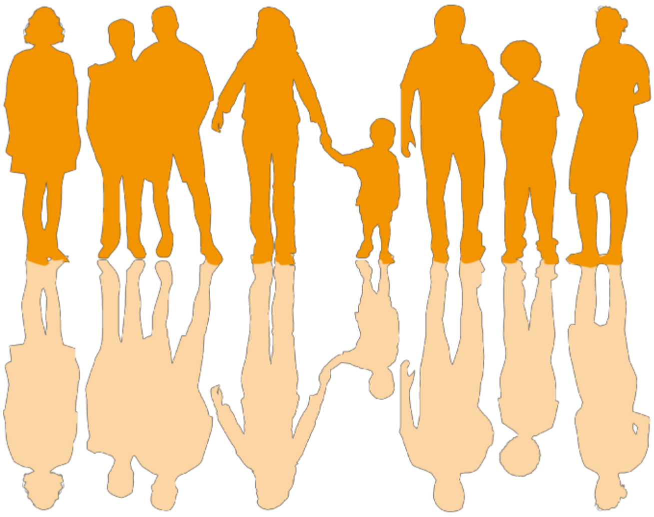

THE PEOPLE LIVING WITH HIV STIGMA INDEX

Jamaica

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Acronyms

ART	Antiretroviral therapy
GNP+	Global Network of People Living with HIV/AIDS
HIV	Human immunodeficiency virus
HP+	Health Policy Plus
JADS	Jamaica Anti-Discrimination System
JN+	Jamaican Network of Seropositives
MSM	Men who have sex with men
PLHIV	People living with HIV
UNAIDS	Joint United Nations Programme on HIV/AIDS
WSW	Women who have sex with women

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Executive Summary

For people living with HIV (PLHIV), stigma and discrimination due to their HIV status that occurs in their homes, workplaces, and communities can harm their mental health and create barriers to treatment for HIV. These negative effects can be compounded for those who face marginalisation associated with other identities, such as gender or sexuality, occupation, or drug use status. In Jamaica, men who have sex with men (MSM), transgender people, and people who sell sex face additional stigma and discrimination due to these identities and/or practices.

The PLHIV Stigma Index gathers information on the stigma and discrimination that PLHIV face, with the hope of improving policymakers' understanding of the situation and empowering the PLHIV involved in the study design and implementation. It is an internationally standardised survey administered by interviewers, who themselves are PLHIV, using cell phones to gather the data electronically. The first PLHIV Stigma Index in Jamaica took place in 2011; this report describes the findings of the Stigma Index 2.0, which took place in between September and November 2019.

The sample for this 2019 survey included 557 PLHIV in Jamaica, selected through a purposive (i.e., non-random) process. All participants were over the age of 18 and provided informed consent to participate. The sample included 290 cisgender women, 211 cisgender men, and 56 transgender or nonbinary people. Ninety-one participants were non-bisexual MSM, 60 were non-bisexual women who have sex with women (WSW), and 35 were bisexual. One hundred forty-three participants reported ever having sold sex, and 22 reported ever having used drugs. In this report, "key populations" refers to MSM, WSW, bisexual people, participants who have ever sold sex, and participants who have ever used drugs.

Most participants (81%) reported that someone else knew about their HIV status, with spouses, partners, and children being the most likely to know the participant's status. Involuntary disclosure was high, however; half of the participants who had experienced any disclosure of their HIV status reported at least one instance of someone else being told about the participant's HIV status without their consent.

Within the past 12 months, 33% of participants reported experiencing at least one form of stigma or discrimination due to their HIV status, with the most common forms of stigma and discrimination being gossip, discriminatory remarks, and verbal harassment. Members of key populations reported experiencing proportionately more discrimination due to their HIV status than did participants who did not belong to any key populations. When asked about the form of discrimination they feared most, the most common answer participants gave was being excluded or isolated by friends and family.

Internalised stigma and discrimination—that is, negative feelings about themselves due to their HIV status—was relatively high: 53% of participants reported that their HIV status makes them feel guilty, ashamed, worthless, and/or dirty. In addition, 74% of participants noted that they find it difficult to tell others of their HIV status; 81% reported that they routinely hide their HIV status from others; and 52% reported carrying out at least one self-isolating behaviour due to their HIV status within the past 12 months, including choosing not to have sex, attend social gatherings, or apply for jobs. In addition, many participants reported poor mental health, with 53% reporting symptoms of at least mild anxiety and depression, and 10% reporting symptoms of severe anxiety and depression; members of key populations generally reported worse mental health than did non-members. Despite these challenges, most participants reported that their HIV status did not affect their resiliency, or their ability to meet their daily needs; within the sample, however, some did report a strong negative effect, whereas others reported a strong positive effect of their HIV status on their ability to meet their needs.

Within the health system, experiences of stigma and discrimination due to HIV status were relatively low, though not zero: 10% of participants reported some form of stigma or discrimination within the past 12 months. The most common forms of stigma and discrimination in a health care environment included the avoidance of touch and the denial of dental care. Fear of stigma and discrimination (known as “anticipated stigma”), was reported as a barrier to treatment, however, with 38% of respondents reporting that anticipated stigma caused them to delay HIV testing and 30% reporting that they delayed HIV treatment due to such fears. In non-HIV care, only 26% of participants report that they usually disclose their HIV status. These fears are compounded by worries that medical records are not confidential: 8% of participants reported certainty that their records have been shared without their consent, and 32% of participants were not sure.

Many participants reported experiencing human rights violations, including rape, public disclosure of HIV status, and forced HIV testing, with 23% of participants reporting ever experiencing one of those violations, and 7% experiencing one within the past 12 months. The Jamaica Anti-Discrimination System (JADS), which exists to provide a reporting mechanism for PLHIV who experience stigma or discrimination, was not very well-known by participants, with only 37% reporting that they had ever heard of the system.

Large proportions of each key population—MSM, WSW, bisexual people, people who have sold sex, and people who have used drugs—reported experiencing some form of stigma or discrimination due to their membership within that key population. The most common forms of stigma and discrimination faced by respondents who identified as a key population member included verbal harassment and discriminatory remarks. In general, their disclosure of their identity or practices were most common with people who shared that identity or practice, followed by family or friends, and distantly followed by their communities at large.

Based on these findings, this report makes several recommendations:

- Civil society organisations and the government should educate PLHIV on their rights, including sexual and reproductive rights. These campaigns should use clear, simple language and emphasise the resources available to PLHIV.
- Civil society organisations should advocate to governments on behalf of PLHIV and other key populations, and educate government officials on how best to serve these populations.
- Civil society organisations should coordinate and provide formal and informal support structures for their members. These resources should be well researched and properly staffed.
- Health care facilities should train their staff on how best to care for PLHIV and members of key populations, including treating their PLHIV clients as complete people not defined by a behaviour or diagnosis and understanding the range of sexual orientations and gender identities they might encounter.
- Schools and churches should provide sex education that accounts for the full array of gender identities and sexual practices.
- The government should develop policies and pass laws to protect PLHIV and members of key populations, and it should redefine policies that harm those people. In particular, the government should define hate speech, remove all references to gender or biological sex in the legal definition of rape, not pass a bill to criminalise HIV, and reference gender instead of biological sex in all legislation and policy.

Introduction

Many people living with HIV (PLHIV) experience stigma—“irrational or negative attitudes, behaviours and judgments”—and discrimination—“unfair treatment, laws and policies”—in their lives.[1] These experiences can occur in many places, including homes, community gathering spaces, workplaces, health care facilities, and places of law enforcement. In addition to their direct negative consequences on the health and well-being of PLHIV, stigma and discrimination can prevent PLHIV from seeking and sustaining the treatment they need. This barrier is often particularly high for people who experience stigma and discrimination along other axes, such as gender or sexuality, occupation, or drug use status; furthermore, many members of these marginalised groups face higher prevalence rates of HIV than the general population, which compounds the effects of stigma and discrimination amongst these most vulnerable groups.[2] In Jamaica, previous studies have demonstrated that stigma and discrimination create barriers between PLHIV and access to treatment, particularly amongst key populations, such as men who have sex with men (MSM), transgender women, sex workers, and people who use drugs.[3]

Project background

To address stigma and discrimination, policymakers and programme designers must understand the types and degrees of stigma and discrimination that PLHIV face. To that end, the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation, and the Joint United Nations Programme on HIV/AIDS (UNAIDS) developed the PLHIV Stigma Index, a standardised survey developed by and for PLHIV. In addition to improving the understanding of stigma experienced by PLHIV, the Stigma Index also increases the capacity of PLHIV involved in the study because the protocol requires that the interviewers must also be PLHIV. The Stigma Index questionnaire was updated in October 2017 to increase the focus on access and adherence to HIV care; stigma experienced within health care settings; and stigma experienced by PLHIV due to other factors, such as sexual orientation or gender identity, drug use, or involvement in sex work.[4] By the time of that update, the original survey had

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[1] UNAIDS, “Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination,” December 10, 2018, https://www.unaids.org/sites/default/files/media_asset/global-partnership-hiv-stigma-discrimination_en.pdf.

[2] Ibid.

[3] Carmen H. Logie et al., “Barriers and Facilitators to HIV Testing among Young Men Who Have Sex with Men and Transgender Women in Kingston, Jamaica: A Qualitative Study,” *Journal of the International AIDS Society* 20, no. 1 (2017): 21385, https://doi.org/10.7448/IAS.20.1.21385; J. Peter Figueroa et al., “Understanding the High Prevalence of HIV and Other Sexually Transmitted Infections among Socio-Economically Vulnerable Men Who Have Sex with Men in Jamaica,” *PLOS ONE* 10, no. 2 (February 6, 2015): e0117686, https://doi.org/10.1371/journal.pone.0117686.

[4] GNP+, ICW, and UNAIDS, “People Living with HIV Stigma Index User Guide,” 2018.

been translated into at least 54 languages and administered in more than 90 countries, including Jamaica, which conducted the survey in 2011. The standardised methodology of the survey allows the experiences of PLHIV to be compared across countries and over time.

Country context

In 2018, Jamaica had 32,617 PLHIV; amongst adults ages 15–49, HIV prevalence was 1.9%.[5] According to the Jamaica Health and Wellness Minister, as of the end of March 2019, 78% of PLHIV knew their status; of PLHIV who knew their status, 49% were receiving antiretroviral therapy (ART); and of PLHIV on ART, 57% had achieved viral suppression.[6] Therefore, in Jamaica, 22% of PLHIV have achieved viral suppression, which means that Jamaica still needs to make a great deal of progress to meet the 90-90-90 target of having 73% of PLHIV achieve viral suppression (i.e., for 90% of PLHIV to know their status, for 90% of those PLHIV who know their status to receive ART, and for 90% of those PLHIV on ART to achieve viral suppression).[7]

In the first PLHIV Stigma Index survey conducted in Jamaica in 2011, 38% of the 509 PLHIV interviewed reported experiencing some form of stigma or discrimination related to their HIV status. Furthermore, 47% of participants reported fearing verbal assault, and 41% feared physical assault. About half of participants reported some measure of internalised shame or guilt over their HIV status, with these measures of shame and guilt decreasing the longer the person had been living with HIV. Participants also reported that their HIV status affected their personal lives, particularly regarding the decision to have children: 61% of participants reported deciding not to have children due to their HIV status. Participants felt that people who identified as gay, lesbian, or bisexual were more likely to experience more severe forms of stigma and discrimination, but the survey did not measure direct experiences of stigma for these groups.[8] Homosexuality is criminalised in Jamaica, and neither gender identity nor sexual orientation are protected classes under the Jamaican Charter of Fundamental Rights and Freedoms.[9,10]

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[5] UNAIDS, "Country: Jamaica," 2019, https://www.unaids.org/en/regionscountries/countries/jamaica.

[6] "Gov't Says It's Working to Achieve UNAIDS 90-90-90 Targets," *Jamaica Observer*, May 11, 2019, http://www.jamaicaobserver.com/news/gov-t-says-it-s-working-to-achieve-unaids-90-90-90-targets_164537?profile=1606.

[7] UNAIDS, "90-90-90: An Ambitious Treatment Target to Help End the AIDS Epidemic," 2014, https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf.

[8] UNAIDS and Jamaican Network of Seropositives, "The People Living with HIV Stigma Index: An Analytical Report Based on Research Findings," October 2013, https://moh.gov.jm/wp-content/uploads/2016/05/Jamaica-PLHIV-Stigma-Index-Study-Updated-Version-March-9-2015-FINAL.pdf.

[9] Human Rights First, "LGBT Issues in Jamaica," n.d., https://www.humanrightsfirst.org/sites/default/files/Jamaica-LGBT-Fact-Sheet.pdf.

[10] Jamaica Forum for Lesbians, All-Sexuals, and Gays (J-FLAG), "The Gay Agenda," February 2018, https://issuu.com/j-flag/docs/the_gay_agenda-2.

