



Jamaica

**THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX**

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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

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}

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-unaid-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

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

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

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.



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 comprehensively, 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

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.

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.

