People Living With HIV/AIDS

Survey Report

2019

PHOENIX FAST TRACK City

ASU Southwest Interdisciplinary Research Center
Arizona State University

ASU School of Social Work
ARIZONA STATE UNIVERSITY

Acknowledgements

Zero Stigma Subcommittee
City of Phoenix Fast Track Cities Initiative
Ad Hoc Committee Members

Arizona State University, Phoenix Arizona

Wendy Wolfersteig, PhD
Director, SIRC Evaluation and Partner Contracts
Southwest Interdisciplinary Research Center
Research Associate Professor, School of Social Work

Mónica Gutiérrez, MSW
Senior Research Specialist, SIRC
Doctoral Student, School of Social Work

Kenja Hassan, MA
Director, Cultural Relations
Office of Government and Community Engagement

Jamal Brooks-Hawkins, MSW
Doctoral Student, Gender Studies

Dominique Roe-Sepowitz, MSW, Ph.D.
Associate Professor, School of Social Work
Director, Office of Sex Trafficking Intervention Research (STIR)

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Fall 2019
Phoenix, Arizona

**Stock photos posed by models and are a depiction of individuals with HIV.*

Contents

Executive Summary

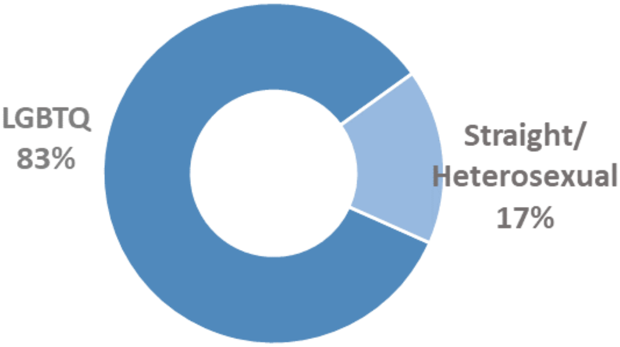
> *HIV/AIDS is an issue that affects everyone, and it demands an all-inclusive, holistic solution. I am proud of the work the ad-hoc committee has accomplished in volunteering so many hours to develop a plan to implement the Fast-Track Cities Initiative in Phoenix.*
>
> -Vice Mayor Laura Pastor

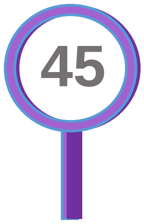
This study is part of a needs assessment to identify issues related to HIV stigma among people living with HIV (PLWH) who reside in Phoenix/Maricopa County. The report provides background information and describes the study, including the methodology used for understanding HIV stigma. The documented results of the needs assessment indicated that for many of the individual stigma questions examined, approximately half of the 296 respondents reported that they strongly agree or agree with the statement, and about half reported disagree or strongly disagree. This showed a diversity of opinions and experiences across the respondents.

About Stigma

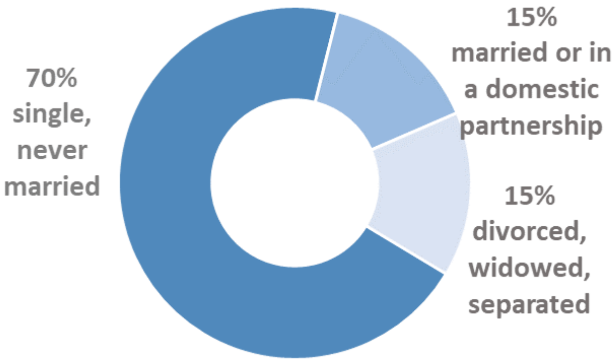
Research shows that HIV stigma experienced by people living with HIV (PLWH) reduces their likelihood of achieving viral suppression, resulting in increased risk for illness and virus proliferation.

Survey Demographics





Median Age



Results

Respondents' perceptions of the public's attitude toward PLWH were also measured.

70% of PLWH worry about discrimination.

69% agreed or strongly agreed that telling someone about having HIV is risky.

68% believe People with HIV are treated like outcasts.

61% feel that most people are uncomfortable around someone with HIV.

59% think most people with HIV are rejected when others find out.

58% indicated it was risky because you can lose your job.

58% believe that most people think that a person with HIV is disgusting.

Several specific themes emerged from these findings.

Social Isolation **Disclosure** **Discrimination** **U=U** **Identity**

These areas might be addressed by prevention and/or intervention strategies, policies and regulations, media campaigns, and other stigma reduction strategies.

Introduction

City of Phoenix Ad Hoc Committee

Alongside other major cities across the globe, the City of Phoenix Fast Track Cities Committee (the Committee) is a voluntary group of appointees dedicated to curbing the spread of HIV/AIDS. Since its inception in 2016, Phoenix's Zero Stigma Subcommittee has examined how HIV stigma interferes with the medical management of HIV-positive people.

The issue is essential given that Maricopa County is identified as one of the 48 counties in the U.S. with the highest rate of new HIV infections. In 2017, a total of 18,190 people lived with HIV/AIDS in Arizona (the Arizona Department of Health Services, 2018). Arizona has an HIV prevalence rate of 262.44 per 100,000 persons. Similarly, the HIV/AIDS prevalence rate in Maricopa County is 294.56 per 100,000 persons.

What is known about Stigma

Stigma towards people living with HIV (PLWH) takes many forms. Two forms of discrimination experienced by HIV-positive people include *interpersonal* and *intrapersonal* stigma. Interpersonal forms of stigma occur when a person living with HIV experiences shame or assault as a direct result of their HIV status. PLWH also report situations where other people avoid physical contact with them or spread rumors about their condition. Another form of interpersonal stigma experienced by HIV-positive people occurs through discriminatory legislation or policies. Also known as structural stigma, these policies can limit PLWH's access to health care and resources (Hatzenbuehler, 2016).

