51% claimed that it was somewhat (33%) or very (18%) reasonable to delay care. There were little to no differences in agreement that delaying engagement under such a scenario was somewhat/very reasonable when compared across age groups, sexual identity, and experiences of economic hardships. Other demographic, situational, and psychosocial characteristics were associated with differences in the rates of agreement. Rates were highest among persons diagnosed 5 or more years ago, men, blacks, those with a history of incarceration, those with high levels of social avoidance, those who were fearful of being socially shunned for testing positive, and those who believe that the criminal justice system is unfair to HIV-positive individuals.

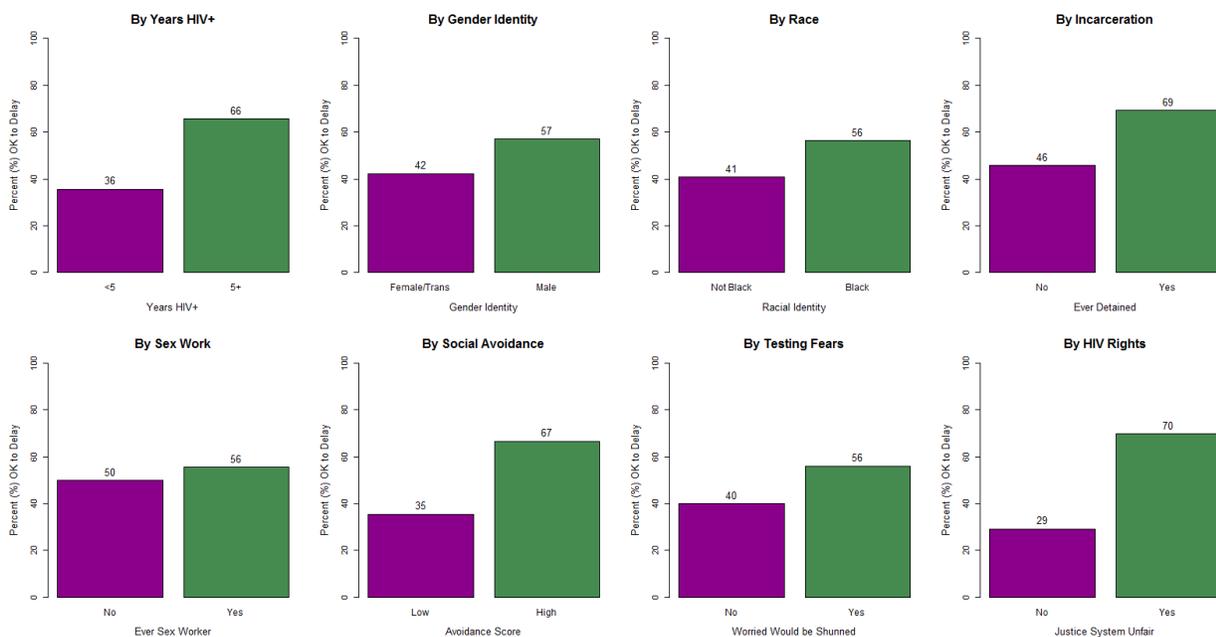


Figure 42. Perceived Reasonableness of Delaying Care out of HIV Prosecution Concerns

E.3. DISCLOSURE

Participants were asked to report whether members of their social and organizational networks were aware of their HIV status, and whether the disclosure was consensual (i.e., “I told them” or “Someone else told them, with my consent”) or not (“Someone else told them, without my consent”). Specifically, they reported on 17 groups of people (‘relations’). The number of people reporting applicable relations (whether or not the relations were aware of their status) ranged from a low of 13 participants reporting on injection drug users to a high of 66 reporting on adult family members. Awareness rates varied considerably among different relationship types (a), with the highest awareness evident for spouses, social workers/caseworkers, providers, other PLHIVs, and adult family members. In general, participants stated that disclosure to these relations were predominately consensual (b). However, disclosure to friends, children, government officials, injection drug users, prison officials, media and teachers were less likely to be consensual or self-directed.

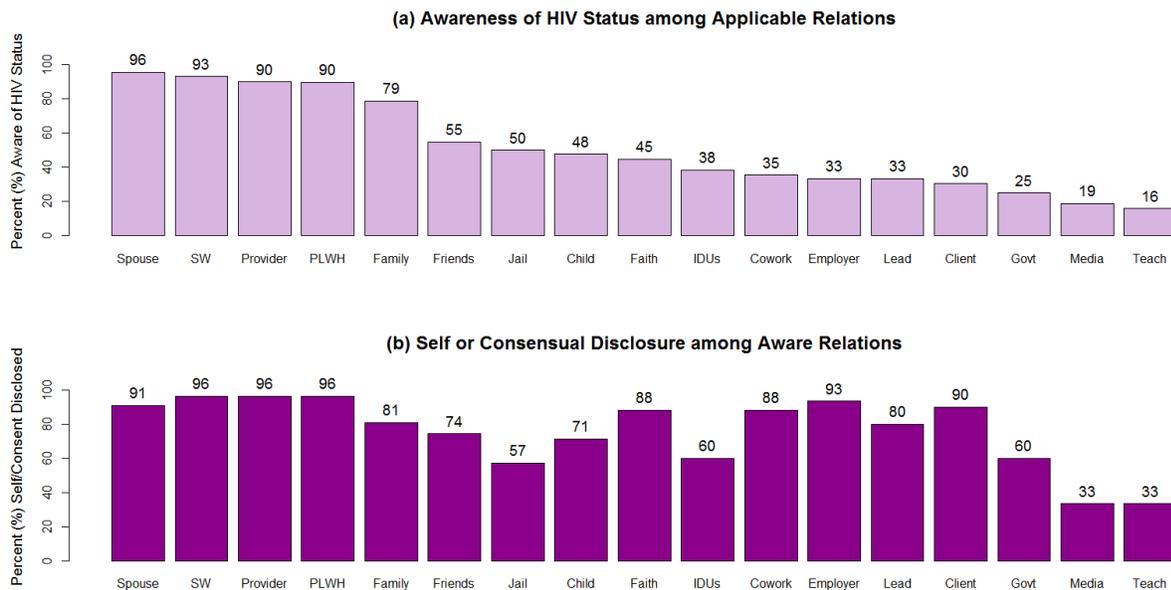


Figure 43. Awareness and Consent of Disclosure among Participants' Relations

Spouse	Your husband/wife/partner
SW	Social workers/counselors
Provider	Health care workers
PLHIV	Other people living with HIV
Family	Other adult family members
Friends	Your friends/neighbors

Jail	Prison officers
Child	Children in your family
Faith	Religious leaders
IDUs	Injecting drug partners
Cowork	People who you work with (your co-workers)
Employer	Your employer(s)/boss(es)
Lead	Community leaders
Client	Your clients
Govt	Government officials
Media	The media
Teach	Teachers

Participants were asked to report on how these groups/people reacted to the initial disclosure of their HIV status. Responses ranged from “very discriminatory” to “very supportive”. Below we list the percent of participants who provided information on supportiveness of relations (a), and the percent describing the reactions as “supportive” or “very supportive” (b). An additional relation group (“AIDS Service Organization staff”) was included in this question, and “government officials” and “prison officers” were excluded from presentation due to non-response. Supportiveness varied considerably by relationship type. Importantly, only roughly half of reporting participants described friends and adult family members (excluding spouses or partners) as supportive. However, institutional relations—staff at ASOs, social workers/caseworkers, and providers—were frequently cited as supportive.