More recently, studies have examined stigma and discrimination against members of key populations living with HIV in Jamaica. Even though health care workers in Jamaica agree that members of these key populations who live with HIV do deserve high-quality care, they also express blame towards key populations, particularly PLHIV who engage in sex work and PLHIV who are also MSM.[11] MSM in Jamaica have an HIV prevalence of about 28–30%, which far exceeds the general population prevalence; similarly, transgender women have an HIV prevalence of about 25%.[12] Female sex workers also face a slightly elevated prevalence of HIV, at 2%.[13]

MSM in Jamaica face pervasive stigma related to their sexual orientation and practices, and at least some of this stigma stems from the societal perspective that MSM are the primary "carriers" of HIV.[14] In a qualitative study of MSM and transgender people ages 18–30 in Kingston, Jamaica, participants shared experiences of health workers discriminating against them based on their sexual orientation, gender identity, and sexual history. They also worried that clinics would not maintain their confidentiality. Many participants, but particularly MSM, noted that stigma around HIV prevented them from wanting to get tested for HIV.[15] Another qualitative study in Jamaica found a strong relationship between homophobia and HIV-related stigma, mediated by class and gender, and that homophobia and HIV-related stigma reduced participants' desire to seek treatment and to disclose their status to potential partners.[16]

Objectives

This study aims to describe the stigma and discrimination experienced in many different areas of life by PLHIV of different identities in Jamaica through the following:

- Documenting the recent experiences of PLHIV in Jamaica regarding stigma and discrimination

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[11] S. J. Rogers et al., "Layered Stigma among Health-Care and Social Service Providers toward Key Affected Populations in Jamaica and The Bahamas," *AIDS Care* 26, no. 5 (May 4, 2014): 538–46, https://doi.org/10.1080/09540121.2013.844762.

[12] Logie et al., "Barriers and Facilitators to HIV Testing among Young Men Who Have Sex with Men and Transgender Women in Kingston, Jamaica."

[13] Jamaica Ministry of Health, "Jamaica's National Strategic Plan for HIV/STI 2020-2025: A Call to Action." (In press).

[14] D. Bourne et al., "Stigma and Discrimination against Men Who Have Sex with Men in Jamaica" (Washington, DC: C-Change/FHI 360, 2012), https://www.c-changeprogram.org/sites/default/files/Stigma-MSM-Jamaica.pdf.

[15] Logie et al., "Barriers and Facilitators to HIV Testing among Young Men Who Have Sex with Men and Transgender Women in Kingston, Jamaica."

[16] Ruth C. White and Robert Carr, "Homosexuality and HIV/AIDS Stigma in Jamaica," *Culture, Health & Sexuality* 7, no. 4 (July 1, 2005): 347–59, https://doi.org/10.1080/13691050500100799.

- Providing information on the recent experiences of stigma and discrimination across key populations living with HIV including MSM, transgender people, people who sell sex, and people who use drugs
- Gathering information to inform the development and implementation of national programmes, policies, and legislation that protect the rights of PLHIV
- Empowering PLHIV in Jamaica by employing them to conduct many aspects of the survey

Methodology

Sample size

The survey sample targeted a final purposive sample of 500 PLHIV, divided geographically by the proportion of PLHIV living in each parish according to UNAIDS Spectrum data for Jamaica.[17] For example, Kingston and Saint Andrew had 35% of Jamaican PLHIV according to the spectrum dataset, so the target sample size for that parish was 176 PLHIV, or 35% of the overall sample of 500. To reflect the makeup of the population of PLHIV in Jamaica, we sought a sample of half men and half women. Within the sample, we set a target of 190 MSM, which reflects the estimated proportion of 40% of PLHIV in Jamaica who are also MSM. In order to have a large enough sample to characterize the unique experiences of female sex workers and transgender and nonbinary people, we also sought to interview 50 PLHIV from each of those groups. To ensure this final sample size, we targeted an initial purposive sample of 550 PLHIV. The target sample sizes and actual sample sizes are summarized in the results section.

Inclusion and exclusion criteria

All participants were required to be at least 18 years of age, mentally sound and capable of giving consent, and having provided informed consent for participation. We also targeted respondents who had known their status for at least one year but did not turn away people who presented themselves for an interview and then reported having been diagnosed within the past 12 months. People were excluded from participation if they were under the influence of substances or suffering an illness that inhibited their ability to understand the study or provide informed consent at the time of the interview. Participants were also not allowed to take the survey more than once.

Recruitment

Participant recruitment occurred through multiple methods: list-based recruitment through network memberships, recruitment through public and private ART clinics, snowball recruitment (i.e., PLHIV asking others if they would be interested in participating), and online and print advertising. In all

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[17] UNAIDS, "Spectrum Data," 2017.

cases, apart from the ART clinics, participants were contacted only through peer-to-peer outreach—that is, by another PLHIV.

A range of organisations working with PLHIV or key populations were contacted and asked to help advertise the study and recruit participants. Organisations with membership lists were asked to participate in list-based recruitment, which involved contacting a random selection of people on their membership lists of PLHIV. The Jamaican Network of Seropositives (JN+), Eve for Life, and Transwave participated in list-based recruitment. The list-based random selection occurred by placing the names of all HIV-positive members of the organisation into a hat and having a member who was already aware of the HIV status of the other members randomly select the names of people to contact. The selected people were contacted by another member of the organisation who was already aware of the potential participant's HIV status. If the person agreed to participate, their first name, telephone number, and time of availability to participate were shared with the research team, who contacted them to set up an appointment for the survey.

In HIV treatment clinics on the days the research team was present, clinic-based health care workers and patient navigators informed all potentially eligible PLHIV about the study using a standard script. PLHIV interested in participating that day were then directed to the location of the research team. People who expressed interest in participating but were unable to do so that day were either put on a list of people to contact later, which included their telephone number and a time to call them, or were given a recruitment coupon with contact information for the research team if they preferred to follow up themselves.

The snowball technique consisted of asking survey respondents if they would be willing to tell other PLHIV about the survey. If the respondent agreed, they received up to five recruitment coupons with contact information for the research team to distribute through their personal networks.

Finally, the research team advertised the study in both print and electronic forms. Flyers were posted in both private and public facilities, and electronic notices were posted on websites and social media sites, such as the Facebook, Twitter, and Instagram pages of JN+, Eve for Life, Transwave, and the Jamaica Forum for Lesbians, All Sexuals, and Gays (J-FLAG). All of the advertisements included basic information about the study, a phone number for the research team, and a physical location where people interested in participating could go for more information.

Survey administration

All participants received $1,500 Jamaican dollars ($11.09 United States dollars, using the mean exchange rate during data collection from XE.com) as compensation for their transportation and time spent on the survey.

All data collectors were themselves living with HIV. Given this requirement, the survey participants might have known their data collector before they took the survey; in that case, they were given the opportunity to request that a different person administer their survey. In any event, the participants' prior knowledge of the implementing organisations could have influenced their responses to the survey.

Survey data collectors attended a five-day training that covered confidentiality and disclosure, gender and sexual diversity, key populations, the Jamaica Anti-Discrimination System for HIV (JADS), methods for responding to a participant's distress, research ethics, informed consent, and survey recruitment methods. The trainees also received instruction on how to use the electronic data system. They practiced getting and recording informed consent and conducted mock interviews. After the training, the data collectors were assigned to five teams, each of which had between two and eight data collectors and one supervisor.

Survey administration took place at a venue of the participants' choosing, including HIV treatment (ART) clinics, offices of organisations working with PLHIV, offices of other civil society organisations, or other private spaces. The survey consists of approximately 100 questions, and the questionnaire took approximately one hour to complete.

The cross-sectional survey was administered using cell phones with the Open Data Kit app, which had previously been used to administer the Stigma Index in multiple countries, including the Dominican Republic, Cambodia, and Uganda. Interviewers sat side by side with the interviewees, which created a more welcoming environment and reassured participants that their responses were being recorded correctly. The encrypted answers were uploaded at the end of each interview or the end of each day, internet connectivity allowing, to a secure server hosted by Health Policy Plus (HP+). At the end of data collection and cleaning, a final de-identified dataset was uploaded to the GNP+ data portal, which hosts all datasets gathered using the Stigma Index 2.0. The data were analysed using SPSS version 11.0 and R version 3.6.2.

Ethics

The study protocol was reviewed and approved in Jamaica in a letter dated 7 June 2019 by the Ministry of Health and Wellness's Advisory Panel on Ethics and Medico Legal Affairs (2019/29), and by Health Media Labs Institutional Review Board (HML IRB) in Washington, DC in a letter dated 17 June 2019, as required.

Results

Background of participants and household composition

Data collection took place from 20 September through 7 November 2019. The survey included 557 participants, of which 304 (55%) identified as female; 214 (38%) identified as male; 32 (6%) identified as transgender; and 6 (1%) identified as neither female, male, nor transgender (Table 1). All participants were over the age of 18, as required by the inclusion criteria, and 398 (71%) were between the ages of 25–54, with about half of the remaining participants younger than 25 and half older than 54.

Table 1: Self-reported participant demographics

Category	Subcategory	N	%
Self-reported gender identity	Female	304	55%
	Male	214	38%
	Transgender	32	6%
	Do not identify as female, male, or transgender	6	1%
	Prefer not to say	1	<1%
Sex assigned at birth	Female	293	53%
	Male	264	47%
Age	18–24	79	14%
	25–34	157	28%
	35–44	121	22%
	45–54	120	22%
	55+	79	14%
	Refused	1	<1%
TOTAL		**557**	**100%**

The sample included 56 transgender and nonbinary people (10%), which includes people who identified as transgender (i.e., the 32 shown in Table 1); people who identified as neither male, female, nor transgender; and people who reported a gender identity that differed from their sex assigned at birth (Table 2). The sample also included 290 cisgender women (52% of the sample) and 211 cisgender men (38%).[18]

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[18] “Cisgender” is the term used for a person whose gender identity matches their sex assigned at birth.

The participants also included 91 MSM (16%), excluding bisexual men, and 60 women who have sex with women (WSW) (11%), excluding bisexual women. These categories included people who identified as an MSM or WSW, people who identified as gay or a lesbian, and people who identified as neither but reported having sex with a person of the same gender. Thirty-five participants (6%) identified as bisexual, including 21 bisexual cisgender men, 8 bisexual cisgender women, and 6 bisexual transgender or non-binary people. Just over a quarter of the sample reported ever having sold sex (143 participants, 26%); of these respondents, only 54 (38%) identified as a sex worker. Only 22 participants (4%) reported ever having used drugs, such as heroin, cocaine, or methamphetamines.

Table 2: Participant membership in key populations (participants may belong to more than one key population) (N = 557)

	N	%
Transgender or nonbinary people	56	10%
Non-bisexual MSM	91	16%
Non-bisexual WSW	60	11%
Bisexual people	35	6%
People who have ever sold sex	143	26%
People who have ever used drugs	22	4%
Cisgender women not in any of the above groups	212	38%
Cisgender men not in any of the above groups	92	17%

The highest proportion of participants came from the South Eastern region of Jamaica, (287 participants, 52%). From the other regions, 123 (30%) came from the Western region, 74 (13%) from the Southern region, and 73 (13%) from the North Eastern region. Figure 1 shows the parishes contained in each region and the distribution of participants in each, with darker colors showing regions with more participants.

Figure 1: Map of regions, with number of participants per region

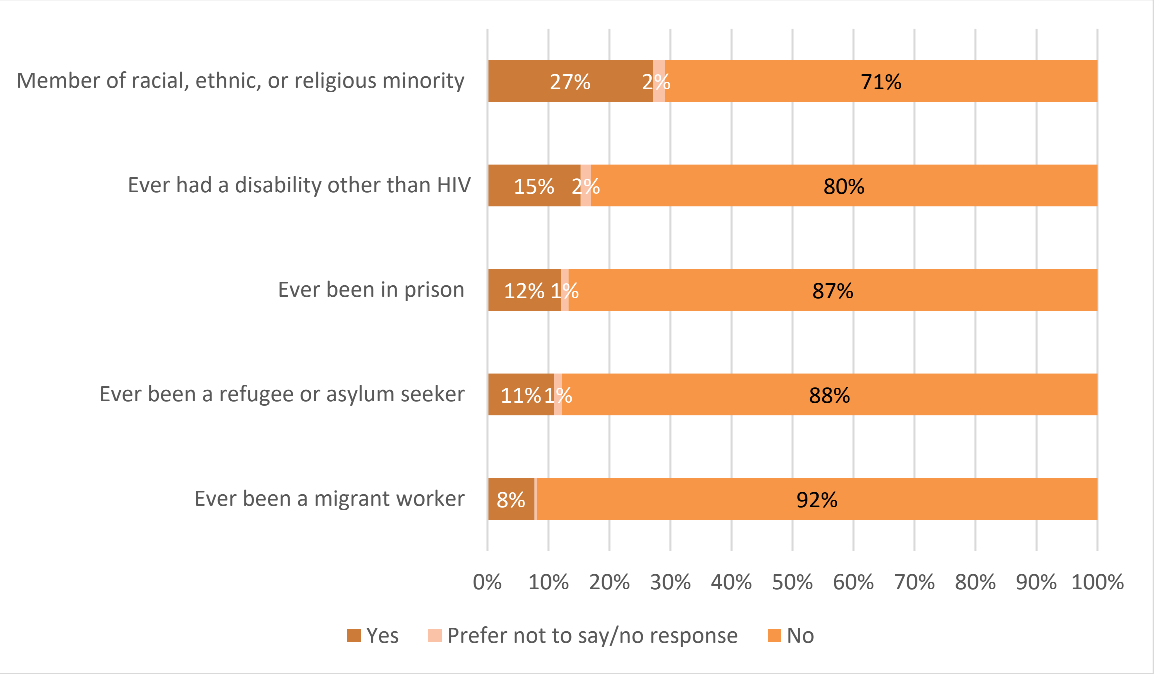
The sample met or exceeded most of the target sample sizes by region, gender, and key population (Table 3). The only exception were cisgender men, with only 211 sampled instead of 225 (94%), and MSM, with only 91 sampled instead of 190 (48%).