The second form of discrimination experienced by PLWH is an intrapersonal stigma. This occurs when HIV-positive people perceive mistreatment as a result of their HIV status. These feelings can extend beyond abuse in the form of internalized stigma which occurs when PLWH feel ashamed or guilty for having HIV (Turan, Budhwani, Fazeli, Browning, Raper, Mugavero, & Turan, 2017). For this reason, PLWH may be reluctant to disclose their HIV status to new partners, or engage in treatment, or even seek medical care. Research shows that HIV stigma experienced by PLWH reduces their likelihood of achieving viral suppression, resulting in increased risk for illness and virus proliferation.

Study Objectives

HIV/AIDS related stigma remains a significant concern for people living with HIV (PLWH) and those who care for them. Moreover, stigma contributes to the disproportionate prevalence rates of HIV/AIDS for particular racial and ethnic groups as it relates to prevention, treatment, and care. The purpose of this report is to describe the current experiences and perceptions of PLWH in the Phoenix Metro Area. Furthermore, these data may be used by the Ad Hoc Committee and other groups for media campaigns to inform PLWH about the importance of receiving care and educating HIV providers and advocates about the negative impact HIV stigma has on the people they strive to serve.

In this report, the following research questions were addressed:

1. How is stigma perceived by HIV positive persons who live in Phoenix/Maricopa County?
2. Does perceived stigma differ by HIV positive persons' characteristics, such as age, education, race, income, housing stability, and perceived health quality?
3. How do HIV positive persons view U=U?
4. How do HIV positive persons' experiences of sexual exploitation impact their general life experience?

Study Definitions

Human Immunodeficiency Virus (HIV)

As defined by the Minority HIV/AIDS Fund, 2019

> HIV is a virus that attacks cells that help the body fight infection, making a person more vulnerable to other infections and diseases. It is spread by contact with certain bodily fluids of a person with HIV, most commonly during unprotected sex (sex without a condom or HIV medicine to prevent or treat HIV), or through sharing injection drug equipment. If left untreated, HIV can lead to the disease AIDS (acquired immunodeficiency syndrome). https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids

Undetectable = Untransmittable (U=U)

Undetectable = Untransmittable was created in February 2016 by the Prevention Access Campaign, a health equity initiative to end the dual epidemics of HIV and HIV-related stigma by empowering people with and vulnerable to HIV with accurate and meaningful information about their social, sexual, and reproductive health (Prevention Access, 2019). U=U is a global community of HIV advocates, activists, researchers, and community partners from 71 countries uniting to clarify and disseminate the fact that people living with HIV on effective treatment do not sexually transmit HIV (Prevention Access, 2019).

The U=U movement was launched in the United States by a group of people living with HIV who created a Consensus Statement backed by global experts to clear up confusion as to the science that supports U=U.

The U=U Consensus Statement reads:

> *People living with HIV on ART* [Anti-Retroviral Therapy] *with an undetectable viral load in their blood have a negligible risk of sexual transmission of HIV. Depending on the drugs employed, it may take as long as six months for the viral load to become undetectable. Continued and reliable HIV suppression requires selection of appropriate agents and excellent adherence to treatment. HIV viral suppression should be monitored to assure both personal health and public health benefits.*
>
> *NOTE: An undetectable HIV viral load only prevents HIV transmission to sexual partners. Condoms also help prevent HIV transmission as well as other STIs and pregnancy. The choice of HIV prevention method may be different depending upon a person's sexual practices, circumstances, and relationships. For instance, if someone is having sex with multiple partners or in a non-monogamous relationship, they might consider using condoms to prevent other STIs.*
> *"NEGLIGIBLE" = so small or unimportant as to be not worth considering; insignificant.*

Stigma

The City of Phoenix Fast Track Cities initiative has defined HIV/AIDS related stigma as "prejudice, negative attitudes and abuse directed at people living with, or perceived to be at high risk of contracting, HIV and AIDS" (AVERT). Like other organizations working to eradicate HIV (e.g. CDC, U.S. Department of Health and Human Services, The Global Network of People Living with HIV/AIDS, International Committee of Women

Living with HIV/AIDS, and UNAIDS), the committee recognizes that stigma is a social process that maintains inequitable access to resources in a society (Dodds, Keogh, Chime, Haruperi, Nabuly, Sseruma & Weaterburn, 2004). Those who are stigmatized may be viewed as morally flawed, lower-value persons who are therefore less worthy of the resources that lead to a fulfilling and healthy life. In the case of HIV/AIDS, stigma overlaps with other existing prejudices, including misogyny, homophobia, race, gender identity, poverty, sex work, and drug use (Johnson Shen, Freeman, Karpiak, Brennan-Ing, Seidel, & Siegler, 2019).

Study Design and Sampling

IRB

The protocols used in the study were approved by the Fast Track Cities Zero Stigma Subcommittee. This study analysis was approved by the Institutional Review Board (IRB) of Arizona State University.

Recruitment and Inclusion Criteria

Participants were recruited through multiple methods, including online (i.e., Facebook, City of Phoenix website, Aunt Rita’s, Grindr), events such as the Phoenix AIDS Walk, and health clinics. Additionally, the evaluation team identified zip codes with high HIV prevalence rates and distributed promotional materials within those geographical areas.

A screener was administered to participants to determine study eligibility. This screener included demographic questions and asked respondents to identify their HIV status as *positive, negative, unknown* or *would rather not say*. Since the focus of this study was the personal experiences of PLWH, only respondents who were HIV/AIDS positive and who resided in Maricopa County were invited to complete the online survey.