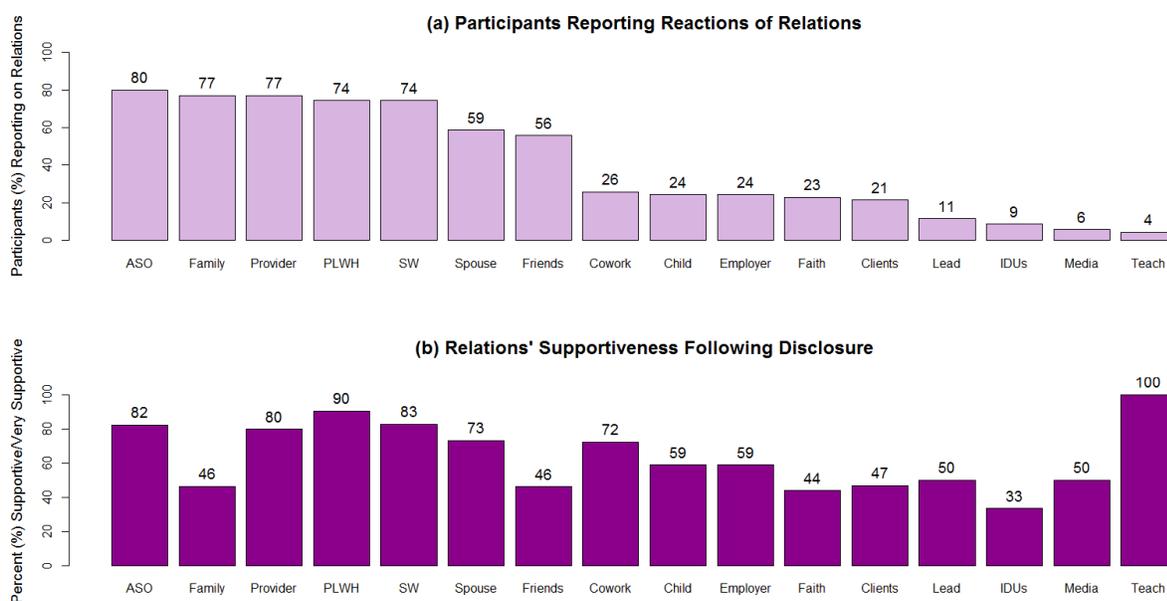


Figure 44. Relations' Reactions Following Initial HIV Disclosure

ASO	HIV/AIDS Service Organization staff
Family	Other adult family members
Provider	Health care workers
PLHIV	Other people living with HIV
SW	Social workers/counsellors
Spouse	Your husband/wife/partner
Friends	Your friends/neighbors
Colleagues	Your co-workers
Child	Children in your family
Employer	Your employer(s)/boss(es)
Religion	Religious leaders
Clients	Your clients
Community	Community leaders
ID Users	Injecting drug partners
Media	The media
Teacher	Teachers

We classified six (6) of the top seven network members to whom individuals disclosed into two groups:

- Social networks: family, spouse, and friends
- Agency networks: ASO staff, providers/health care workers, and social workers/counsellors.

We attained average scores for each of these network groups for individuals who disclosed to at least one member in each group. A total of 57 (81%) participants had scores for both social networks and agency networks. In the following series of graphs we highlight comparisons in the average social and agency supportiveness scores by participant characteristics associated with the most variation. The scores represent the average reactions of persons in the respective network and range from a low of -2 (“very discriminatory”) to 0 (“no different”) to +2 (“very supportive”).

When compared participants who had been diagnosed 5 or more years ago, those who were recently diagnosed reported greater differences in the levels of agency relations relative to social relations, with the former higher than the latter. On average, women and trans participants rated supportiveness of social and agency relations as comparable, whereas men rated agency supportiveness as substantially higher than supportiveness among social relations.

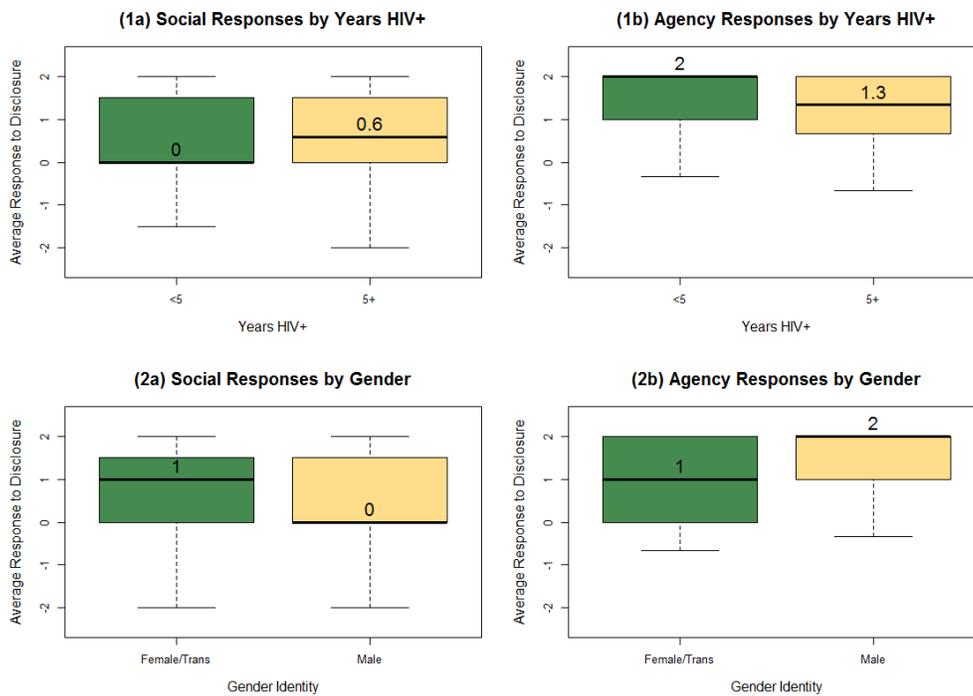


Figure 45. Comparisons of Social and Agency Relations Supportiveness by Time since Diagnosis and Gender Identity

Differences in the perceived supportiveness of agency versus social relations were more pronounced among those who did not have a history of incarceration or sex work. However, participants who had been incarcerated or had been/currently were sex workers tended to rate both social and agency relations as supportive.