Table 3: Targeted and achieved sample sizes, by region, gender, and key population

		Target sample (N)	Achieved sample (N)	Achieved sample (percentage of target)
Total		**500**	**557**	**111%**
Region	South eastern	258	287	111%
	Western	113	123	109%
	North eastern	67	73	119%
	Southern	62	74	111%
Gender	Cisgender male	225	211	94%
	Cisgender female	225	290	109%
	Transgender or nonbinary	50	56	112%
Other key populations	Cisgender females who ever have sold sex	50	64	128%
	Men who have sex with men (MSM)	190	91	48%

A little over a quarter of participants—151 (27%)—reported membership in a religious, ethnic, or racial minority (Figure 2). Eighty-two participants (15%) reported that they had or ever have had some form of disability, such as a vision, hearing, mobility, or intellectual disability, other than their HIV status. About 10% of participants reported ever having been a refugee or asylum seeker, a migrant worker, and/or an imprisoned person.

Figure 2: Participant membership in marginalised groups (N = 557)



Most of the participants reported having completed at least some level of schooling, with only 15 (3%) having received no formal education (Table 4). The highest educational degree for 53% of participants was a secondary school diploma. Ninety-two (17%) reported a trade or vocational school degree; only 32 participants (6%) reported some form of tertiary degree. Half of participants are entirely unemployed, counting full-time work, part-time work, self-employment, and informal employment. Forty-eight participants (8%) reported currently being in school. Only 66 participants (12%) said they had experienced no trouble in the previous 12 months with meeting their basic needs, such as food, shelter, or clothing. The majority of participants reported having had trouble meeting their basic needs at least some of the time, and 39 participants (7%) said they had experienced trouble during all of the previous 12 months.

Table 4: Participant work and education status

Category	Subcategory	N	%
Highest level of education	No formal education	15	3%
	Primary/elementary school	122	22%
	Secondary/high school	296	53%
	Trade/vocational school	92	17%
	University/tertiary	32	6%
Work status	Full time (employee)	88	16%
	Part time (employee)	69	12%
	Full time (self-employed)	50	9%
	Casual/odd jobs	72	13%
	Unemployed	278	50%
School status	Currently in school	48	8%
	Not currently in school	509	91%
How often within past 12 months unable to meet basic needs	All of the time	39	7%
	Most of the time	122	22%
	Some of the time	330	59%
	Never	66	12%
TOTAL		**557**	**100%**

The number of participants in an intimate or sexual relationship—including both married and unmarried relationships—almost exactly equaled the number not in such a relationship (278 and 279, respectively) (Table 5). Of those with an intimate partner, 103 (37%) said they had a partner who also lives with HIV. Some participants—9, or 14% of those with an intimate partner—were not sure of their partner’s HIV status. Participants reported being responsible for a median of 1 child (interquartile range [IQR] 0–2; range 0–10), but 257 (46%) of participants reported having no children in their home for which they were responsible.

Of participants with an intimate or sexual partner, 14% were unsure of their partner’s HIV status.

Table 5: Participant households

Category	Subcategory	N	%
Intimate relationship status (N = 557)	In an intimate relationship	278	50%
	Not in an intimate relationship	279	50%
Intimate partner HIV status, amongst those with an intimate partner (N = 278)	Partner living with HIV	103	37%
	Partner not living with HIV	136	49%
	Unsure	39	14%
Number of children in household (N = 557)	0	257	46%
	1	105	19%
	2	98	18%
	3+	94	17%
	No response	3	1%

Participants reported a median of 7 years (IQR 3–13 years; range 0–35 years) since their HIV diagnosis (Table 6). One hundred ninety-seven participants (35%) reported membership in an HIV support group.

Table 6: Participants' HIV status

Category	Subcategory	N	%
Years since HIV diagnosis	<1	37	7%
	1–3	103	19%
	4–6	117	21%
	7–9	72	13%
	>10	76	14%
	Can't recall	61	11%
Member of an HIV support group	Yes	197	35%
	No	360	65%
TOTAL		**557**	**100%**

Disclosure

Table 7 displays the types of people who know about the participants' HIV status and whether the participant voluntarily told them. Spouses, partners, and family members other than the participants' children were the groups most likely to know a participant's HIV status, followed by friends and children. In total, 112 participants (20%) reported that no one other than themselves knew about their HIV status.

Of the 449 participants (82%) who reported that someone else knows about their HIV status, 228 (51%) reported at least one instance of involuntary disclosure.

In all cases, involuntary disclosure was a relatively common occurrence. For most categories, a little over half of the participants who reported that their status was known by people in that category also reported that they had told those people voluntarily. About half of the participants who reported that people knew their status reported at least one instance of involuntary disclosure (Table 7). Although relatively few participants reported that their neighbors knew about their status, two-thirds of those who did so said their neighbors learned of their status without their consent.

Table 7: Voluntary and involuntary disclosure of HIV status, by person type

	Is this group applicable to you?				If the group is relevant to you, do they know your HIV status?				If you have someone in the group who knows your status, did you voluntarily disclose your status?*			
	Yes		No		Yes		No		Yes		No	
	N	%	N	%	N	%	N	%	N	%	N	%
Any group of people	**549**	**99%**	**8**	**1%**	**449**	**82%**	**100**	**18%**	**221**	**49%**	**228**	**51%**
Other family members	538	97%	19	3%	306	57%	232	43%	167	55%	139	45%
Spouse/ partner(s)	377	68%	180	32%	211	56%	166	44%	145	69%	66	31%
Friends	524	94%	33	6%	217	41%	307	59%	120	55%	97	45%
Children	403	72%	154	28%	157	39%	246	61%	104	66%	53	34%
Employer	266	48%	291	52%	49	18%	217	82%	32	65%	17	35%
Co-workers	265	48%	292	52%	45	17%	220	83%	27	60%	18	40%
Neighbors	519	93%	38	7%	78	15%	441	85%	26	33%	52	67%
Teacher(s)	39	7%	518	93%	6	15%	33	85%	5	83%	1	17%
Community	477	83%	80	17%	57	12%	420	88%	36	63%	21	37%
Classmates	40	7%	517	93%	2	5%	38	95%	-	-	2	100%

** For the last set of columns, the summary row reflects the number of people who reported any involuntary disclosure of their status.*

Of the 424 participants (76%) who reported at least one person they feel close to (e.g., a partner, family member, or friend) knows their HIV status, 305 (72%) said that disclosure was a positive or somewhat positive experience, and 308 (55%) reported that the people to whom they feel close were at least somewhat supportive when they learned the participant's status. For the 411 participants (74%) who reported that at least one person they do not know very well knows their status, 219 (53%) reported the disclosure as a positive or somewhat positive experience, and 210 (51%) said that those people were at least somewhat supportive. A total of 145 participants (26%) reported that disclosing their HIV status has become easier over time, with an additional 125 (22%) reporting that it has become somewhat easier.

Experiences of stigma and discrimination outside of health care services

When asked if they had experienced some form of stigma or discrimination related to their HIV status (not including in the health system) within the past 12 months, 183 participants (33%) answered affirmatively; 268 (48%) reported ever having experienced stigma or discrimination related to their status (Table 8). The most common forms of stigma and discrimination were gossip and discriminatory remarks, followed by verbal harassment. In a follow-up question, participants reported that the form of stigma and discrimination they most feared was isolation from friends and family, with 235 participants (42%) reporting that form as the one they feared most. Although all age groups reported this fear as the most common, more older participants reported it than did younger participants, with 54% of participants older than 55 reporting it as their top fear, but only 32% of 18- to 24-year-olds doing so.

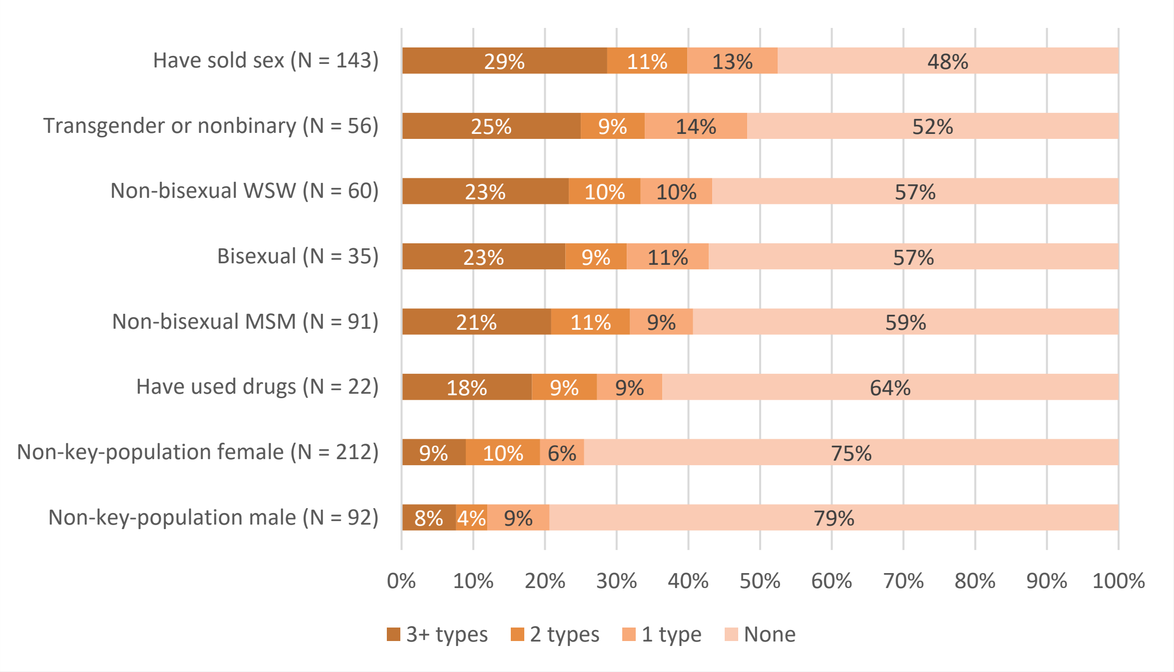
Table 8: Experiences of stigma and discrimination related to HIV status outside of health facilities (N = 557)

	Yes, within the last 12 months		Yes, ever	
	N	%	N	%
Experienced any of these 12 forms of stigma or discrimination due to HIV	**183**	**33%**	**268**	**48%**
Been aware of people other than family members making discriminatory remarks or gossiping about you	122	22%	189	34%
Been aware of family members making discriminatory remarks or gossiping about you	91	16%	152	27%
Been verbally harassed	86	15%	131	24%
Been refused employment or lost a source of income or job because of HIV status	30	5%	64	11%

	Yes, within the last 12 months		Yes, ever	
	N	%	N	%
Known your wife/husband or partner(s) has experienced discrimination because of your HIV status	38	7%	62	11%
Been blackmailed	36	7%	53	10%
Been excluded from social gatherings or activities	33	6%	60	11%
Been excluded from family activities	34	6%	55	10%
Been physically harassed or harmed	25	5%	48	9%
Had the job description or the nature of your job changed or been denied a promotion	17	3%	32	6%
Excluded from religious activities or places of worship	14	3%	25	4%
Been excluded from school activities or other education facilities	7	1%	13	2%

When looking at how PLHIV experience stigma and discrimination due to their HIV status, it differs by other intersectional identities. As shown in Figure 3, people who have ever sold sex reported experiencing proportionately more forms of discrimination within the past 12 months due to their HIV status when compared with people not in any of the key populations. The same holds true for transgender and nonbinary people, MSM, and WSW, though to a somewhat lesser extent than for people who have ever sold sex.

Figure 3: Number of types of stigma and discrimination (as shown in Table 8) experienced within the past 12 months, by group*



**Groups are not mutually exclusive; that is, if a respondent identified with more than one group, they are included in both groups.*

Internalised stigma and resilience

More than half of respondents reported internalised stigma, with 296 participants (53%) reporting that their HIV status makes them feel guilty, ashamed, worthless, and/or dirty (Table 9). In addition, 411 participants (74%) noted that they find it difficult to tell others of their HIV status, and 451 (81%) reported that they hide their HIV status from others.

Although participants generally reported that their HIV status has not affected their ability to meet their emotional needs, 53% of participants reported that their HIV status makes them feel guilty, ashamed, worthless, and/or dirty, and 52% reported carrying out at least one self-isolating behaviour due to their HIV status within the past 12 months.