Survey

Both paper and online surveys were administered for this study in the beginning months of 2019. The survey included demographic questions specific to income, race/ethnicity, educational level, current health rating, marital status, and sexual orientation. In addition, several validated scales were used to measure stigma, and other life experiences and U=U questions were also added. These measures were utilized:

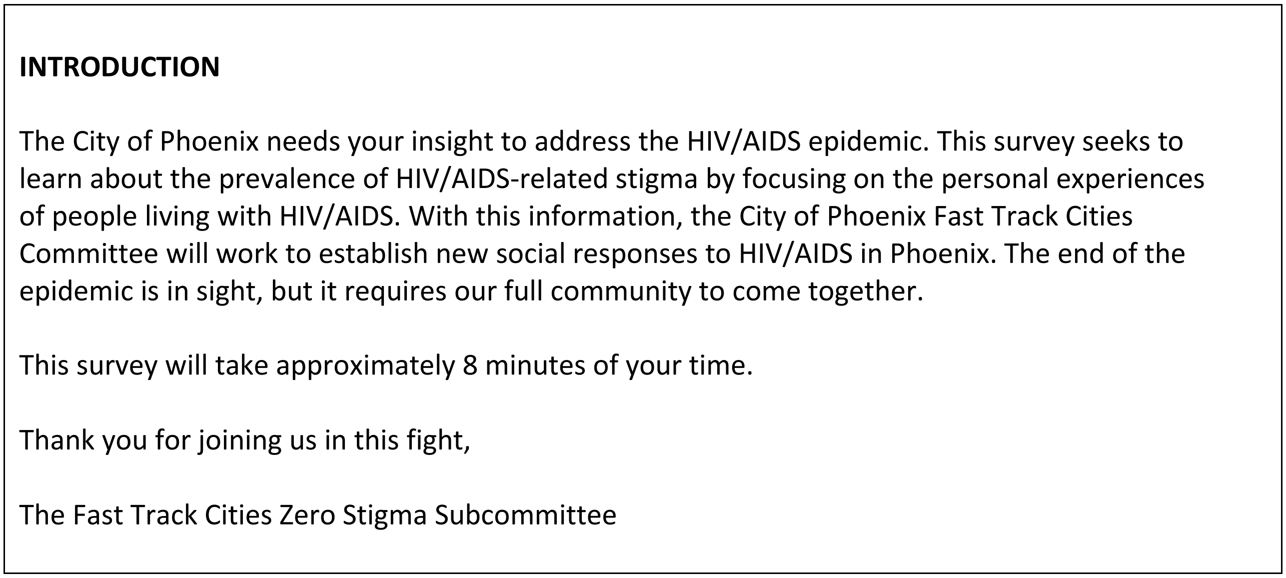
The *Berger HIV Stigma Scale* is a 40-item measure consisting of four subscales that assess personalized stigma, disclosure concerns, negative self-image, and concern for public attitudes. Using a 4-point Likert scale (strongly disagree, disagree, agree, strongly agree), an index score is created. A total score and each subscale score are calculated by dividing the total possible score for each domain.

National Alliance of State and Territorial AIDS Directors (NASTAD) Stigma & Discrimination Survey contains eight questions answered using a four-point Likert scale (never, rarely, sometimes, often).

U=U (undetectable = untransmittable) includes four items regarding the participants knowledge about U=U, how the U=U concept impacts them, how confident the participants' feel about the concept of U=U, and with whom they have discussed U=U.

General Life Experiences is comprised of 10 items specific to life situations the participant may have experienced related to sexual exploitation.

A $15.00 gift card was provided to participants for their participation in the study. A total of 296 respondents completed the survey for this study.



INTRODUCTION

The City of Phoenix needs your insight to address the HIV/AIDS epidemic. This survey seeks to learn about the prevalence of HIV/AIDS-related stigma by focusing on the personal experiences of people living with HIV/AIDS. With this information, the City of Phoenix Fast Track Cities Committee will work to establish new social responses to HIV/AIDS in Phoenix. The end of the epidemic is in sight, but it requires our full community to come together.

This survey will take approximately 8 minutes of your time.

Thank you for joining us in this fight,

The Fast Track Cities Zero Stigma Subcommittee

Data Analysis

For each question, the number and percent for each possible response was calculated. Additional analyses were completed to examine the association between stigma and participant characteristics: ethnicity, income, education, and housing status. Additional analysis included correlations between participant characteristics and U=U responses.

Findings and Discussion

Demographics

A total of 296 respondents participated in this study. The majority of respondents identified as LGBTQ (n = 247, 83.4%) and 49 respondents (16.6%) identified as straight/heterosexual.

Participants were asked both their race and ethnicity. A total of 89 respondents (30.1%) were Hispanic/Latino, and 60 indicated an ethnicity other than Hispanic. Over half of respondents were White (59.5%, n = 176) and 48 respondents (16.2%) were African American.

Table 1. Race by Ethnicity

	Not Hispanic Number	Hispanic Number	Total Number	Percentage
American Indian/Alaskan Native	6	14	20	6.8%
Asian	4	0	4	1.4%
Black/African American	36	12	48	16.2%
Native Hawaiian/Other Pacific Islander	2	0	2	0.7%
White	151	25	176	59.5%
Multiple Races	8	18	26	8.8%
Other	0	20	20	6.8%
Total	207	89	296	100.0%
Percentage	69.9%	30.1%		

Respondents' high school graduation year was used to estimate their age. Respondents' age ranged between 18 and 77 years old (average age = 43.6, median age = 45, standard deviation = 13.7). Further, about a quarter of the respondents were in each of the following age range groups: 18-31, 32-44 and 45-54, and 55-77.

About 70% of respondents were single, never married (n=207, 69.9%). Forty-three respondents (14.5%) were married or in a domestic partnership. About 15% were divorced, widowed, or separated.