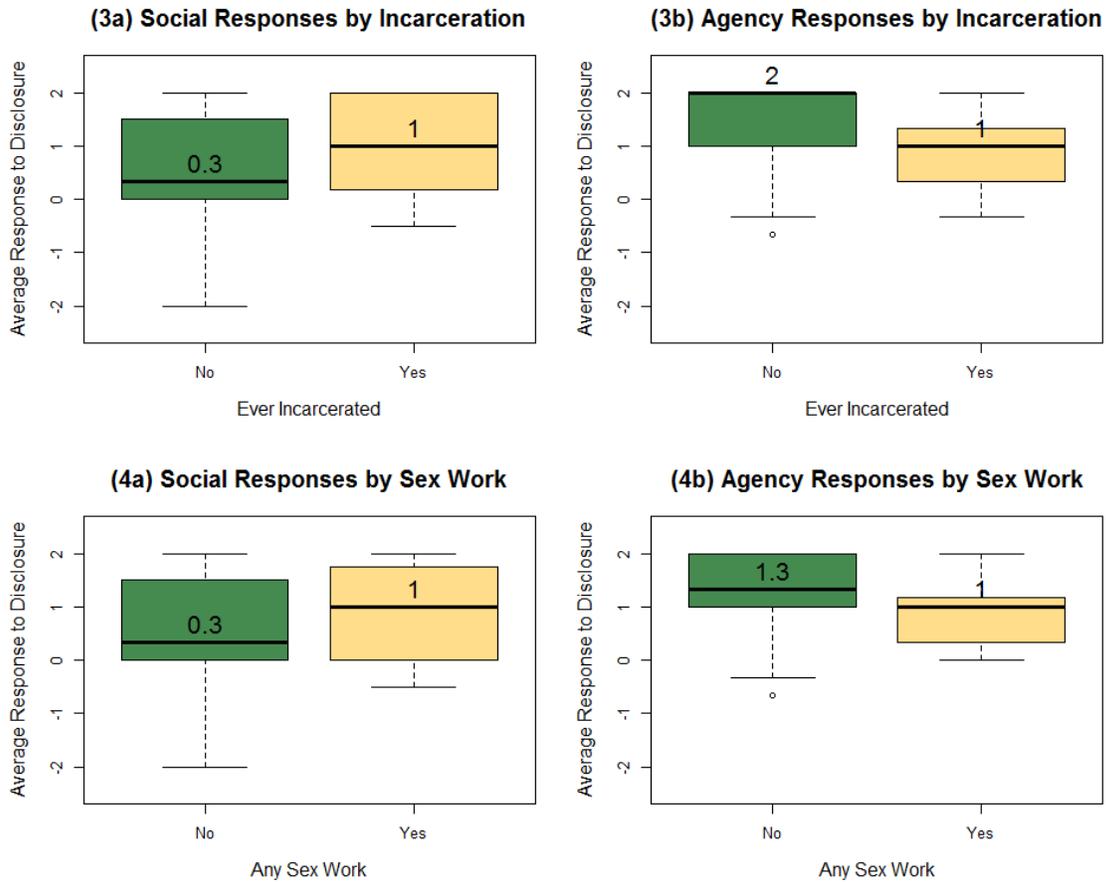


Figure 46. Comparisons of Social and Agency Relations Supportiveness by History of Incarceration and Sex Work

Participants experiencing recent economic hardships reported lower perceived levels of supportiveness among both social and agency relations relative to other participants. Whereas participants reporting higher levels of social support held more positive views of supportiveness among both social and agency relations compared to participants with lower perceived levels of social support. Again, however, agency supportiveness was generally higher than social supportiveness among all groups.

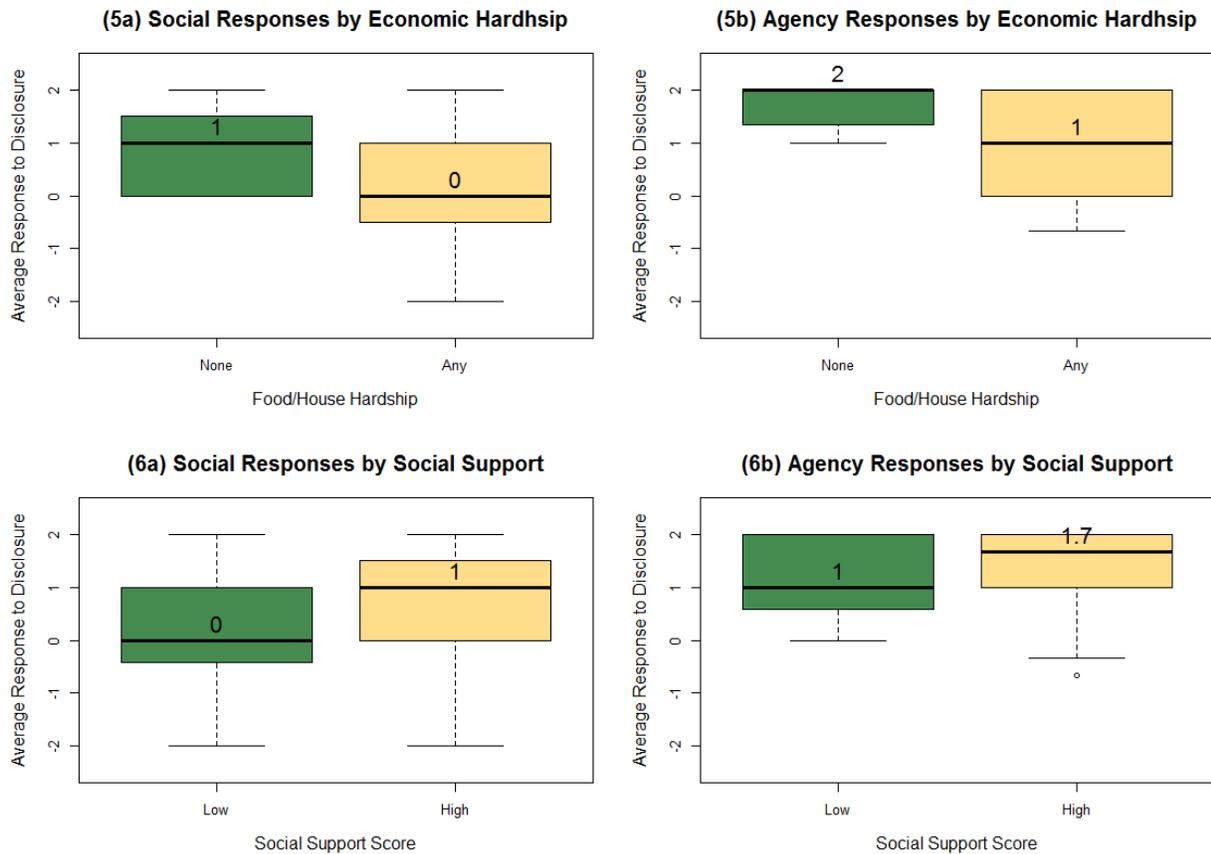


Figure 47. Comparisons of Social and Agency Relations Supportiveness by Experience of Economic Hardship and Level of Social Support

The relative supportiveness of agency relations compared to social relations were more pronounced among participants with higher reported intensity of social discrimination and/or more negative consequences of social discrimination compared to other participants.