Table 9: Agreement with indicators of internalised stigma due to HIV status (N = 557)

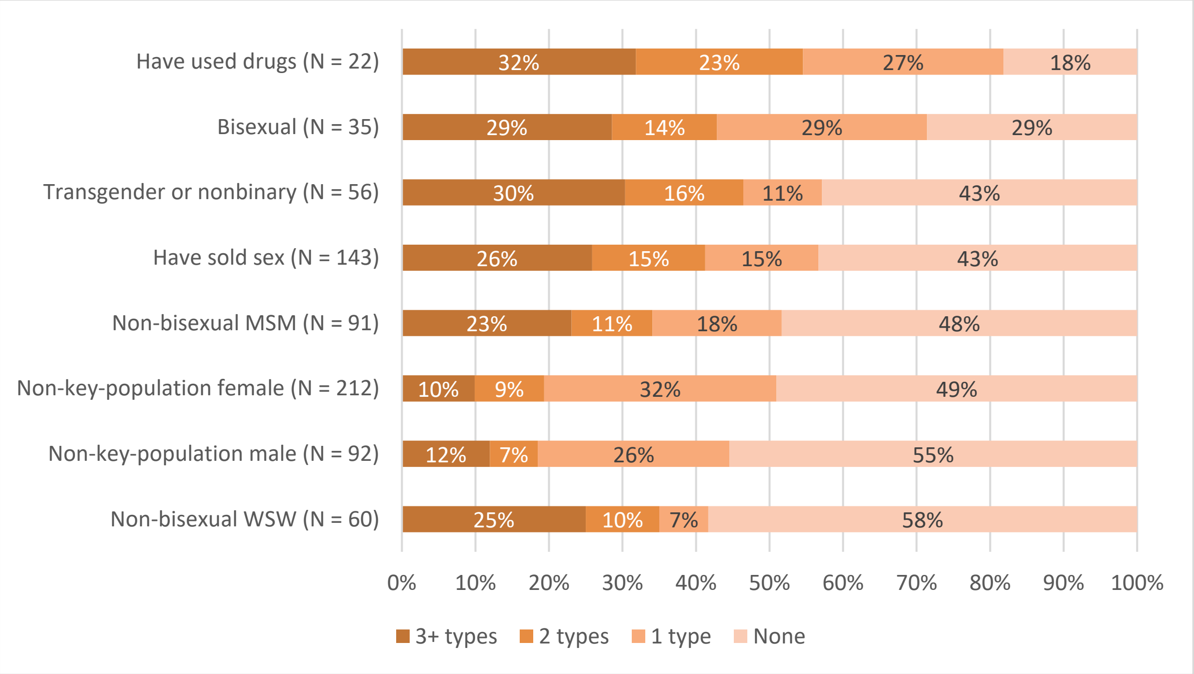
	Agree	
	N	%
Agree with at least one of the following statements	**296**	**53%**
I feel guilty that I am HIV positive	234	42%
I am ashamed that I am HIV positive	202	36%
I sometimes feel worthless because I am HIV positive	162	29%
Being HIV positive makes me feel dirty	150	27%

Table 10 shows the self-isolating behaviours that participants reported doing within the past 12 months. Although only one-third or fewer of participants reported exhibiting any single self-isolating behaviour, 289 participants (52%) reported carrying out at least one such behaviour within the past 12 months. Compared to participants as a whole, members of key populations—people who used drugs, bisexual people, transgender and nonbinary people, people who have sold sex, and MSM—reported a higher incidence of multiple self-isolating behaviours within the past 12 months (Figure 4).

Table 10: Self-isolating behaviours due to HIV status within past 12 months (N = 557)

	Yes		No		N/A or no response	
	N	%	N	%	N	%
At least one self-isolating behaviour	**289**	**52%**	**268**	**48%**	**---**	**---**
Chosen not to have sex	184	33%	351	63%	21	4%
Chosen to isolate self from family/friends	140	25%	400	72%	17	3%
Chosen not to attend social gatherings	90	16%	442	79%	25	4%
Chosen not to apply for jobs	81	15%	433	78%	43	8%
Chosen not to seek social support	80	14%	460	83%	17	3%
Chosen not to seek health care	53	10%	493	89%	11	2%
Chosen not to attend school	18	3%	322	58%	216	39%

Figure 4: Number of self-isolating behaviours engaged in (as shown in Table 10), by group,* within the past 12 months



**Groups are not mutually exclusive.*

Resiliency was measured by asking participants about their ability to meet a range of emotional or personal needs. For most measures, a majority of participants reported that their HIV diagnosis had not affected them (Table 11). Amongst those who reported an effect in each category, approximately the same number of participants reported a negative effect as reported a positive one. These factors can be combined according to a method described by Gottert et al. which produces a score that ranges from -10 (extremely negatively affected) to 10 (extremely positively affected).[19] Participants reported a mean resiliency score of 0.33, which represents a low net effect of their HIV status. Reported scores, however, ranged from -10 to 10, which indicates that some participants feel their HIV status has greatly negatively affected their ability to meet their needs, whereas others feel the reverse.

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[19] A. Gottert et al., “The People Living with HIV (PLHIV) Resilience Scale: Development and Validation in Three Countries in the Context of the PLHIV Stigma Index,” *AIDS and Behavior*, 3, supplement 2 (September 2019): 172. https://doi.org/10.1007/s10461-019-02594-6.

Table 11: Degree to which participants' ability to meet their needs is affected by their HIV status (N = 557)

	Positively affected		Not affected		Negatively affected	
	N	%	N	%	N	%
Ability to have close and secure relationships	133	24%	285	51%	119	21%
Ability to cope with stress	132	24%	285	51%	133	24%
Achievement of personal and professional goals	126	23%	324	58%	88	16%
Self-confidence	119	21%	320	58%	112	20%
Ability to find love	112	20%	294	53%	127	23%
Ability to practice religion/faith	109	20%	341	61%	68	12%
Ability to respect others	103	19%	389	70%	55	10%
Desire to have children	102	18%	239	43%	102	18%
Self-respect	102	18%	365	66%	82	15%
Ability to contribute to community	94	17%	338	61%	86	16%

Interactions with health care services

HIV testing and treatment

Most participants—481 (86%)—reported that they chose to be tested for HIV. Amongst these people, the most common primary reason for seeking out testing was that they believed they were at risk for HIV (262 participants, 54% of those who chose to be tested), a provider recommended testing (118, 25%), and they just wanted to know (53, 11%). Also, amongst these participants, 312 (65%) reported that they got tested within six months of first thinking they should get tested, 72 (15%) took between six months and two years, and 29 (6%) waited more than two years to get tested. The remainder could not remember how long it took them to get tested. One hundred eighty-two participants (38%) reported that they delayed testing due to fears about how other people would respond if they received a positive HIV diagnosis.

For those who did not choose to be tested, 59 (11% of all participants) reported they were tested without their knowledge or consent, 12 (2%) were born with HIV, and 5 (1%) were forced to be tested. After participants got tested for HIV, 251 (45%) reported that they started treatment the same day they were diagnosed, and another 161 (30%) reported starting treatment within six months of receiving their diagnosis. Fifty-two (9%) waited between six months and two years to

start treatment; another 52 (9%) took more than two years to begin. Sixteen participants (3%) reported that they have never been on treatment for HIV.

Two hundred and fourteen participants (44%) reported that they had reasons for delaying their treatment (Table 12). Participants reported that their concern that other people would find out about their status caused them to delay treatment (139 respondents, 29%), as did their own unwillingness to deal with their HIV diagnosis (123, 26%). One hundred forty-six participants (27%) reported that they have missed a dose due to fears that other people would find out about their HIV status, whereas 103 participants (21%) reported being afraid that health workers would mistreat them or disclose their status without permission and 75 (16%) reported already having had a bad experience with a health worker that caused them to delay their HIV treatment.

Table 12: Reasons why participants delayed HIV treatment (N = 481)

	Total	
	N	%
At least one reason for delaying HIV treatment	**214**	**44%**
Worried other people would find out status	139	29%
Worried partner, family, or friends would find out status	135	28%
Not ready to deal with your HIV infection	123	26%
Afraid health workers would treat you badly or disclose status	103	21%
Had a bad experience with a health worker previously	75	16%

Two hundred and ninety participants (52%) reported that they were virally suppressed at some point within the past 12 months. Seventy-five (13%) reported that they had not had a viral test within the past 12 months, 66 (12%) reported they had had a test within the past 12 months that detected the virus, and 63 (11%) reported having had a test recently and that they were waiting for the results. Fifty-three participants (10%) reported not knowing what viral load or viral suppression are.

Mental health

Many of the participants reported symptoms of anxiety and depression, as measured by the Patient Health Questionnaire-4 (PHQ-4), a globally validated measure (Figure 5).[20] About half of the participants reported experiencing each of the four signs collected in the survey at least once within the past two weeks, and about 10% reported that they had experienced each sign most of the time.

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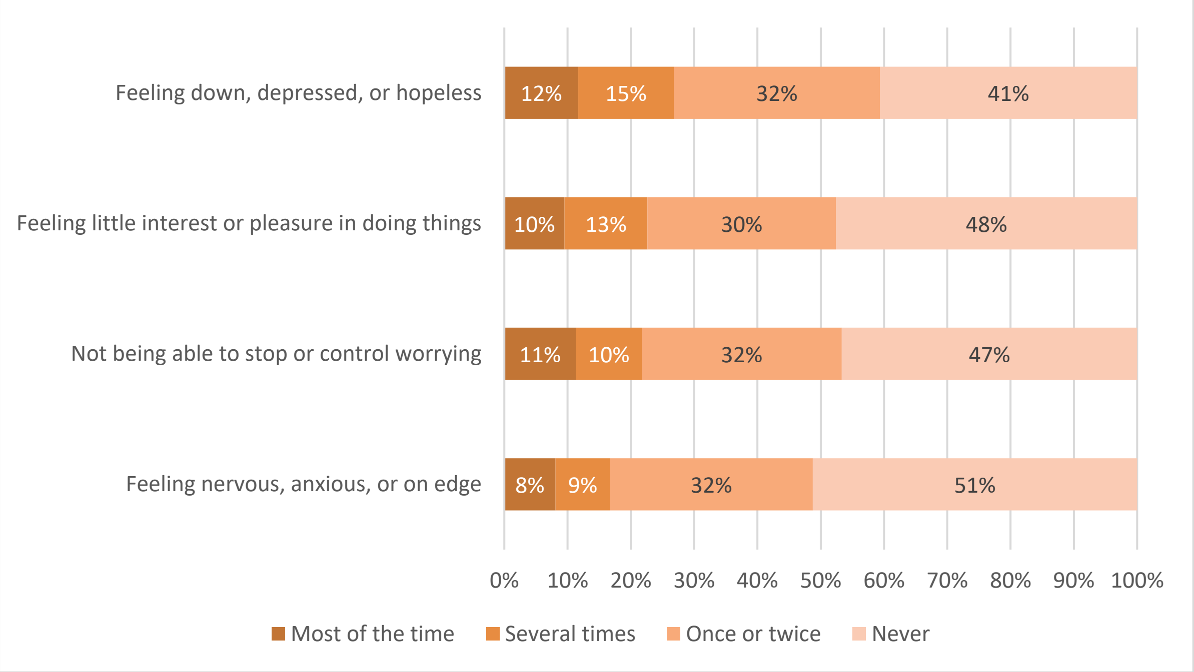
[20] Kurt Kroenke et al., “An Ultra-Brief Screening Scale for Anxiety and Depression: The PHQ-4.,” *Psychosomatics* 50, no. 6 (December 2009): 613–21, https://doi.org/10.1176/appi.psy.50.6.613.

When analysed according to the weights provided by Kroenke et al.,[21] 56 participants (10%) reported signs of severe anxiety and depression, 72 (13%) reported signs of moderate anxiety and depression, 168 (30%) reported signs of mild anxiety and depression.

Figure 5: Frequency of indicators of anxiety and depression within the past 2 weeks (N = 557)



People who had been diagnosed with HIV within the past year reported a slightly higher prevalence of anxiety and depression symptoms than those who had known their diagnosis for more than a year. Of the 59 participants diagnosed with HIV within the previous year, 34 (58%) reported signs of at least mild anxiety and depression; of the 477 who were diagnosed more than a year prior to the survey and who remembered how many years previously they had received their diagnosis, 254 (53%) reported signs of at least mild anxiety and depression. Similarly, severe anxiety and depression were slightly more common among those who had been diagnosed with HIV within the previous year (9 out of 59, 15%) than among those who had not been diagnosed within the previous year (47 out of 477, 10%).