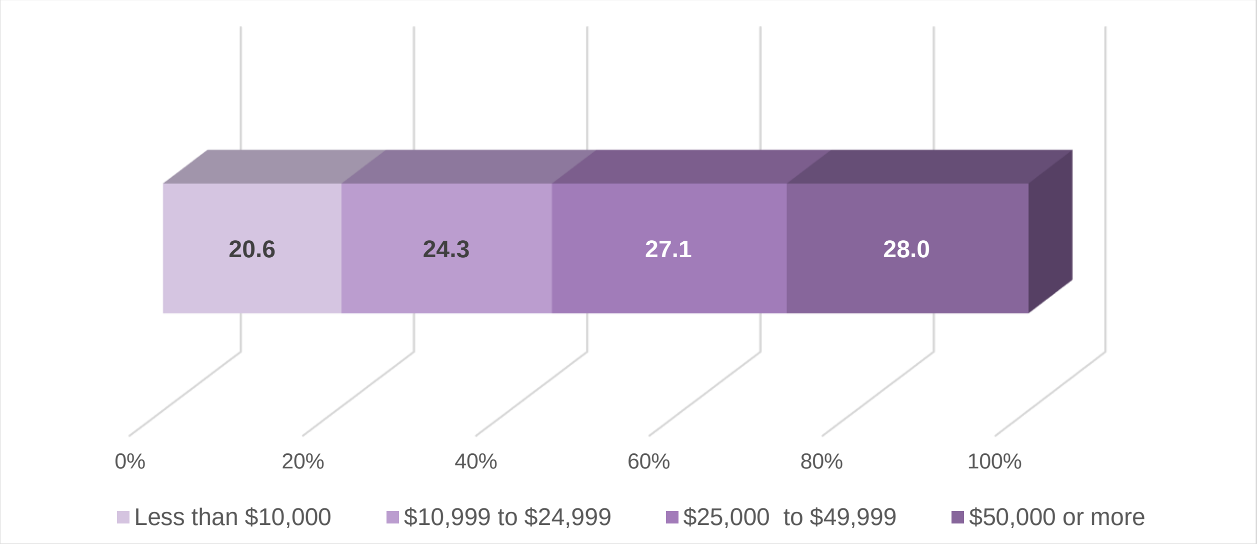
Almost half of the respondents reported living alone in a house or apartment (n=135; 45.6%); 55 (18.6%) lived with someone else, a friend, roommate or housemate; 38

(12.8%) lived with a spouse, domestic partner, or lover; and 12 (4.1%) reported living in a shelter, dorm, or hotel. There were 43 (14.5%) respondents who reported other living arrangements. Nine (3%) respondents were homeless.

Respondents reported their highest level of education completed. Two (0.7%) respondents completed middle school, 14 (4.7%) had some high school, and 49 (16.6%) completed high school. A total of 142 respondents (48%) had some college, trade school, or an associate's degree. A total of 89 (30.1%) respondents had a bachelor's, masters or doctoral degree.

Although respondents were not asked about their employment status or their source of income, about 45% of respondents reported incomes less than $25,000. About 20.6% of respondents earned less than $10,000 as total household income, and approximately one-quarter (24.3%) had an income of $10,000 to $24,999. Another 27.1% reported an income between $25,000 and $49,000 with 28% earning an income of $50,000 or greater. This finding – that so many people had an income of less than $25,000 - suggests that social security and other benefits may be primary financial supports for PLWH who were in this sample.

Figure 1. Participant Reported Income



Over half (63.5%) of respondents reported their health as excellent (n=50, 16.9%) or good (n=138, 46.6%); for another quarter (n=77, 26.4%), their health was reported as fair, and 23 (7.8%) reported that their health frequently varies. Only seven people (2.3%) reported their health as poor or very poor.

Stigma Scale and Subscales

The Berger HIV Stigma Scale has 40 questions with four subscales, several of which use the same questions: personalized stigma (18 questions), disclosure concerns (10 questions), negative self-image (13 questions), and concern with public attitudes about people with HIV (20 questions). Each of the subscales showed a high-reliability factor rating using the Cronbach's alpha: personalized stigma (.957), disclosure concerns (.870), negative self-image (.925), and concern with public attitudes about people with HIV (.942).

To create the index score, the total score and each subscale score was calculated by dividing the overall possible score for each domain. The higher mean (average) scores represent more participants who agreed with the multiple questions on each scale. The highest mean score was for the subscale of Disclosure, indicating that respondents agreed with statements that they needed to be careful about how and to whom they disclosed their HIV status and worried they would be discriminated against and judged.

Table 2. Stigma Scale and Subscales Average Scores

	Average/Mean	Std. Deviation
HIV Overall stigma score divided by the total possible score creating an index	.6226	.14412
Personalized stigma score divided by the total possible score creating an index	.6056	.16982
Disclosure stigma score divided by the total possible score creating an index	.6876	.14931
Negative self-image stigma score divided by the total possible score creating an index	.5851	.16823
Public attitudes stigma score divided by the total possible score creating an index	.6199	.15023

Interestingly, when the individual questions were examined, approximately half of respondents reported strongly agree or agree with the statement, and about half disagree or strongly disagree. This was especially true for the personalized stigma, negative self-image, and concern with public attitudes about people with HIV subscales. For the disclosure subscale, six of the ten items showed wider margins between the positive and negative responses.

For the personalized stigma subscale, responses for some questions around the idea of how others react to being told about one having HIV leaned negative. More than half of respondents agreed that telling others one has HIV can lead to being hurt (q24), feeling regret (q26) or rejected (q16), stopping socializing with people (q35), and having people act as though it is my fault (q34).

However, for the most part, since these responses were not overwhelming, it appeared that for most of the questions, about half of PLWH regretted that they told others; however, 59.1% disagreed that telling someone was a mistake (q27). The one positive exception was that only a third of respondents (35.5%) felt others ignored their good points (q38).