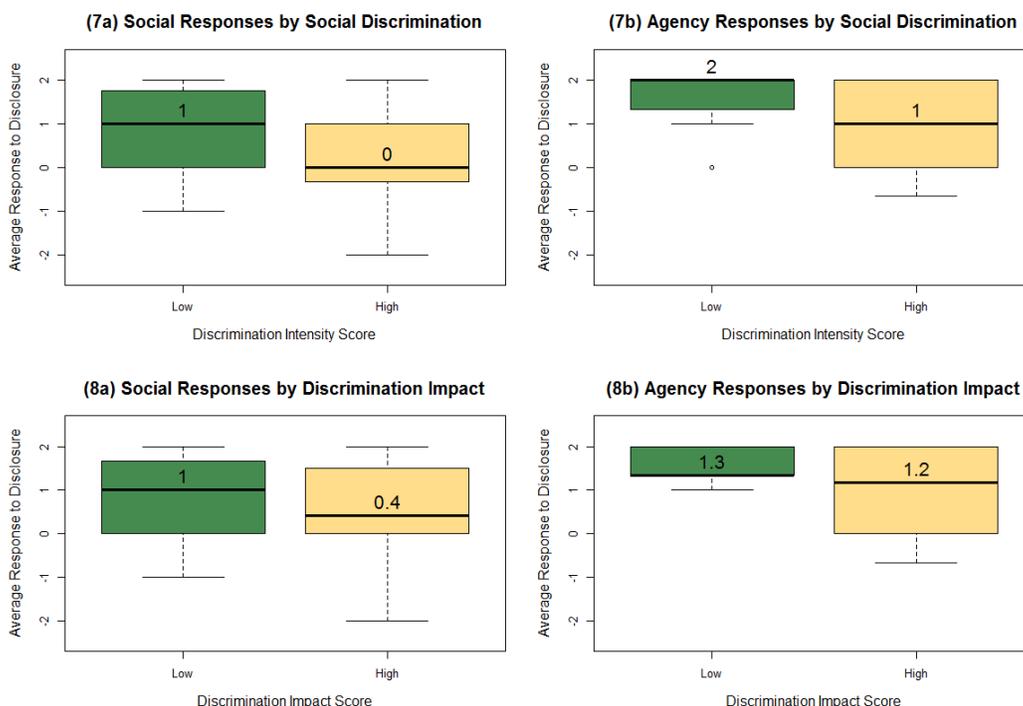


Figure 48. Comparisons of Social and Agency Relations Supportiveness by Experiences and Impact of HIV Discrimination

When asked “How often do you feel pressure from other individuals or groups of people living with HIV to disclose your HIV status?” 59% of participants responded that they never felt such pressure, 30% said they occasionally (once/few times) felt pressured, and 11% responded that they often experienced such pressure to disclose.

Participants were asked to state the perceived reasonableness of the following scenario “A person does not disclose his or her positive HIV status to a current sexual partner for fear of being prosecuted.” Roughly 46% of participants agreed that it would be reasonable for an individual to not disclose under this scenario. Substantial differences in attitudes about disclosure were evident by time since diagnosis, age, race, history of incarceration or sex work, and perceptions of the fairness of the criminal justice system for HIV-positive persons.

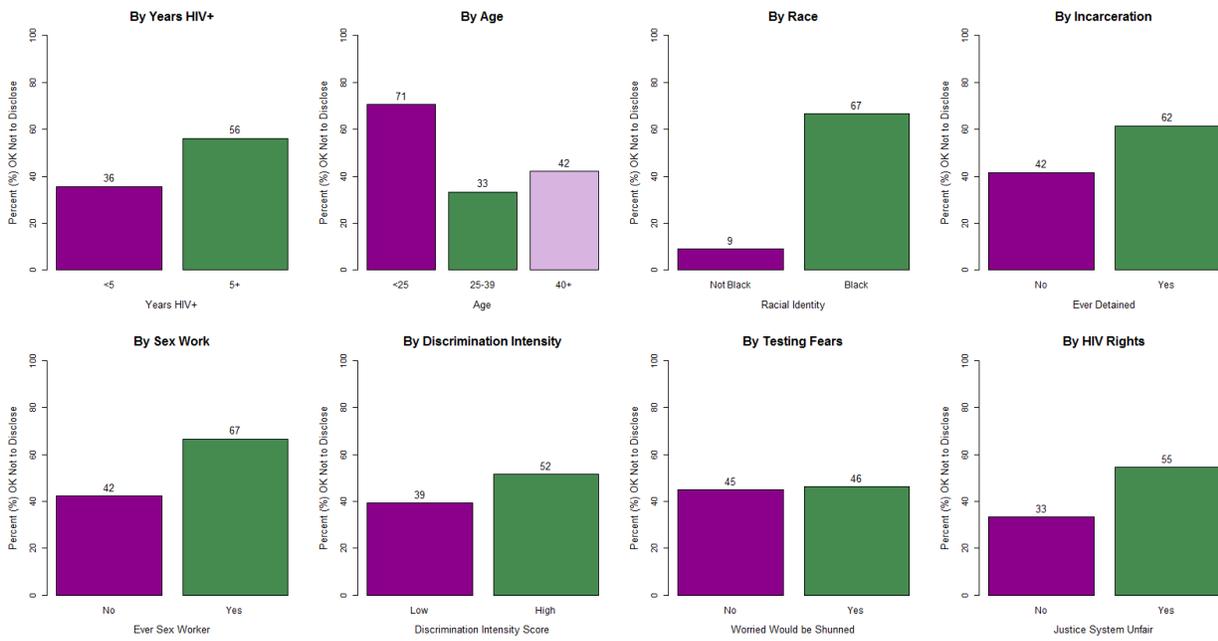


Figure 49. Perceived Reasonableness of Non-Disclosure due to HIV Prosecution Concerns

SECTION F

COLLECTIVE ACTION & SOCIAL CHANGE

Collective action is a fundamental component of promoting and effecting social change in areas such as stigma and discrimination. Here we highlight participant perspectives regarding current efforts and opportunities to address HIV stigma in MI.