Overall, prevalence of anxiety and depression symptoms was higher in all key populations—bisexual people, people who had sold sex, transgender and nonbinary people, WSW, and MSM—than in those who belonged to no key population. In addition, the incidence of symptoms suggesting major depression and anxiety was higher amongst people who are transgender or nonbinary (14 out of 56, or 25%); bisexual (7 out of 35, 20%); or who had sold sex (24 out of 143, or 17%) than amongst those

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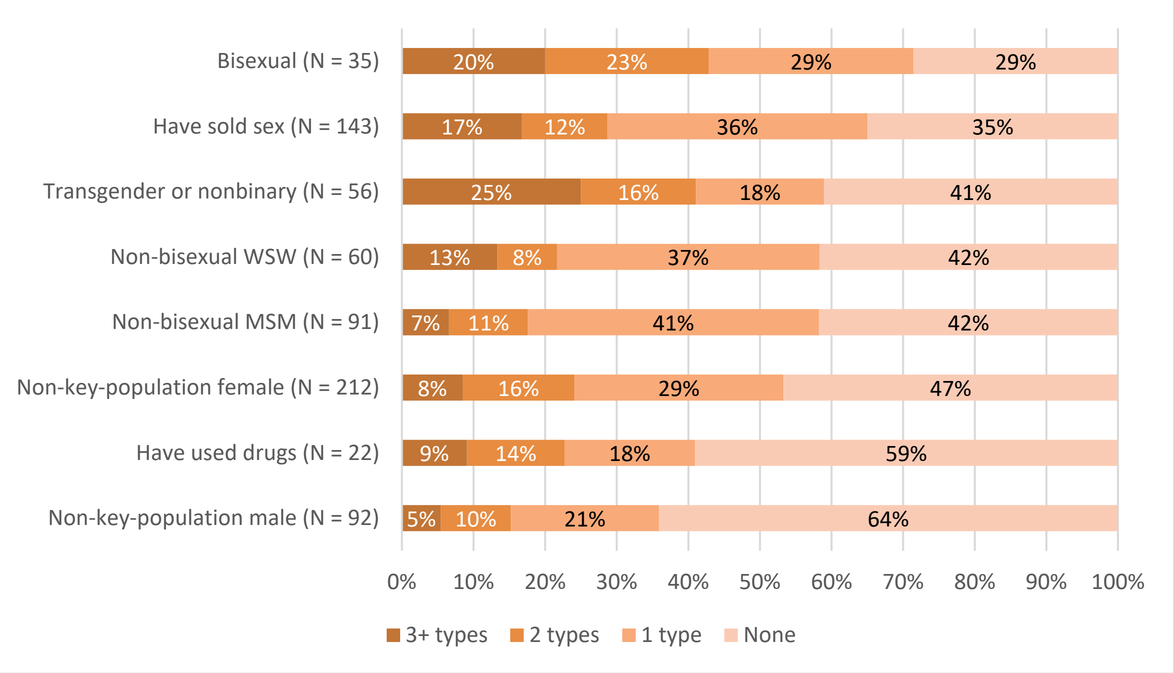
[21] Kurt Kroenke et al., “An Ultra-Brief Screening Scale for Anxiety and Depression: The PHQ-4.,” *Psychosomatics* 50, no. 6 (December 2009): 613–21, https://doi.org/10.1176/appi.psy.50.6.613.

not belonging to those groups (Figure 6). Amongst those who had experienced at least one of these symptoms within the past two weeks, only 117 (30%) reported having received any support for those symptoms within the past 12 months. The most common source of support was counselling (66 participants, 56% of those receiving support).

Figure 6: Reported levels of anxiety and depression symptoms within the past 2 weeks, by key populations



Experiences with health facility staff

When seeking HIV care, 54 participants (10%) reported that they had experienced some form of stigma or discrimination from a health care worker in the past 12 months (Table 13). Amongst the 190 (34%) who had sought some other (non-HIV) form of health care within the past 12 months, 29 (15%) reported experiencing some form of stigma or discrimination from a health care worker. Less than a third of participants, however, said they usually disclose their HIV status when they seek non-HIV care; amongst the 50 (26%) who do usually disclose their status, the prevalence of stigma and discrimination was even higher, with 13 (26%) reporting at least one such experience in the past 12 months. The most common forms of stigma and discrimination reported in a health care setting were the avoidance of physical contact and denial of dental care.

Table 13: Stigma and discrimination experienced in health care settings within the past 12 months

	HIV care		Non-HIV care					
	All (N = 557)		All (N = 190)		Usually disclose HIV status (N = 50)		Do not usually disclose HIV status (N = 140)	
	N	%	N	%	N	%	N	%
At least one experience of stigma or discrimination in a health care setting	**54**	**10%**	**29**	**15%**	**13**	**26%**	**16**	**11%**
Experienced avoidance of physical contact with you/taking extra precautions (such as wearing double gloves) by health facility staff because of your HIV status	18	3%	11	6%	8	16%	3	2%
Denied dental care by health facility staff because of your HIV status	-	-	10	5%	5	10%	5	4%
Advised not to have sex by health facility staff because of your HIV status	17	3%	6	3%	2	4%	4	3%
Talked badly about or gossiped about by health facility staff because of your HIV status	15	3%	5	3%	2	4%	3	2%
Experienced health facility staff telling other people about your HIV status without your consent	13	2%	9	5%	3	6%	6	4%
Denied health services by health facility staff because of your HIV status	9	2%	9	5%	4	8%	5	4%
Verbally abused by health facility staff because of your HIV status	9	2%	4	2%	3	6%	1	1%
Physically abused by health facility staff because of your HIV status	9	2%	1	1%	0	0%	1	1%

The majority of patients (60%) were certain that medical records related to their HIV status are being kept confidential, but 47 (8%) were certain their records are not being kept confidential, and 32% of participants reported they were uncertain (Table 14). A higher percentage of older participants expressed certainty in the confidentiality of their medical records than did younger participants; 14% of 18- to 24-year-olds were certain that their medical records had been shared without their consent, compared to 4% of respondents ages 55 and older.

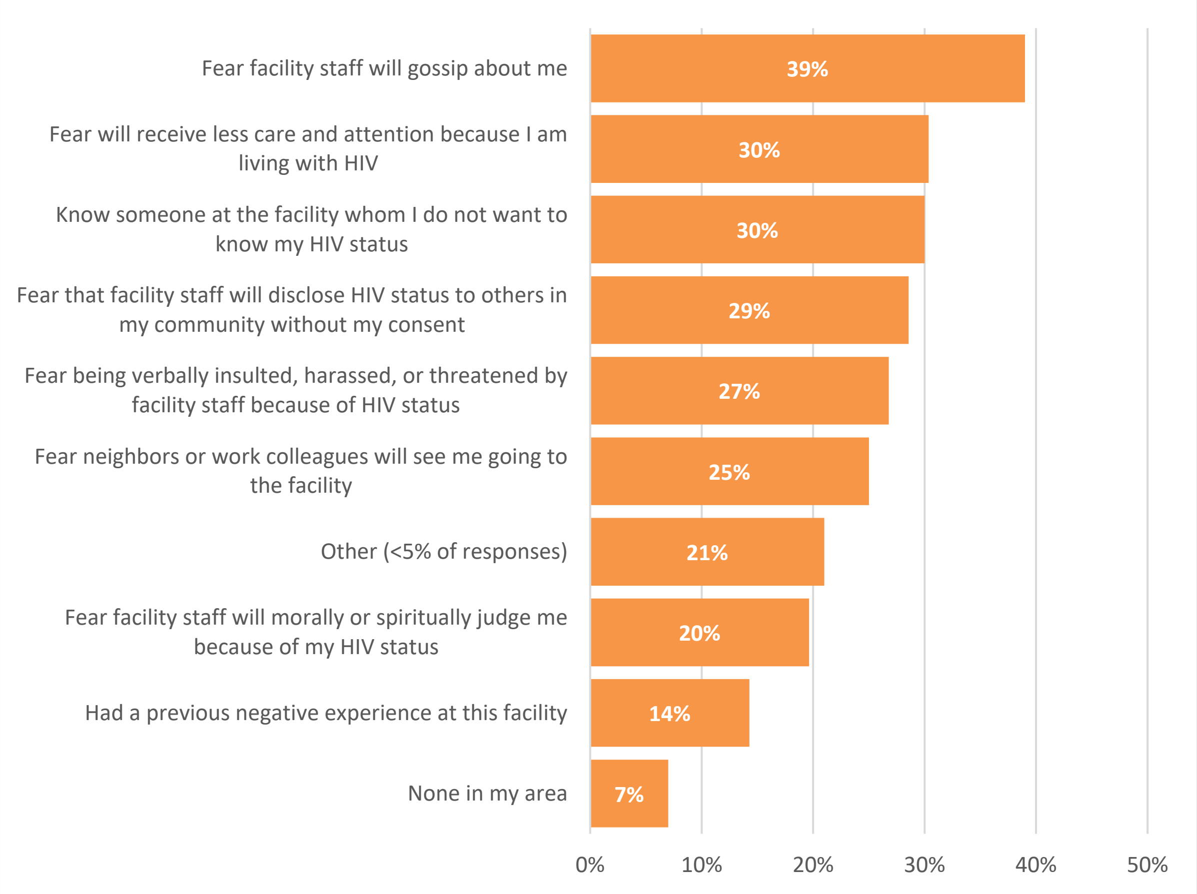
Table 14: Participants' certainty that medical records related to their HIV status are confidential

	Sure that they are confidential		Unsure		Sure that they are not confidential		
Age group	**N**	**%**	**N**	**%**	**N**	**%**	**N**
Total	**333**	**60%**	**177**	**32%**	**47**	**8%**	**557**
18–24	44	56%	24	30%	11	14%	79
25–34	88	56%	56	36%	13	8%	157
35–44	69	57%	45	37%	7	6%	121
45–54	73	61%	34	28%	13	11%	120
55+	59	75%	17	22%	3	4%	79

Two hundred sixteen participants (39%) said they receive their HIV treatment from a location other than the place they were diagnosed with HIV. Of these, 66 (31%) simply did not want to go to their original facility; 65 (30%) said they find their original facility inconvenient, which includes those who had moved since their diagnosis and those who had been tested far from their homes; 48 (22%) were tested at facilities that do not offer treatment, including testing buses and community fairs; and 34 (16%) were referred to their current facility from where they had been tested. Five participants (2%) explicitly volunteered stigma and/or discrimination related to their testing facility as a reason for seeking out a different facility for their treatment.

Fifty-six participants (10%) said they do not receive their HIV care in the area where they reside. Most of the reasons volunteered for that decision revolved around concerns that if participants sought care close to where they reside, their HIV status would become known to people to whom they would prefer not to disclose, whether through community members seeing the participants seek care, knowing someone at the facility, facility staff gossip, or unauthorised disclosure by health facility staff (Figure 7). Some participants also expressed concern that the facility staff would offer them substandard treatment, insult them, or judge them.

Figure 7: Reasons participants choose to seek HIV care away from where they live (N = 56)



Sexual and reproductive health

Forty-six participants (8%) reported that a health care provider had performed some action within the past 12 months that had negatively affected the participants' sexual or reproductive health because of the participant's HIV status. For actions relevant to people of any gender, 36 participants (6%) reported experiencing at least one negative action (Table 15). The most common of these negative actions were exerting pressure or providing incentives for getting sterilised (16 people, 3%) or advising them not to have children (14, 3%). Four participants (1%) reported having been sterilised without their knowledge or consent within the past 12 months solely because of their HIV status. For negative actions specific to female participants, 22 participants (8%) reported experiencing at least one (Table 16). The most common forms of such actions were pressure to use a particular infant feeding practice (15 participants, 5% of female participants) and pressure to use ART during pregnancy (12 participants, 4%). Three participants (1% of female participants) reported that they had been advised to terminate a pregnancy within the past 12 months solely because of their HIV status.

Table 15: Participants who had a health care provider negatively affect their sexual and reproductive health solely because of their HIV status within the past 12 months (N = 557)

	N	%
At least one of the below	**36**	**6%**
Pressured or incentivised you to get sterilised	16	3%
Advised you not to mother/father a child	14	3%
Told you that in order to get your HIV (antiretroviral) treatment, you had to use contraception or a specific method of contraception	8	1%
Sterilised you without your knowledge or consent	4	1%
Denied you contraception/family planning services	2	<1%

Table 16: Female participants who had a health care provider negatively affect their sexual and reproductive health solely because of their HIV status within the past 12 months (N = 293)

	N	%
Any of the below	**22**	**8%**
Pressured you to use a particular infant feeding practice	15	5%
Pressured you to take antiretroviral treatment during pregnancy to reduce the chance of HIV transmission rather than counselling you on this as an option	12	4%
Pressured you to use a particular method of giving birth/delivery option	5	2%
Pressured you to use a specific type of contraceptive method rather than counselling you on a range of available options	4	1%
Advised you to terminate a pregnancy	3	1%

Human rights violations

One hundred thirty participants (23%) reported having ever experienced a violation of their human rights, 40 (31%, or 7% of all participants) of whom had experienced such a violation within the last 12 months (Table 17). The most common violation of rights was rape (75 participants, 13%). Of those who had experienced at least one violation within the past 12 months, only 9 (23%) reported that they had tried to do something about the matter, including filing a complaint, contacting a lawyer, or contacting a community organisation for support. Of those, only 2 (22%) reported a positive resolution as a result of their actions. Amongst those who did not try to do something, the most common reason given was that they did not know what to do or where to go in response (7 respondents, 18%). Others expressed feeling too intimidated or scared (4 participants, 10%), a lack

of confidence that following up would do anything useful (3, 8%), a lack of financial resources (3, 8%), and a fear that others would find out about their HIV status (3, 8%).