Table 3. Personalized Stigma Subscale

	Strongly Agree		Agree		Disagree		Strongly Disagree	
	Number	Row %	Number	Row %	Number	Row %	Number	Row %
13. Since learning I have HIV, I feel set apart and isolated from the rest of the world.	39	13.2%	102	34.5%	98	33.1%	57	19.3%
16. Most people with HIV are rejected when others find out.	32	10.8%	144	48.6%	93	31.4%	27	9.1%
18. Some people who know I have HIV have grown more distant.	35	11.8%	115	38.9%	109	36.8%	37	12.5%
24. I have been hurt by how people reacted to learning I have HIV.	46	15.5%	128	43.2%	91	30.7%	31	10.5%
26. I regret having told some people that I have HIV.	56	18.9%	107	36.1%	88	29.7%	45	15.2%

27. As a rule, telling others that I have HIV has been a mistake.	30	10.1%	91	30.7%	129	43.6%	46	15.5%
28. Some people avoid touching me once they know I have HIV.	32	10.8%	98	33.1%	120	40.5%	46	15.5%
29. People I care about stopped calling after learning I have HIV.	23	7.8%	108	36.5%	103	34.8%	62	20.9%
30. People have told me that getting HIV is what I deserve for how I lived my life.	32	10.8%	101	34.1%	93	31.4%	70	23.6%
31. Some people close to me are afraid others will reject them if it becomes known that I have HIV.	23	7.8%	108	36.5%	112	37.8%	53	17.9%
32. People don’t want me around their children once they know I have HIV.	29	9.8%	96	32.4%	113	38.2%	58	19.6%
33. People have physically backed away from me when they learn I have HIV.	29	9.8%	106	35.9%	106	35.9%	54	18.3%
34. Some people close to me act as though it’s my fault I have HIV.	40	13.5%	119	40.2%	86	29.1%	51	17.2%
35. I have stopped socializing with some people because of their reactions to my having HIV.	35	11.8%	125	42.2%	92	31.1%	44	14.9%
36. I have lost friends by telling them I have HIV.	34	11.5%	101	34.1%	108	36.5%	53	17.9%
38. People who know I have HIV tend to ignore my good points.	32	10.8%	73	24.7%	136	45.9%	55	18.6%
39. People seem afraid of me once they learn I have HIV.	36	12.2%	93	31.4%	118	39.9%	49	16.6%
40. When people learn I have HIV, they look for flaws in my character.	30	10.1%	97	32.8%	121	40.9%	48	16.2%

Respondents were asked about their perceptions relating to disclosing their HIV status. About 64% to 84% of PLWH agreed or strongly agreed that they were careful who they told (83.5%, q17), worried about being judged (80.7%, q22), perceived discrimination (69.9%, q19), or worried that people who knew would tell others (64.9%, q25). As to disclosing one's HIV status, only about half of PLWH agreed or strongly agreed that they were comfortable with telling others. About 54.4% (q1) did not tell people in many areas of their life about having HIV, and 51.3% (q6) worked hard to keep it a secret. Indeed, 42.9% said it was easier to avoid new friendships than worry about telling (q11). Yet, 64.2% said they never felt the need to hide the fact of having HIV. These disclosure questions indicated that the majority of respondents were wary of telling others and intentional with whom they spoke about their HIV status.

Table 4. Disclosures Concerns Stigma Subscale

	Strongly Agree		Agree		Disagree		Strongly Disagree	
	Number	Row %	Number	Row %	Number	Row %	Number	Row %
1. In many areas of my life, no one knows that I have HIV.	55	18.6%	106	35.8%	79	26.7%	56	18.9%
4. Telling someone I have HIV is risky.	63	21.3%	141	47.6%	64	21.6%	28	9.5%
6. I work hard to keep my HIV a secret.	54	18.2%	98	33.1%	102	34.5%	42	14.2%
11. It is easier to avoid new friendships than worry about telling someone that I have HIV.	21	7.1%	106	35.8%	109	36.8%	60	20.3%
17. I am very careful about whom I tell that I have HIV.	105	35.5%	142	48.0%	36	12.2%	13	4.4%
19. Since learning I have HIV, I worry about people discriminating against me.	58	19.6%	149	50.3%	63	21.3%	26	8.8%
21. I never feel the need to hide the fact that I have HIV. (Reversed)	72	24.3%	118	39.9%	86	29.1%	20	6.8%
22. I worry that people may judge me when they learn I have HIV.	72	24.3%	167	56.4%	39	13.2%	18	6.1%
25. I worry that people who know I have HIV will tell others.	60	20.3%	132	44.6%	80	27.0%	24	8.1%
27. As a rule, telling others that I have HIV has been a mistake.	30	10.1%	91	30.7%	129	43.6%	46	15.5%

Fewer than half of respondents agreed to the negative statements of self-image. About 40.9% (q2) of respondents felt guilty, 37.2% (q7) felt not as good as others, 38.2% (q12) felt unclean, and 30.1% (q15) felt they were a bad person. Just about half agreed that they had shame (47.0%, q23), but also about half never felt ashamed (53.7% q8). Further, nearly half felt set apart and isolated (47.7%, q13), which was similar to other responses across the subscales.

Table 5. Negative Self-image Stigma Subscale

	Strongly Agree		Agree		Disagree		Strongly Disagree	
	Number	Row %	Number	Row %	Number	Row %	Number	Row %
2. I feel guilty because I have HIV.	29	9.8%	92	31.1%	92	31.1%	83	28.0%
3. People's attitudes about HIV make me feel worse about myself.	43	14.5%	114	38.5%	84	28.4%	55	18.6%
6. I work hard to keep my HIV a secret.	54	18.2%	98	33.1%	102	34.5%	42	14.2%
7. I feel I am not as good a person as others because I have HIV.	31	10.5%	79	26.7%	104	35.1%	82	27.7%
8. I never feel ashamed of having HIV.	53	17.9%	106	35.8%	89	30.1%	48	16.2%
11. It is easier to avoid new friendships than worry about telling someone that I have HIV.	21	7.1%	106	35.8%	109	36.8%	60	20.3%
12. Having HIV makes me feel unclean.	23	7.8%	90	30.4%	98	33.1%	85	28.7%
13. Since learning I have HIV, I feel set apart and isolated from the rest of the world.	39	13.2%	102	34.5%	98	33.1%	57	19.3%
15. Having HIV makes me feel that I'm a bad person.	23	7.8%	66	22.3%	124	41.9%	83	28.0%
23. I have shame because HIV is in my body.	36	12.2%	103	34.8%	99	33.4%	58	19.6%
27. As a rule, telling others that I have HIV has been a mistake.	30	10.1%	91	30.7%	129	43.6%	46	15.5%
38. People who know I have HIV tend to ignore my good points.	32	10.8%	73	24.7%	136	45.9%	55	18.6%
39. People seem afraid of me once they learn I have HIV.	36	12.2%	93	31.4%	118	39.9%	49	16.6%

Respondents' perceptions of the public's attitude toward PLWH were also measured. About 68.9% (q4) of respondents agreed or strongly agreed that telling someone about having HIV is risky. About 58.2% (q5) indicated it was risky because you can lose your job, be treated as an outcast (67.9%, q9), be rejected (59.4%, q16), think a person with HIV is disgusting (58.1%, q14), worry about discrimination (69.9%, q19), and make other people uncomfortable (60.8%, q20).