Key Takeaways

- Immediate and visible efforts to reduce stigma (e.g., public education, awareness-raising, and advocacy) were ranked as higher priority among participants relative to addressing other “upstream” influences on stigma and discrimination (e.g., socioeconomic exclusion).
- Affiliation with or access to organizational and institutional support was a strong predictor of PLHIVs capacity and willingness to address social stigma and influence HIV-relevant policies and programs.

F.1. ORGANIZATIONAL ENGAGEMENT & SUPPORT

Three-quarters (75%) of participants responded affirmatively to the question “Do you know of any organizations or groups that you can go to for help if you experience stigma or discrimination?” Awareness rates differed substantially by age and race. Younger and black PLHIVs had lower awareness of where to seek help dealing with stigma and discrimination.

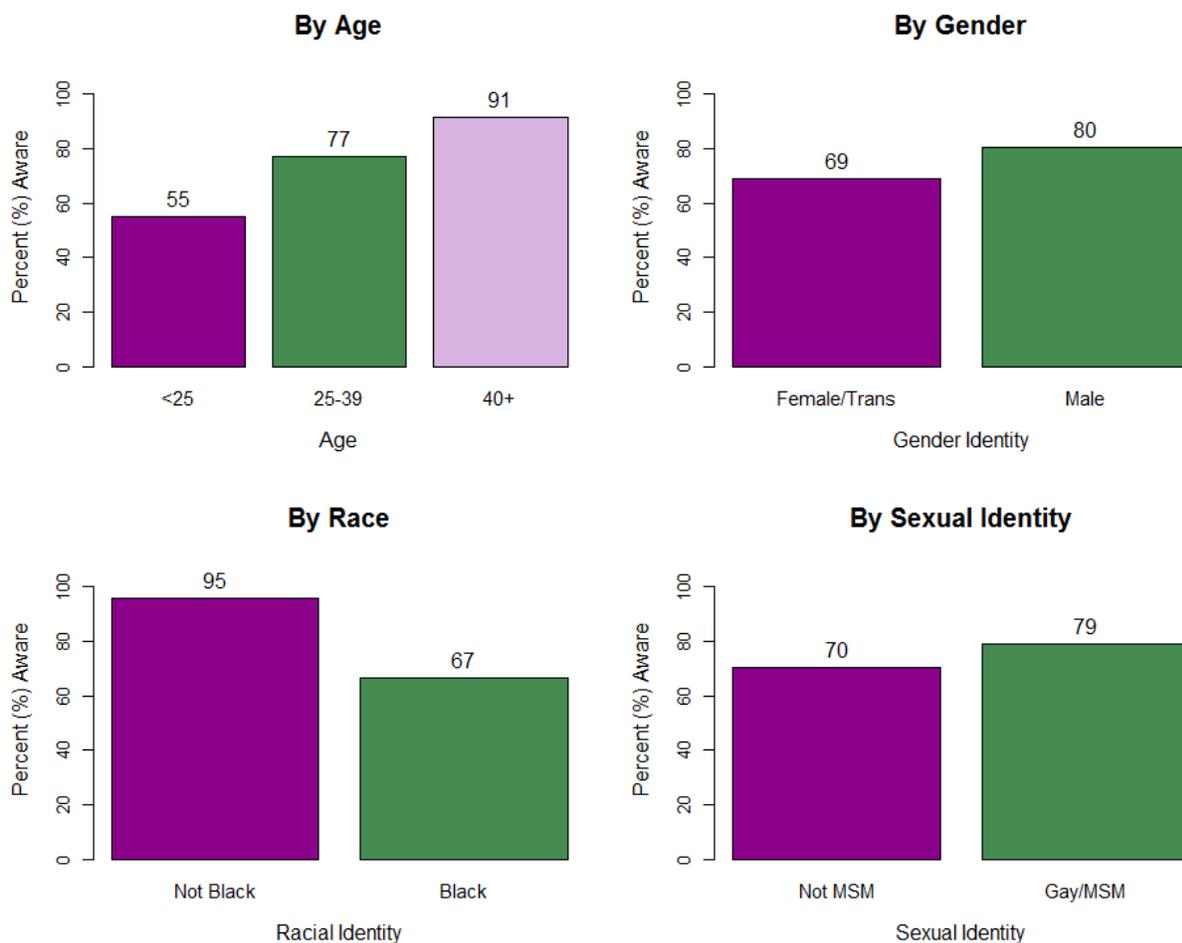


Figure 50. Participant Awareness of Stigma/Discrimination Support Organizations and Groups by Demographics

There was considerable variation in awareness across different types of groups and organizations. Most participants had awareness of supports through local resources and groups, particularly ASOs and HIV support groups.

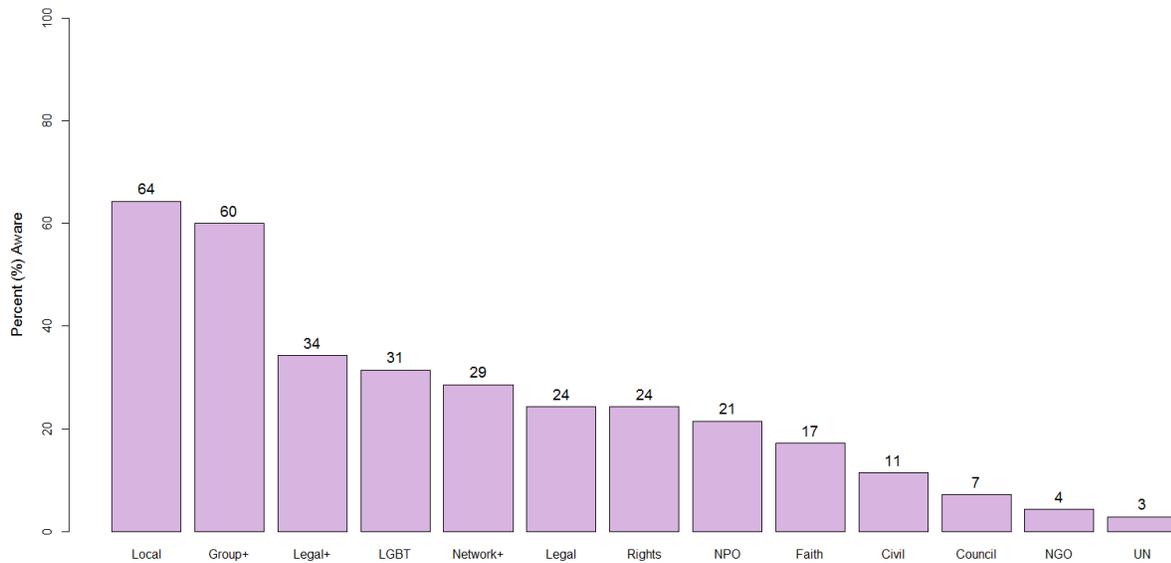


Figure 51. Awareness of Stigma/Discrimination Support Organizations and Groups by Type