Table 17: Human rights violations experienced by participants (N = 557)

	Yes, within the last 12 months		Yes, ever	
	N	%	N	%
Experienced at least one of the following human rights violations	**40**	**7%**	**130**	**23%**
Forced to have sex when I did not want to	20	4%	75	13%
Forced to disclose my HIV status publicly, or my status was publicly disclosed without my consent	8	1%	30	5%
Forced to get tested for HIV or disclose my status in order to get health care	6	1%	17	3%
Forced to get tested for HIV or disclose my status in order to apply for a job or get a pension plan	4	<1%	12	2%
Forced to get tested for HIV or disclose my status in order to get medical insurance	3	<1%	15	3%
Detained or quarantined because of my HIV status	3	<1%	12	2%
Forced to get tested for HIV or disclose my status in order to attend an educational institution or get a scholarship	2	<1%	7	1%
Denied a visa or permission to enter another country because of my HIV status	1	<1%	7	1%
Denied residency or permission to stay in another country because of my HIV status	1	<1%	5	1%
Forced to get tested for HIV or disclose my status to obtain a visa or to apply for residency/citizenship in a country	0	0%	7	1%
Arrested or taken to court on a charge related to my HIV status	0	0%	3	1%

When asked about the existence of legal protection against discrimination specifically for PLHIV in Jamaica, 191 (34%) correctly responded that there are no such legal protections, and 238 participants (43%) were unsure. One hundred twenty-six (23%) incorrectly responded that laws exist to protect PLHIV, perhaps conflating other legal

43% of participants are unsure if laws exist to protect PLHIV in Jamaica.

protections that PLHIV might have due to other identities with protections that specifically cover them due to their HIV status.

Two hundred twenty-four participants (40%) reported that they had ever engaged in some act of social support, education, or advocacy activities on behalf of themselves or other PLHIV (Table 18). The most common acts were providing support to other PLHIV, challenging or educating people who were discriminating against PLHIV, and participating in an organisation or educational campaign that works to address stigma and discrimination against PLHIV.

Table 18: Social support, education, and advocacy activities (N = 557)

	Yes, within the last 12 months		Yes, ever	
	N	%	N	%
Engaged in at least one of the below actions	**149**	**27%**	**224**	**40%**
Provided emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination	106	19%	167	30%
Challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV	95	17%	157	28%
Participated in an organisation or educational campaign working to address stigma and discrimination against people living with HIV	68	12%	121	22%
Challenged or educated someone who was engaging in stigma or discrimination against you	64	12%	117	21%
Encouraged a community leader to take action about issues of stigma and discrimination against people living with HIV	19	3%	39	7%
Encouraged a government leader or a politician to take action about issues of stigma and discrimination against people living with HIV	16	3%	34	6%
Spoke to the media about issues of stigma and discrimination against people living with HIV	7	1%	22	4%

Jamaica Anti-Discrimination System

JADS, formerly known as the National HIV-related Discrimination Reporting and Redress System (NHDRRS), provides a mechanism for PLHIV to report stigma and discrimination they experience. Two hundred eight participants (37%) had heard of this system (Table 19). Of those, only 28 (13%)

had used it to report stigma or discrimination, of which 26 (93%) reported that they would use the system again, though only 16 (57%) were satisfied with the response they received.

Table 19: Awareness and use of the Jamaica Anti-Discrimination System (JADS) (N = 557)

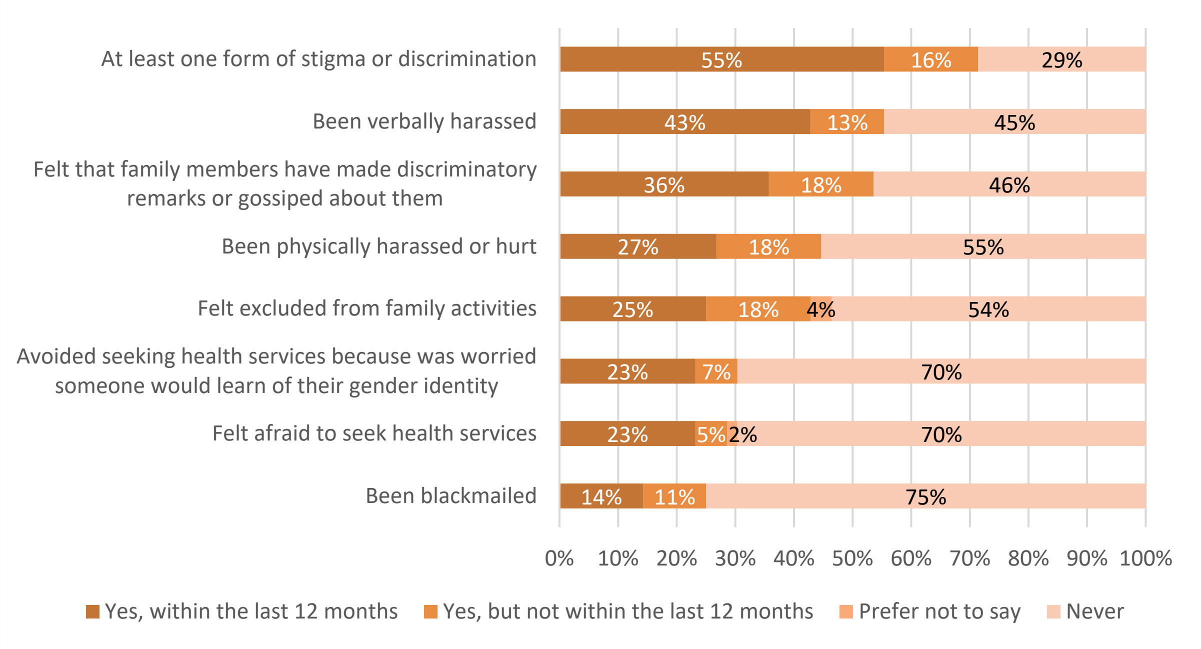
Awareness	N	%
Had heard about JADS	208	37%
Had heard of JADS and had used it to report discrimination	28	13%
Had used JADS and were satisfied with the response	16	57%
Had used JADS and would use it again	26	93%

Stigma and discrimination experienced for reasons other than HIV status

Transgender and nonbinary people

In the sample of 557 PLHIV, 56 participants (10%) identified as transgender; identified as a gender other than male, female, or transgender; or identified as a gender that differed from their sex assigned at birth. Of these participants, 40 (71%) reported ever experiencing some form of stigma and discrimination due to their gender identity, and 31 (55%) reported experiencing such stigma or discrimination within the past 12 months (Figure 8). The most common forms of stigma and discrimination experienced due to participants' gender identity were verbal harassment from others and discrimination or gossip from family members, though 25 transgender or nonbinary participants (45%) reported ever experiencing physical assault due to their gender identity. Twenty-one transgender or nonbinary participants (38%) reported ever avoiding health services to prevent disclosure of their gender identity or being afraid to seek health services. Eight (14%) participants reported having been blackmailed due to their gender identity within the past 12 months.

Figure 8: Stigma and discrimination experienced by transgender and nonbinary participants due to their gender identity (N = 56)



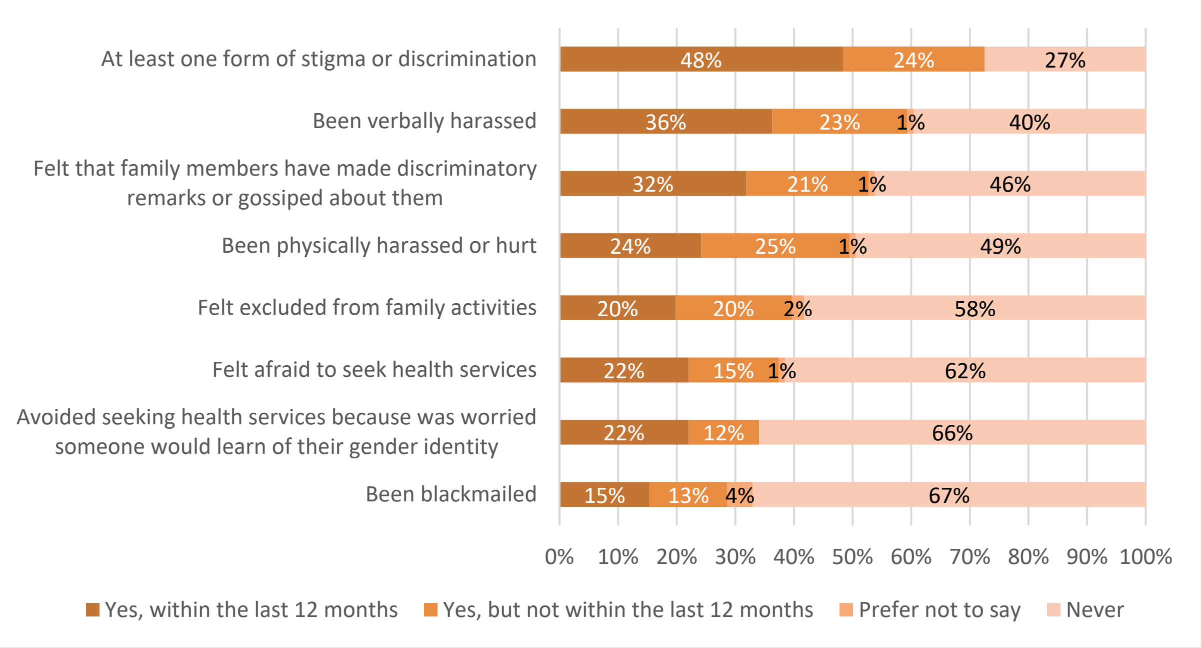
The majority of transgender and nonbinary participants reported that at least one group knows about their gender identity, with only four (7%) reporting that no one knows. Forty-eight (86%) said that other transgender or nonconforming people know their status, 46 (82%) said their family and friends generally know, and 39 (70%) said their community at large generally knows. Nineteen (34%) reported belonging to a support group for transgender people or people whose gender identity differs from their sex assigned at birth.

Men who have sex with men (MSM)

Of the 557 participants, 91 (16%) were non-bisexual MSM. This group includes all people who identified as men and also had ever had sex with another man or identified as gay, homosexual, or an MSM; it excluded men who identified as bisexual. The experiences of people identifying as bisexual are examined in a separate section below.

The overall levels and types of stigma and discrimination faced by MSM in the sample due to their sexual identity and/or practices were very similar to the levels and types faced by transgender and nonbinary people in the sample due to their gender identity (Figure 9). However, MSM reported a somewhat lower level of stigma and discrimination due to their sexual practices and/or identities within the past 12 months than did transgender or nonbinary people due to their gender identities.

Figure 9: Stigma and discrimination experienced by MSM due to their sexual identity and/or practices (N = 91)



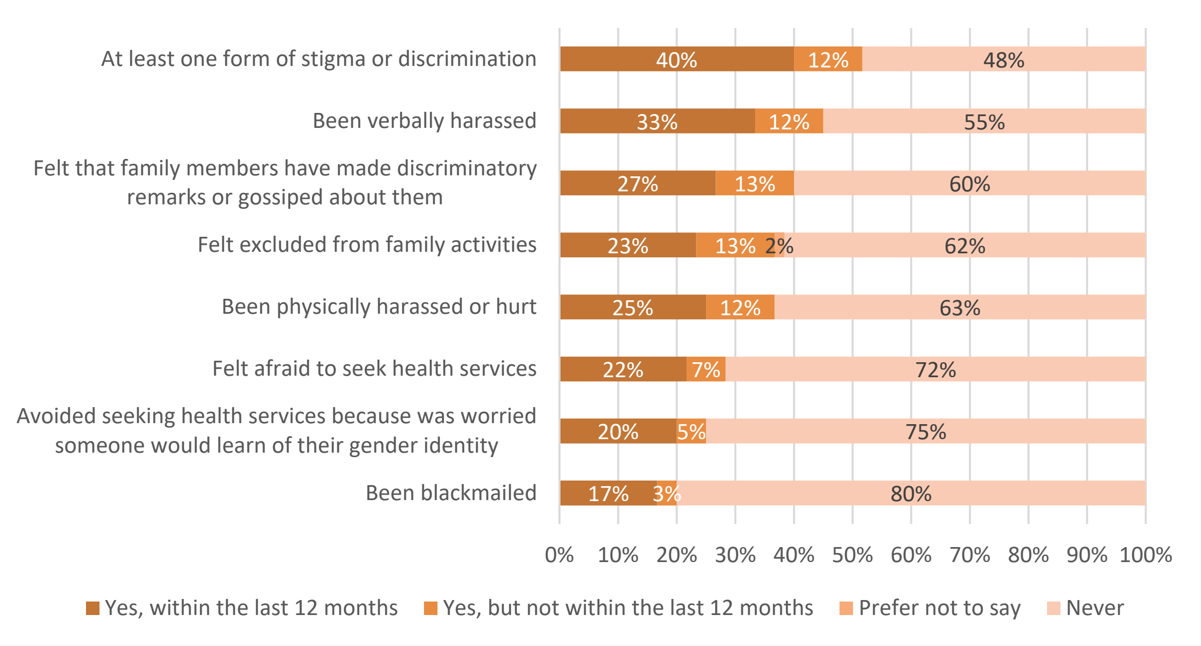
As with transgender and nonbinary participants, most MSM reported that at least one other group of people knows they are MSM, with only 7 MSM (8%) reporting that no one knows. Almost all reported knowing some other MSM who knew the participant is an MSM (83 participants, 91% of all MSM), 60 (66%) said that their friends or family generally knew, and 55 (60%) said that their community generally knew. Thirty-one MSM (34%) reported being a member of a support group for MSM or people who identify as gay or homosexual.