While 8 in 10 PLWH responded that they disagreed or strongly disagreed that identifying a person who has HIV as dirty is acceptable, 20% of PLWH indicated it was acceptable to identify a PLWH as dirty.

Table 6. Public Attitudes Stigma Subscale

	Strongly Agree		Agree		Disagree		Strongly Disagree	
	Number	Row %	Number	Row %	Number	Row %	Number	Row %
4. Telling someone I have HIV is risky.	63	21.3%	141	47.6%	64	21.6%	28	9.5%
5. People with HIV can lose their jobs when their employers find out.	49	16.6%	123	41.6%	89	30.1%	35	11.8%
9. People with HIV are treated like outcasts.	48	16.2%	153	51.7%	75	25.3%	20	6.8%
10. Identifying a person who has HIV as dirty, is acceptable.	11	3.7%	48	16.2%	62	20.9%	175	59.1%
11. It is easier to avoid new friendships than worry about telling someone that I have HIV.	21	7.1%	106	35.8%	109	36.8%	60	20.3%
13. Since learning I have HIV, I feel set apart and isolated from the rest of the world.	39	13.2%	102	34.5%	98	33.1%	57	19.3%
14. Most people think that a person with HIV is disgusting.	36	12.2%	136	45.9%	97	32.8%	27	9.1%
16. Most people with HIV are rejected when others find out.	32	10.8%	144	48.6%	93	31.4%	27	9.1%

19. Since learning I have HIV, I worry about people discriminating against me.	58	19.6%	149	50.3%	63	21.3%	26	8.8%
20. Most people are uncomfortable around someone with HIV.	47	15.9%	133	44.9%	99	33.4%	17	5.7%
23. I have shame because HIV is in my body.	36	12.2%	103	34.8%	99	33.4%	58	19.6%
27. As a rule, telling others that I have HIV has been a mistake.	30	10.1%	91	30.7%	129	43.6%	46	15.5%
28. Some people avoid touching me once they know I have HIV.	32	10.8%	98	33.1%	120	40.5%	46	15.5%
30. People have told me that getting HIV is what I deserve for how I lived my life.	32	10.8%	101	34.1%	93	31.4%	70	23.6%
32. People don’t want me around their children once they know I have HIV.	29	9.8%	96	32.4%	113	38.2%	58	19.6%
33. People have physically backed away from me when they learn I have HIV.	29	9.8%	106	35.9%	106	35.9%	54	18.3%
34. Some people close to me act as though it’s my fault I have HIV.	40	13.5%	119	40.2%	86	29.1%	51	17.2%
38. People who know I have HIV tend to ignore my good points.	32	10.8%	73	24.7%	136	45.9%	55	18.6%
39. People seem afraid of me once they learn I have HIV.	36	12.2%	93	31.4%	118	39.9%	49	16.6%
40. When people learn I have HIV, they look for flaws in my character.	30	10.1%	97	32.8%	121	40.9%	48	16.2%

Everyday Stigma and Discrimination Scale

The Everyday Stigma and Discrimination Scale examined multiple questions. When analyzed by LGBTQ (n=247) compared to heterosexual (n=49), there were no significant differences between the responses of the two groups. Respondents reported that they rarely felt that people acted as if they were better than they were (*M*=1.52, *SD*= 0.953), and they never felt threatened or harassed (*M*=0.84, *SD*=0.865).

Table 7. Everyday Stigma and Discrimination Scale Averages*

	Average/Mean	Std. Deviation
You are treated with less courtesy than other people.	1.21	0.871
You are treated with less respect than other people.	1.26	0.893
You received poorer service in restaurants or stores.	0.89	0.838
People act as if they are better than you.	1.52	0.953
People act as if they are afraid of you.	1.11	0.907
You are called names or harassed.	0.96	0.933
You are threatened or harassed.	0.84	0.865
People act as if you are not smart.	1.08	0.972

*Note: 0=never; 1=rarely, 2=sometimes; 3=often
Lower average scores are preferred

The majority of responses to the Everyday Stigma and Discrimination Scale were positive, with 60 to 70% of PLWH stating that never or rarely did they encounter some of the negative situations asked about in the statements that were common life occurrences. However, that also means that 30 to 40% of the time, there were sometimes or often negative interactions such as being treated with less courtesy (39.9%) or less respect (40.9%) than other people, and that over half of the time (56.8%) other people acted as if they were better than you. Whether this discrimination is from knowing one’s HIV status and/or the roles that socio-economic or ethnic status plays in these interactions is unclear, but experiencing stigmatization and discrimination is common for many PLWH.