Local+	Local AIDS Service Organization
Group+	People living with HIV support group
Legal+	A legal practice specializing in HIV/AIDS cases
LGBT	A lesbian, gay, bisexual, transgender rights organization
Network+	Network of people living with HIV
Legal	A legal practice
Rights	A human rights organization
NPO	A national non-profit organization
Faith	Faith-based organization
Civil	A civil rights organization focused on racial or ethnic justice
Council	National AIDS council or committee
NGO	International nongovernmental organization
UN	UN organization

Roughly 53% of participants stated that they were currently “a member of a people living with HIV support group, network, activist group or organization.” In general, this rate was consistent across demographic traits, except for age where participation rates increased with age group.

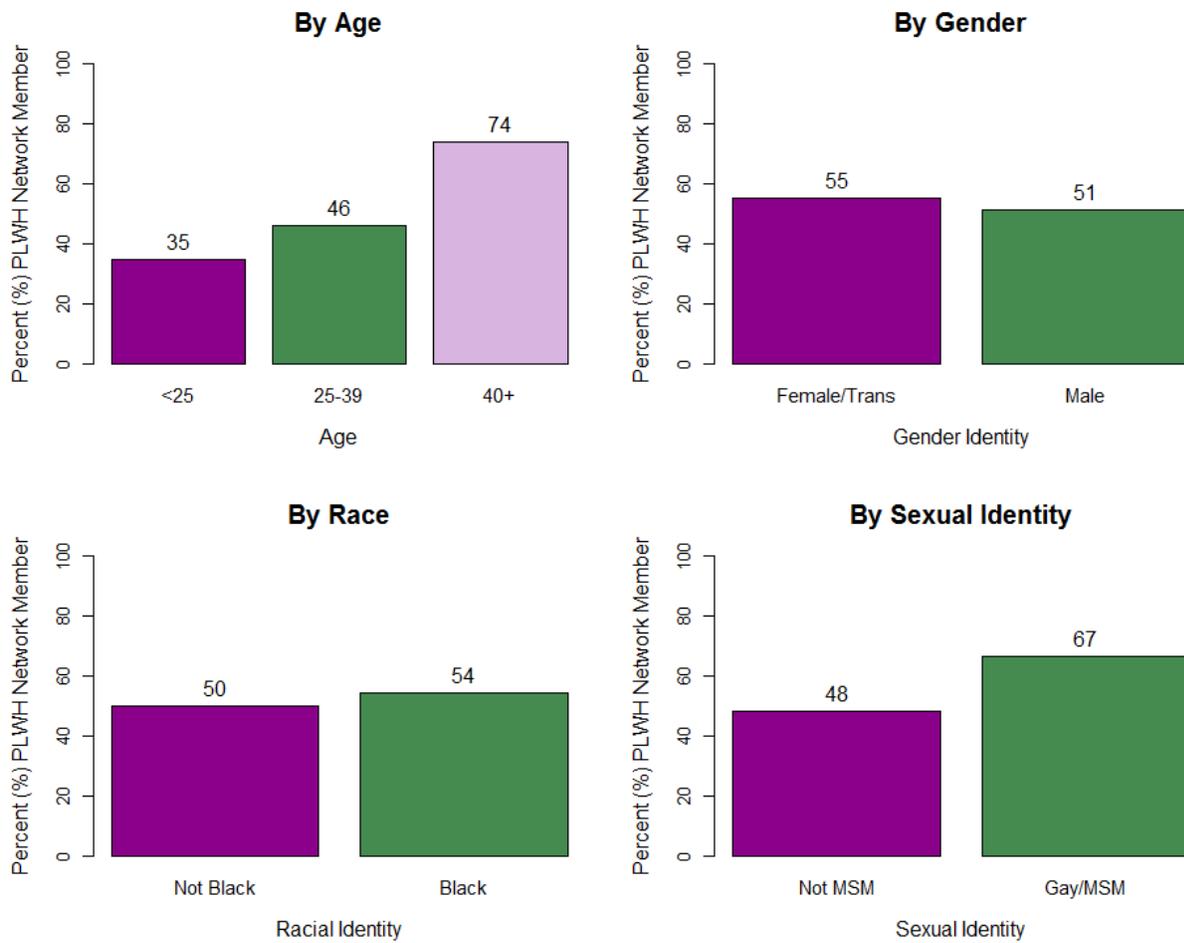


Figure 52. Current Membership in a PLWH Support Group, Network, Activist Group, or Organization by Demographics

F.2. SOCIAL CHANGE PRIORITIES & EFFECTING CHANGE

Numerous organizations and groups of people living with HIV have been working against stigma and discrimination through various approaches including awareness-raising and education, advocacy and legal representation, policy making, and addressing economic and other factors that encourage social and institutional stigma and discrimination. Participants were asked to rank 7 such strategies in order of importance. Specifically, they were asked: "If one of them [organizations of PLHIVs] asked you, 'What is the most important thing we should be doing as an organization to address stigma and discrimination?' what would you recommend?" On average, 4 of the 7 items were generally rated as most important: (1) HIV awareness-raising among the general public, (2) HIV rights advocacy, (3) supporting treatment literacy and other health and wellness education among PLHIVs, and (4) strengthening social supports for PLHIVs.