Women who have sex with women (WSW)

Of the 557 participants, 60 (11%) were WSW. This group includes all people who identified as women and also had ever had sex with another woman or identified as gay, lesbian, homosexual, or a WSW; it excluded people who identified as bisexual. The experiences of people identifying as bisexual are examined in a separate section below.

As with MSM, the majority of WSW reported having experienced some form of stigma or discrimination due to their sexual identity and/or practices (52%) (Figure 10). Although a smaller proportion of WSW had experienced any form of such stigma and discrimination compared to MSM—52% versus 72%—a similar proportion reported having experienced such stigma or discrimination within the past 12 months—48% for MSM and 42% for WSW. The most common forms of stigma and discrimination for WSW were the same as for MSM and transgender or nonbinary people.

Figure 10: Stigma and discrimination experienced by WSW due to their sexual identity and/or practices (N = 60)

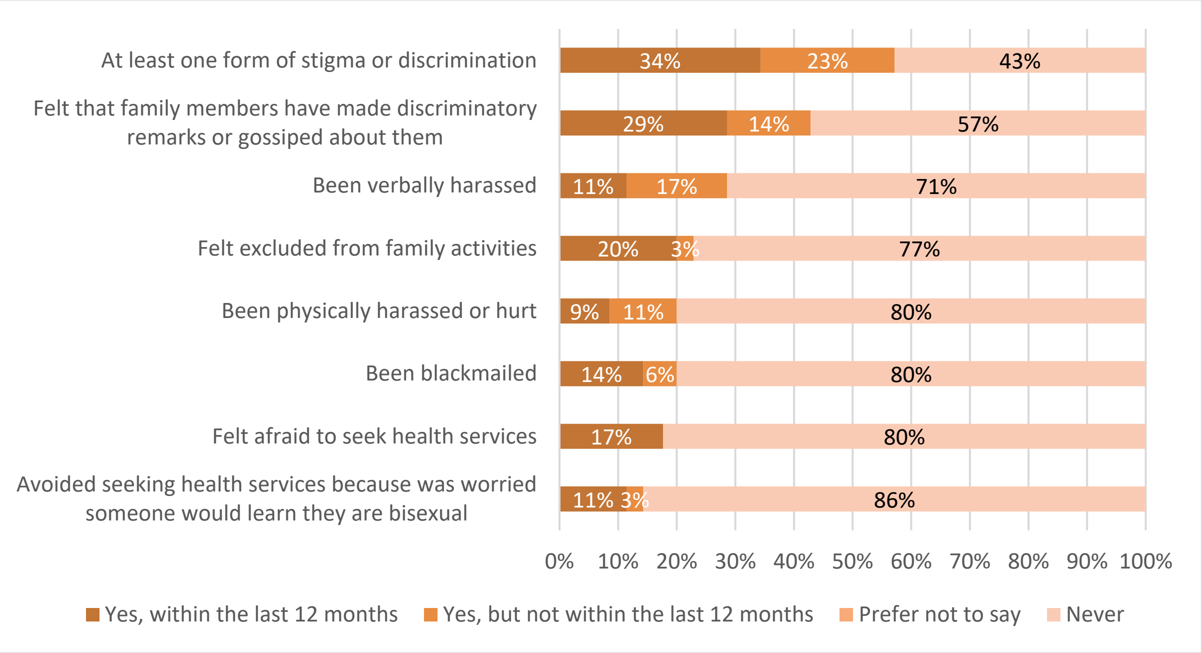


Most WSW in the sample reported that at least one other group of people knows they are WSW, with 48 (80%) reporting that at least one network knew their status. Forty-eight (80%) reported that other WSW generally knew the participant is a WSW, 41 (68%) reported that their family and friends knew, and 34 (57%) reported that other community members generally knew. Eighteen WSW (30%) reported being in a support group for WSW or lesbian, gay, or homosexual women.

Bisexual people

Thirty-five participants (6%) identified as bisexual and/or a person who has sex with men and women, including participants of any gender. In general, bisexual people reported experiencing a somewhat lower prevalence of stigma and discrimination compared to non-bisexual MSM and WSW (Figure 11). Discriminatory remarks and verbal harassment were still the most common forms of stigma and discrimination that bisexual people reported, but bisexual people reported a lower prevalence of physical harassment and fear related to seeking health care due to their sexual identity or practices than did non-bisexual WSW or MSM.

Figure 11: Stigma and discrimination experienced by bisexual people due to their sexual identity and/or practices (N = 35)

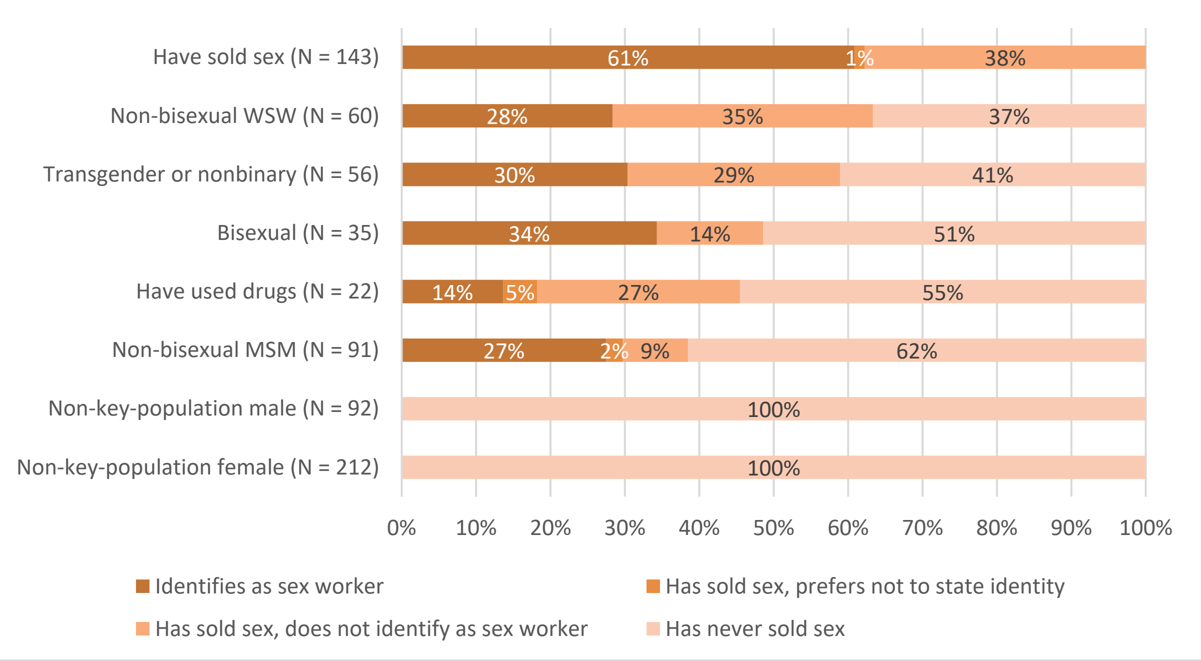


As with both MSM and WSW, most bisexual participants reported that at least one group of people generally knew their status (31 or 89%). Twenty-eight said that other bisexual people generally knew (80%), 22 (63%) said that their family and friends generally knew, and 13 (37%) said that other community members generally knew. These subgroup percentages are smaller than for both MSM and WSW. Only four bisexual people (11%) reported being in a support group for bisexual people.

People who have sold sex

In the sample of 557 people, 143 (26%) reported ever having sold sex. Of the key populations, WSW and transgender or nonbinary people reported the highest proportion of selling sex (Figure 12). Of all those who have sold sex, only 54 (38%) identified as a sex worker. Amongst those who had sold sex, MSM were the most likely to identify as a sex worker, with 25 out of the 35 MSM who sold sex (71%) identifying as sex workers.

Figure 12: Proportion of respondents who have sold sex and/or identify as sex workers, by key population*

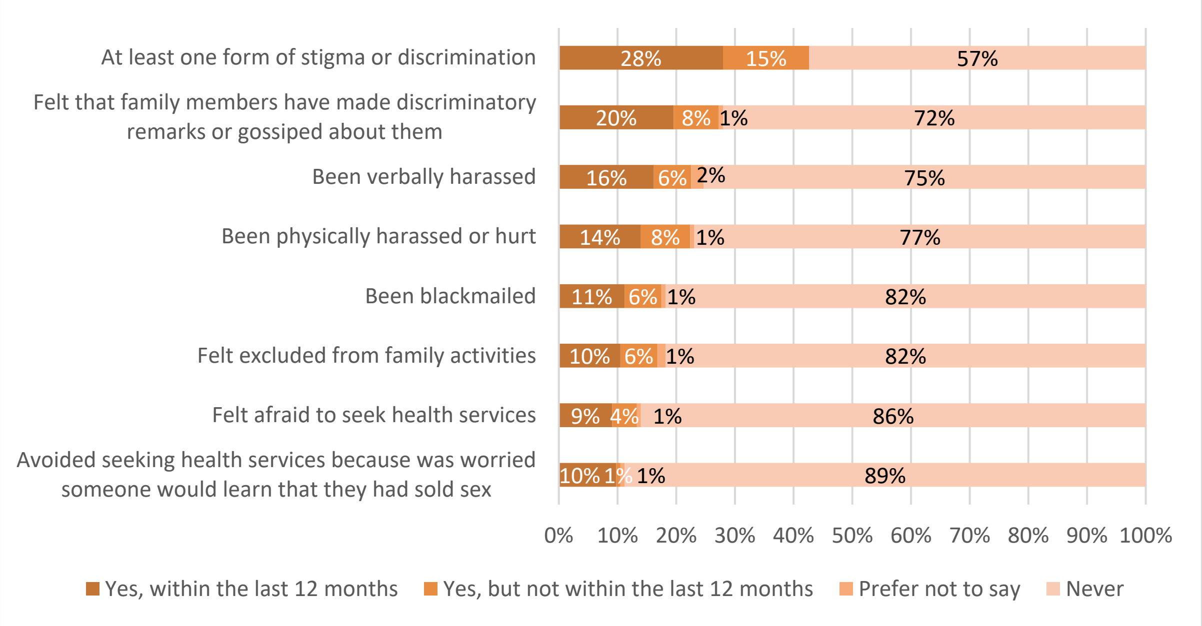


**Key populations are not mutually exclusive; if a participant identified with more than one key population, they were counted in all relevant key populations.*

Amongst participants who said they had sold sex, 61 (43%) reported that they had ever experienced stigma or discrimination due to selling sex (Figure 13). The most common forms of stigma and discrimination again were gossip and verbal harassment, followed by being physically harassed. Twenty-five people who had ever sold sex (17%) reported having been blackmailed due to selling sex.

About half of people who had ever sold sex (75, 52%) reported that at least one other group of people is generally aware they have sold sex. Sixty-two (43%) reported that other people who have sold sex know, 52 (36%) said their family or friends generally know, and 37 (26%) said other community members generally know. Only 16 participants (11%) were in a support group for people who have ever sold sex.

Figure 13: Stigma and discrimination experienced by people who have sold sex and/or identify as sex workers due to selling sex (N = 143)



People who have used drugs

Within the sample, 22 people (3%) reported having injected or habitually used drugs, such as heroin, cocaine, or methamphetamines. Of these, 9 (41%) identified as drug users. Amongst the 22 people who had used drugs, 3 (14%) said they had experienced stigma or discrimination due to their drug use within the past 12 months, and an additional 7 (32%) reported having experienced it, but not within the past 12 months. Given the small number of participants in this category, the types of stigma and discrimination experienced are not presented here.

Amongst those who had ever used drugs, almost all reported that at least one group of people knew about their drug use, with 20 (91%) saying that was the case. The most common group of people to know was other people who used drugs (17, 77%), followed by family and friends (9, 41%), then the wider community (4, 18%). Only 1 participant (5%) reported being in a support group for people who used drugs.

Discussion

The overall results of this cross-sectional survey show that amongst the respondents surveyed, HIV stigma and discrimination, whether anticipated, experienced, or internalised, continue to be present in many spheres of life. Members of key populations—that is, transgender or nonbinary people, people who have had sex with people of the same gender, people who have sold sex, and people who have used drugs—reported higher levels of HIV stigma and discrimination, in addition to stigma and discrimination experienced based on their key population status. In line with the objectives of the study, this report documents these experiences of stigma and discrimination for PLHIV in Jamaica, placing a particular focus on the experiences of members of key populations, including MSM, transgender and nonbinary people, people who sell sex, and people who use drugs.

Over one-third of respondents reported experiencing at least one of 12 forms of HIV stigma or discrimination measured by the survey in the past 12 months (excluding experiences in the health facility), with closer to 50% reporting ever having experienced stigma or discrimination. This overall figure masks marked differences in the experiences of HIV stigma by key population status. For example, 52% of respondents who had ever sold sex and 48% of transgender or nonbinary respondents reported having experienced at least one form of stigma or discrimination related to HIV status, compared to 25% of women and 21% of men who did not identify with any key population group. Members of key population groups also reported experiencing many more forms of HIV-related stigma or discrimination than those reporting no membership in key populations. For those who had ever sold sex, 29% said they had experienced three or more forms of stigma in the past 12 months, compared to 9% of females and 8% of males who reported not being members of any key population group.