Table 8. Everyday Stigma and Discrimination Scale

	Never		Rarely		Sometimes		Often	
	Number	Row %	Number	Row %	Number	Row %	Number	Row %
You are treated with less courtesy than other people.	71	24.0%	107	36.1%	102	34.5%	16	5.4%
You are treated with less respect than other people.	66	22.3%	109	36.8%	98	33.1%	23	7.8%
You received poorer service in restaurants or stores.	116	39.2%	103	34.8%	71	24.0%	6	2.0%
People act as if they are better than you.	55	18.6%	73	24.7%	126	42.6%	42	14.2%
People act as if they are afraid of you.	88	29.7%	107	36.1%	82	27.7%	19	6.4%
You are called names or harassed.	116	39.2%	93	31.4%	69	23.3%	18	6.1%
You are threatened or harassed.	126	42.6%	101	34.1%	58	19.6%	11	3.7%
People act as if you are not smart.	103	34.8%	90	30.4%	78	26.4%	25	8.4%

U=U Concept

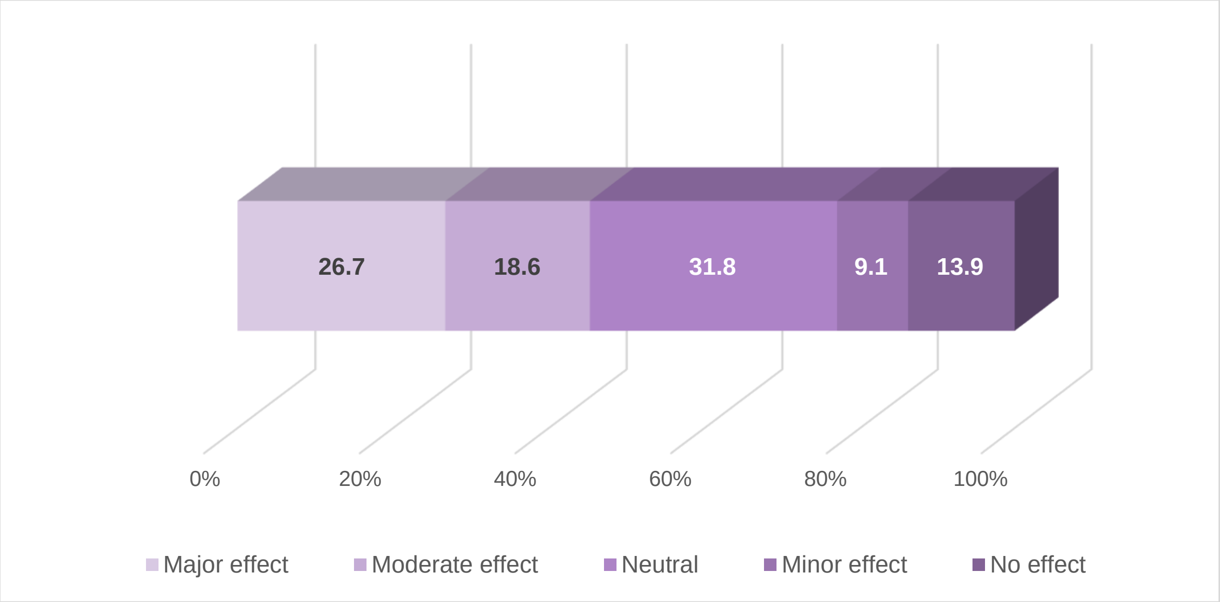
Of the 296 survey respondents, 71.3% (211) reported they were familiar with the concept of U=U prior to completing this survey. However, 28.7% (85) of the study respondents reported they did not hear about the concept of U=U prior to completing this survey. While the percentage who do not know of U=U has decreased over the past several years with multiple media campaigns and health providers distributing information, this still leaves many people who need to be reached with this information.

Table 9. Heard about U=U before the Survey

	Number	Percent
No	85	28.7
Yes	211	71.3
Total	296	100.0

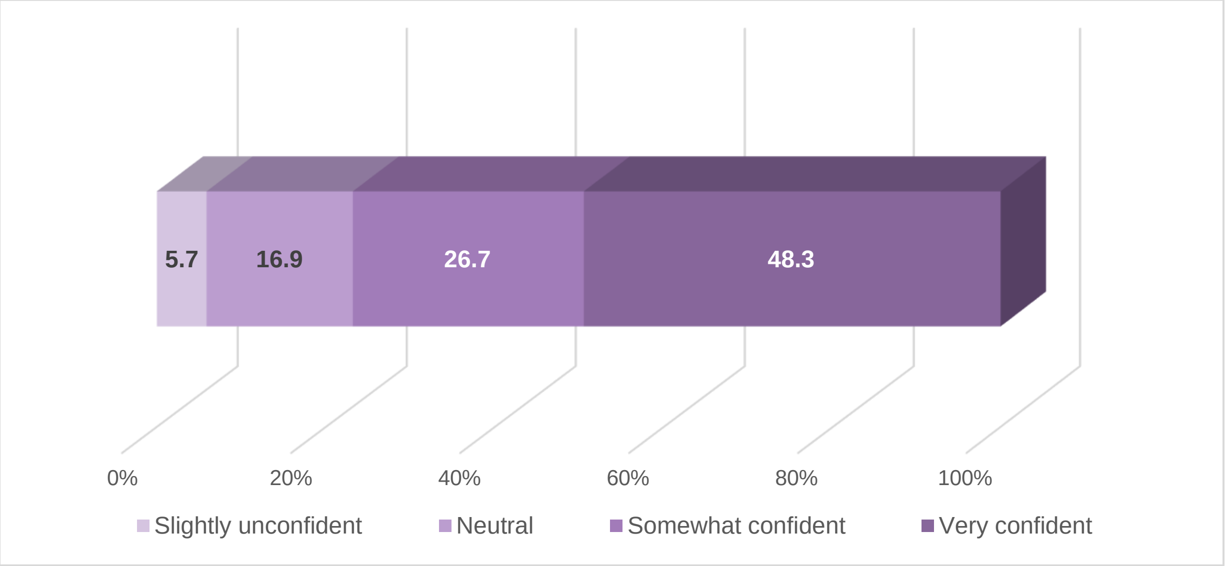
Respondents were asked about the perceived effect of the U=U concept. A total of 45.3% of respondents reported a major to moderate effect, 31.8% reported a neutral effect, and 23% reported either a minor or no effect of the U=U concept on them.