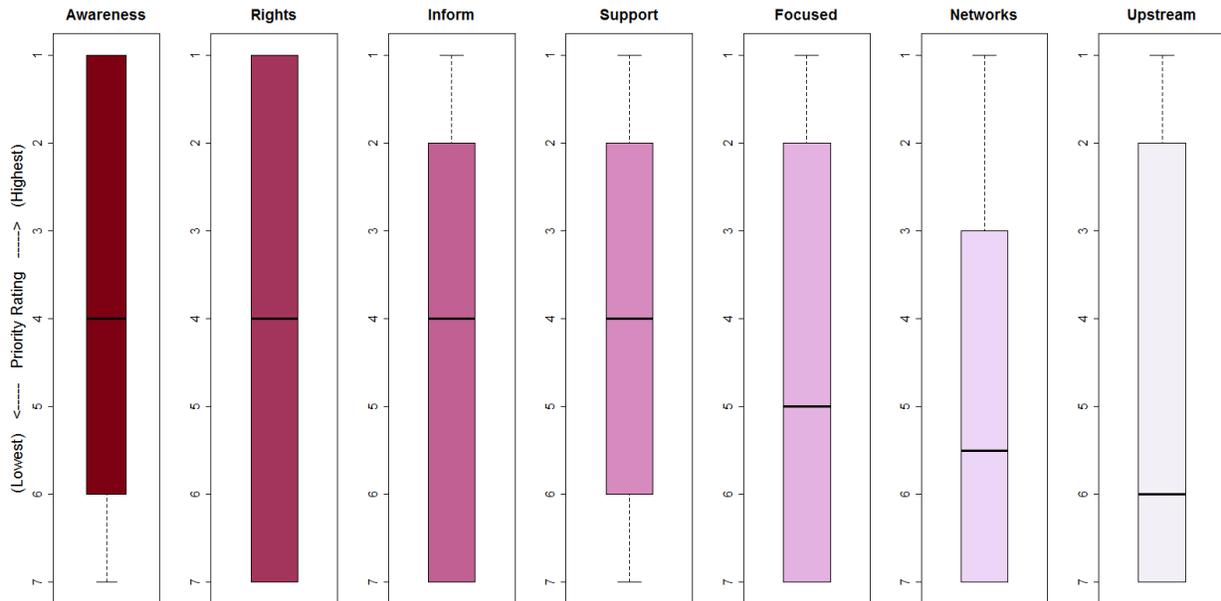


Figure 53. Participant Rankings of Organizational Priorities to Address HIV Stigma and Discrimination

Awareness	Raising the awareness and knowledge of the public about HIV
Rights	Advocating for the rights of all people living with HIV
Inform	Educating people living with HIV about living with HIV (including treatment literacy)
Support	Providing support to people living with HIV by providing emotional, physical and referral support
Focused	Advocating for the rights and providing support to particularly marginalized groups (men who have sex with men, transgender people, injecting drug users, sex workers, people incarcerated)

With respect to **awareness-raising**, participants were asked, “In the last 12 months, have you confronted, challenged or educated someone who was stigmatizing and/or discriminating against you?” as well as a related item, “In the last 12 months, have you confronted, challenged or educated someone who was stigmatizing and/or discriminating against another person with HIV?” Overall, 61% reported challenging someone who was stigmatizing/discriminating against them and/or someone else half of the participants reported challenging someone who was stigmatizing/discriminating against them and/or another PLHIV. Specifically, 50% reported addressing stigma directed at them personally. Similarly, 50% reported addressing stigma directed at other PLHIVs. We examined these rates by (a) participant awareness of organizations or groups to turn to for help in addressing stigma/discrimination, and (b) participation in PLHIV support groups, networks, activist groups or other organizations. Awareness of support resources was strongly associated with participants reporting that they challenged stigmatizing/discriminatory behaviors directed at self or others.

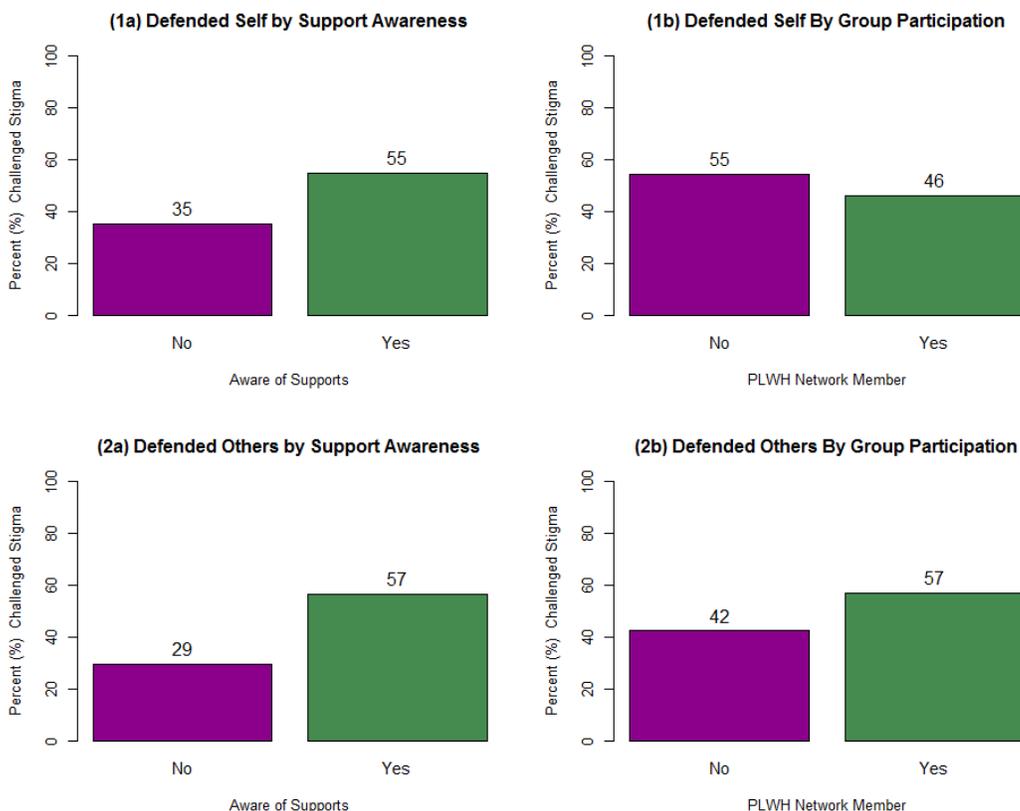


Figure 54. Challenging Stigmatizing/Discriminatory Actions among the Public by Organizational Awareness and Participation

With respect to **HIV rights advocacy** and **programmatic support of PLHIVs**, participants were provided a list of 6 possible areas of influence related to addressing legal/rights issues, government policies, and projects intended to benefit PLHIVs. Participants were asked, “Do you feel that you have the power to influence decisions in any of the following aspects.” A seventh category, “none of these” was included among this list. In all, 40% of participants felt they were unable to influence any of the 6 areas. However, nearly half felt that they could influence local projects, 41% felt they had some influence over legal matters, and more than one-third agreed that they could influence local policy.