The reported experiences of stigma and discrimination specifically within health facilities was lower than those reported as occurring outside of health facilities and differed depending on the type of care being sought—HIV specific or non-HIV specific care. When seeking HIV care within the past 12 months, 10% of all respondents reported experiencing at least 1 of 7 forms of stigma or discrimination measured. Amongst respondents who sought non-HIV care in the past 12 months, however, 15% reported experiencing at least 1 of 8 forms of stigma or discrimination, the most common forms being avoiding physical contact, taking extra precautions (e.g., double gloves), or denying dental care. The proportion experiencing HIV stigma or discrimination within non-HIV care increased to 26% if the respondent usually disclosed their HIV status when seeking non-HIV care, compared to 11% for respondents who sought non-HIV care and did not usually disclose their status. This differential may explain in part why only 26% of respondents who sought non-HIV care in the past 12 months usually disclosed their HIV status when seeking non-HIV care. Although the overall prevalence of health facility stigma was lower than that experienced in the wider community, given the critical role that health facilities play in both individual and public health, the target should be zero.

The difference between the experiences in HIV and non-HIV care, and particularly differences when HIV status is routinely disclosed in non-HIV care settings, points to the need to address stigma and discrimination throughout the health system, not just in HIV services. With HIV now a chronic condition and PLHIV experiencing more non-HIV related health conditions, such as the noncommunicable diseases of aging, it is increasingly critical to address stigma and discrimination towards PLHIV within non-HIV health services. The health of PLHIV must be addressed comprehensibly, ensuring access to health services beyond those related to HIV. It should be noted that most respondents were recruited and interviewed at HIV treatment (ART) clinics. This recruitment setting may have introduced bias into the figures related to health facility stigma and discrimination both because respondents were interviewed at their place of care and therefore may not have felt comfortable reporting stigma and discrimination experienced in that facility and because PLHIV linked to care may be those less affected by stigma and discrimination.

In addition to experiencing external stigma and discrimination, over half (53%) of respondents reported internalised stigma as measured by answering yes to at least one of four statements, reflecting how the presence of external stigma, whether personally experienced or not, can be internalised. Respondents indicated that they felt guilty (42%), ashamed (36%), worthless (29%), or dirty for living with HIV (27%). In addition, over half of respondents reported engaging in at least one self-isolating behaviour in the past 12 months—for example, self-isolation from friends and family. The number of self-isolating behaviours reported was higher for key population PLHIV, compared to both female and male respondents who reported not being members of any key population group. For each of four symptoms of anxiety and depression measured, roughly half of respondents reported having experienced them at least once in the past two weeks, with 10% saying they experienced them most of the time. Amongst those who had experienced at least one of these symptoms within the past two weeks, a third (30%) reported having received any support for those symptoms within the past 12 months, which indicates a potentially large gap in mental health treatment needs for PLHIV. As with experienced HIV stigma and discrimination, PLHIV who were also members of key populations reported higher levels of anxiety and depression than PLHIV who were not members of key populations.

In addition to capturing HIV-specific stigma and discrimination, the study also asked respondents who self-identified as members of key populations about their experiences of stigma and discrimination specific to key population status. For each key population group, stigma and discrimination experienced in the past 12 months due to key population status was between 14-61%, as captured by reporting having experienced at least one of 7 forms of enacted stigma. This percentage was generally higher than the experienced HIV stigma reported by respondents belonging to that key population, except for the stigma and discrimination experienced by those who have ever used drugs. In addition to this key population stigma, PLHIV from key populations also faced higher rates of HIV stigma than PLHIV not from key populations. The burden of stigma and discrimination due to key population status in addition to that of HIV stigma and discrimination is important to recognise and requires a response for key population PLHIV.

The negative effects that stigma and discrimination, no matter the source, can have on the health of PLHIV as well as the wider HIV response, is underscored by how anticipated stigma (fear of stigma) can undermine HIV testing, as well as starting and adhering to treatment. Over one-third (38%) of respondents reported that they delayed HIV testing due to fears about how other people would respond if they received a positive diagnosis of HIV, whereas 30% of respondents reported that fears that other people might learn about their HIV status delayed their start on treatment, and 27% reported missing at least one dose of medication due to these fears.

It is important to note that although respondents faced both experienced and internalised stigma, they also reported resiliency and participation in supporting each other and engaging in education and advocacy activities. Resiliency was measured by asking respondents whether their ability to meet a range of 10 personal needs (ranging from self-respect to ability to find love or contribute to the community) in the past 12 months was positively affected, not affected, or negatively affected by their HIV status. Three-quarters or more of respondents answered for each of the 10 items that their HIV status did not affect them or had a positive effect, indicating a strong resiliency even in the face of stigma. When asked about participation in social support, education, and advocacy activities, 27% of respondents reported engaging in at least one activity in the past 12 months, whereas 40% reported ever having done so. For example, 17% reported in the past 12 months having challenged or educated someone who was engaging in stigma and discrimination against other PLHIV. Both the presence of resiliency and actions to help others and challenge stigma point to a strong foundation within the community of PLHIV on which to strengthen and expand stigma-reduction activities. A key response to stigma and discrimination in Jamaica is JADS. Through this mechanism, PLHIV can report stigma and discrimination. Over a third (37%) of respondents had heard of the system, which indicates space for further outreach and dissemination within the PLHIV community about it.

Although the data between the 2011 and 2019 Jamaica Stigma Indexes are not completely comparable—in particular, the sections on stigma and discrimination within the health system and the sections on stigma and discrimination due to key population status, which are new in the 2019 edition—stigma and discrimination experienced by PLHIV in Jamaica are similar or at slightly lower levels than those reported from 2011. Reported levels of gossip, verbal harassment, and physical assault within the 12 months before the survey have all declined slightly. The prevalence of quite serious negative actions, including rape, blackmail, and forced sterilisation due to participants' HIV status, remains a concern. On the whole, participants continue to note relatively high levels of fear that their status will isolate them from friends and family—a particularly concerning fact, given that participants continue to report levels of self-isolating activities similar to those reported in 2011.

Limitations and challenges

This report has several limitations. The sample was purposive rather than a random sample of all PLHIV in Jamaica, which means it cannot be generalised as the experience of all PLHIV in Jamaica. Almost all recruitment occurred at HIV treatment (ART) clinics, which means that the participants were almost all on treatment for HIV; therefore, this report cannot shed light on the experiences of PLHIV not on treatment for HIV in Jamaica and who are likely those who face the most stigma and discrimination. In addition, many of the surveys were administered in the clinics where the participants were receiving treatment, which might have biased participants' responses about their experiences there. Nonetheless, the data do provide a valuable picture of the experiences of PLHIV in Jamaica, including members of key populations, and provide a strong basis for advocacy and program development.

Recommendations

The third objective of this report is to inform the development and implementation of national programmes, policies, and legislation that protect the rights of PLHIV. In a dissemination meeting with representatives of Jamaican civil society organisations, academia, United Nations organisations, international donor agencies, and the Government of Jamaica, stakeholders identified the following programme, policy, and legislation recommendations based on the findings of this report. Many of the participants in the meeting were PLHIV, and the organisations represented constitute many of those that will need to implement these recommendations. To avoid unnecessary repetition, many of these subsections refer to PLHIV and members of key populations together. As shown in this report, however, although the needs of PLHIV and members of key populations—some of whom are also PLHIV—overlap a great deal, they are not identical; any efforts undertaken due to these recommendations should account for these similarities and differences.

Civil society organisations and the government should educate PLHIV on their rights.

Forty-three percent (43%) of participants reported not knowing whether laws providing specific protections for PLHIV existed. Civil society organisations and the government should conduct outreach and awareness campaigns through the media, town hall meetings, etc. about the protections extended to PLHIV, such as sexual and reproductive health rights. These campaigns should particularly seek to reach low literacy populations of all ages through simple, clear explanations, and they should provide materials in multiple languages. Multiple stakeholders, including religious, governmental, and educational systems, should be invited to collaborate with these education campaigns, and the messages should center the voices of PLHIV champions.

Two particularly important topics for outreach are the JADS and the National Workplace Policy on HIV/AIDS. Additional advertisement for JADS should emphasise less punitive and faster responses to rights violations, such as mediation, which could encourage people to report even less-serious rights violations. The National Workplace Policy for HIV/AIDS seeks to foster a “caring, supportive, and responsible working environment” for PLHIV that reduces stigma and discrimination related to HIV and assists in reducing its transmission.[22] The majority of PLHIV included in this Stigma Index, however, did not report knowing about this policy, which means they would not know how to invoke it in their own workplaces.

Civil society organisations should educate government officials on the needs of PLHIV and members of key populations.

As civil society organisations have turned to providing services for PLHIV, some stakeholders feel that the organisations’ emphasis on advocacy work has diminished. Government officials, including legislators, parliamentarians, and police officers, remain unaware of the needs of PLHIV and key populations. In addition, many members of government lack knowledge of the diversity of gender and sexual identities in the populations they serve. Civil society organisations should serve as a link between the people and the government. Their advocacy efforts should include multiple approaches, ranging from high-level meetings with government officials to consistent presences in town halls to letters to the editor in popular newspapers. The messages in these outreach campaigns should integrate other health-related issues that PLHIV face, such as mental health struggles and non-communicable diseases.

Civil society organisations should strengthen and expand support structures for the PLHIV they serve.

In addition to linking their members with public and private health care services, civil society organisations should provide structures for PLHIV to receive support from their peers. They should consider setting up an HIV hotline to help PLHIV connect with each other, such as informal networking as well as formal support groups. The organisers of formal support groups should use tested guidelines and curricula that can educate their members on useful topics, such as sexual and

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[22] Policy is available at: https://moh.gov.jm/wp-content/uploads/2015/07/NATIONAL_WORKPLACE_POLICY_ON_HIV_February-2008.pdf.

reproductive rights and disclosure. In addition, mental health professionals should be hired to provide trained support for PLHIV.

Health care facilities should train their staff on how best to care for PLHIV and members of key populations.

Amongst those participants who sought out non-HIV health care within the past 12 months, only 26% usually reported their HIV status. At least some of this lack of disclosure probably stems from fear that health care workers would treat the person living with HIV differently if they knew the person’s status; those who said they usually disclosed their status reported a higher prevalence of experiencing HIV-related stigma or discrimination in a health care setting. Health care centers should train their staff, including doctors and nurses but also ancillary health center employees, on how best to serve PLHIV and members of key populations. Health care workers should be taught to see such PLHIV and members of key populations as whole people, rather than as being defined by a diagnosis or identity, or as serving as a means to meet donors’ targets. The trainings should cover such topics as how to avoid stigma and discrimination against PLHIV and members of key populations, how to respect diverse gender and sexual identities, and how to provide inclusive care for people who engage in different sexual practices. Health care practitioners should receive this training as part of their onboarding process and should receive additional periodic refresher trainings updated with current best practices. These trainings should help to reduce the stigma and discrimination that PLHIV face in health care settings, which in turn should reduce the unwillingness of PLHIV to share their status with their medical providers and thereby improve the quality of care they receive.

Schools and churches should provide sex education on diverse sexual practices.

Sex education should present information on a wide array of sexual practices in a way that includes people of all gender and sexual identities. Members of the populations being educated should be consulted in developing and administering the curricula. Schools are a key location for providing this education, but community representatives should approach their churches as possible additional locations for spreading awareness about safer sex practices.

The government should pass legislation to protect PLHIV and members of key populations.

The current legal environment in Jamaica leaves many PLHIV and members of key populations vulnerable to harm. The government should do the following:

- Develop a clear policy on anti-hate speech.
- Pass an anti-discrimination law that protects people of different gender and sexual identities from the harm done by hate speech.
- Redefine rape in the Sexual Offences Act to protect all people. The Sexual Offences Act currently defines rape only in terms of a man raping a woman.[23] Other non-consensual sexual acts, such as cases in which a man rapes another man, are currently defined as the less-serious “grievous sexual assault.” The definition of rape should not reference the sex or gender of either the rapist or the victim.
- Not pass the bill currently under debate that would criminalise the willful transmission of HIV, which would likely increase the stigma associated with PLHIV.
- Develop a policy that defines gender inclusively in legal terms and reference that policy in all future policies. Outdated policies should also be updated to reference that policy. Such an effort will require gender and sexual diversity trainings across the government, which could build off of previous efforts to mainstream gender in the government. The Ministry of Culture, Gender, Entertainment, and Sport should champion these efforts.

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[23] The act is available at: https://moj.gov.jm/sites/default/files/laws/Sexual%20Offences%20Act.pdf.

Disclaimer

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination. In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower people living with HIV on human rights related to HIV.

Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants, interviewees have a right to anonymity and to confidentiality regarding their responses.

In addition to the empowerment function, appropriate uses of the data are for advocacy and to inform stigma/ discrimination reduction programming and policy responses in the national response to HIV as well as contribute to what we know (from the lived experience of PLHIV) about HIV-related stigma globally.