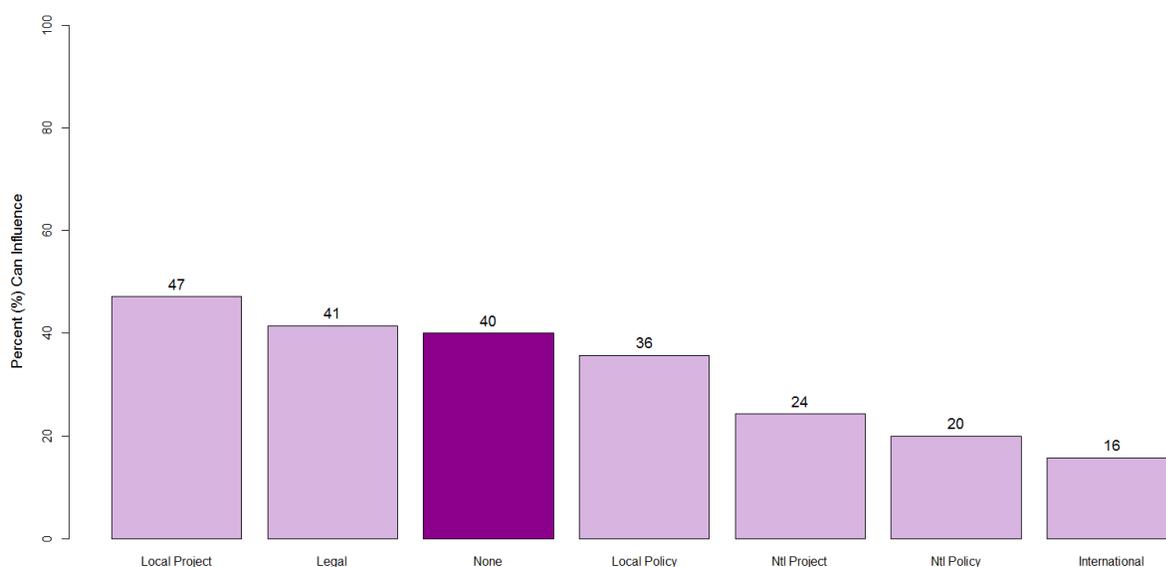


Figure 55. Participants’ Perceived Capacity to Influence Policies, Programs, and Legal Matters

Local Project	Local projects intended to benefit people living with HIV
Legal	Legal/rights matters affecting people living with HIV
None	None of these things
Local Policy	Local government policies affecting people living with HIV
Ntl Project	National programs/projects intended to benefit people living with HIV
Ntl Policy	National government policies affecting people living with HIV
International	International agreements/treaties

Additional items explored participants’ recent involvement in projects and programs, and legal and policy areas. Thirty-four percent (34%) of participants stated that they had “been involved, either as a volunteer or as an employee, in any program or project (either government or nongovernmental) that provides assistance to people living with HIV” in the last 12 months. By contrast, only 17% stated that they had “been involved

in any efforts to develop legislation, policies or guidelines related to HIV (local, state, federal, or global)” during the same time period. We explored differences in these rates of involvement as well as in the overall perceptions of influencing one or more of the above policy/program areas by (a) participant awareness of organizations or groups to turn to for help in addressing stigma/discrimination, and (b) participation in PLHIV support groups, networks, activist groups or other organizations. Organizational awareness and organizational participation were highly associated with differences in (1) perceived capacity to influence one or more of the 6 policy/program/legal areas, (2) involvement in PLHIV support programs, and to a lesser extent (3) involvement in legislative or policy efforts.

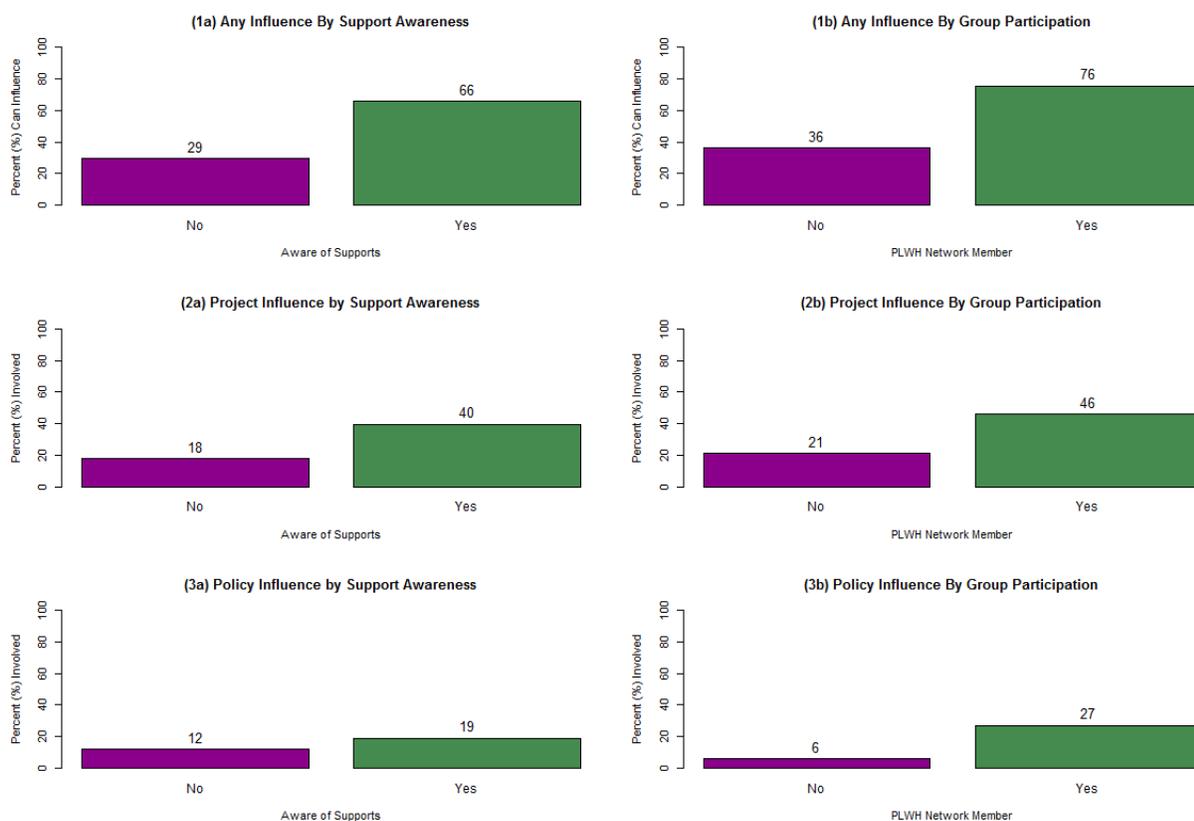


Figure 56. Perceived Policy/Program Influence, and Project and Policy Involvement by Organizational Awareness and Participation

Participants reported providing various levels of support to other PLHIVs. We asked, “In the last 12 months, have you supported other people living with HIV?” with respect to 3 types of social support: “emotional support (e.g. counselling, sharing personal stories and experiences),” “practical support (e.g. providing money or food, doing an errand for them),” and “referral to other services.” Sixty percent (60%) reported providing emotional support, 37% provided service referrals, and 33% provided practical support. Overall, 74% of participants provided at least one type of social support to other PLHIVs during the prior year. Provision of the supports to other PLHIVs was strongly associated

with (a) organizational awareness, and (b) participation in PLHIV groups; particularly with respect to emotional and referral supports.