Figure 2. Effect of U=U on You



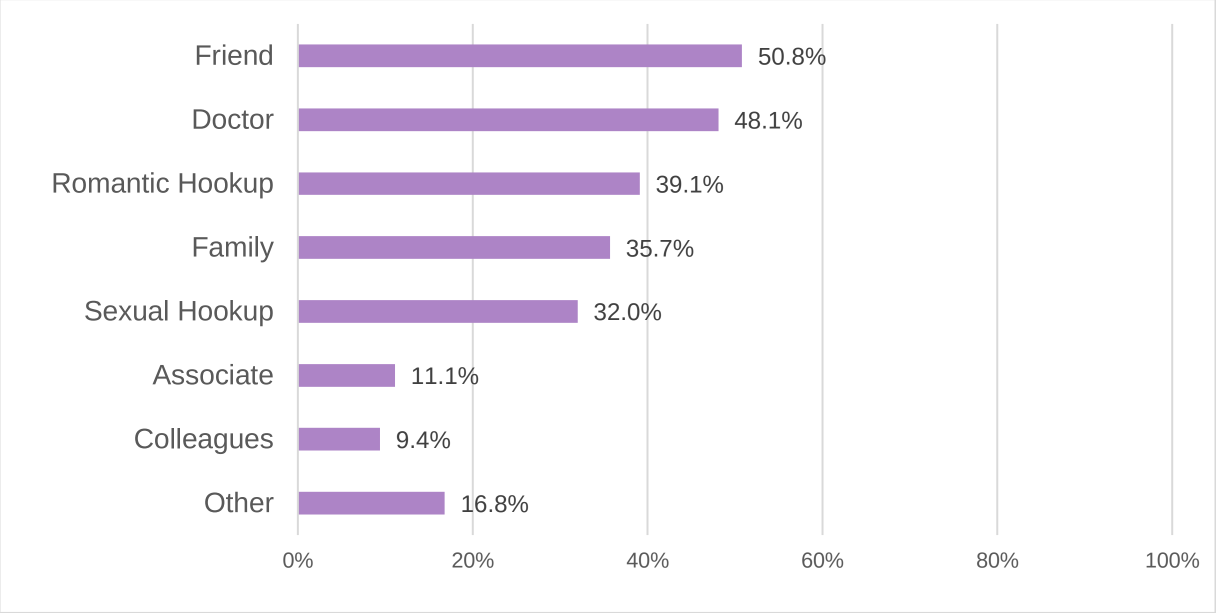
There was a moderately high level of confidence reported by participants related to the U=U concept. Almost half (48.3%) of respondents reported feeling very confident with the concept, and another quarter (26.7%) stated they felt somewhat confident; there were 16.9% of PLWH who reported neutral feelings and 5.7% who felt slightly unconfident.

Figure 3. Level of Confidence in U=U Concept



Results from another question indicated that the top five others who PLWH discussed U=U with were a friend (50.8%), a doctor (48.1%), a romantic hookup (39.1%), a family member (35.7%), and a sexual hookup (32%). This finding reinforces the intentionality of with whom respondents discussed their HIV status as reported in the disclosure subscale. Also, it can be seen as either a positive or negative that only about half of PLWH had discussed the important U=U concept with their doctor. It is also interesting that about one-third of PLWH talked to someone with whom they were having a sexual hookup or a romantic hookup.

Figure 4. Who Discussed U=U with



Trafficking Items

These items examined some concerns around trafficking, sexual exploitation, and being controlled by other people. While not directly addressing sex trafficking, between 8.8% to 18.9% of PLWH reported they had experienced at least one of four situations that were sexual in nature. These situations involved having sex in exchange for things of value (housing, food, gifts, or substances). Further, 13.2% responded that they experienced having had a person control their finances, physical wellbeing, or ability to come and go as they pleased.

Table 10. Experienced any of the Following Situations (select all that apply)

	No		Yes	
	Number	Row %	Number	Row %
Forced or pressured you to do anything you didn't want to do in order to pay back or in exchange for helping to migrate to the U.S.	278	93.9%	18	6.1%
Ever worked in a place where the work was different than what you were told it would be and sexual in nature	263	88.9%	33	11.1%
Threaten to harm your family, friends, associates, or yourself if you did not agree to perform sexual acts	270	91.2%	26	8.8%
Lived in the same place you worked (excluding, the ability to claim your residential space as a place of work)	264	89.2%	32	10.8%
Worked or lived somewhere where there were locks on the doors or windows that prevented you from leaving.	270	91.2%	26	8.8%
Forced to get or use false identification	283	95.6%	13	4.4%
pressured you to touch another person or have any unwanted physical (or sexual contact with another)	257	86.8%	39	13.2%
Put your photo on the internet without your permission for the purposes of advertising sexual services of any kind	266	89.9%	30	10.1%
Have sex for things of value (for example, housing, food, gifts, or substances)	240	81.1%	56	18.9%
Had a person control your finances, physical wellbeing, or ability to come and go as you please	257	86.8%	39	13.2%

Relationships of Stigma Scales to LGBTQ or Hispanic identity

LGBTQ.

LGBTQ (including asexual) compared to heterosexual: There were no significant differences on the Everyday Discrimination or HIV Stigma scale and subscales.

Of life experiences, only LGBTQ participants were significantly more likely to report having had sex for something of value (housing, food, gifts, or substances) than non-LGBTQ participants (x2 4.428, 1, 296, p = .035)

Latino/Latina (yes/no).

Latino compared to non-Latino: There were no significant differences on the Everyday Discrimination or HIV Stigma scale and subscales.

Latino participants were more likely to report that they had been forced or pressured to do anything you didn’t want to do in order to pay back or in exchange for help to migrate to the U.S. than non-Latino participants (x2 5.921, 1, 296, p = .015).

Latino participants were more likely to report that they had worked or lived somewhere where there were locks on the doors or windows that prevented you from leaving than non-Latino participants (x2 7.665, 1, 296, p = .006).

Latino participants were significantly more likely to report having had sex for something of value (housing, food, gifts, or substances) than non-Latino participants (x2 4.897, 1, 296, p =.027).

Latino participants were significantly more likely to report that they had a person control their finances, physical wellbeing, or ability to come and go as you please than non-Latino participants (x2 4.605, 1, 296, p = .032).

Stigma scores: t-tests of significance

Stigma scores and who have they spoken about U=U to others showed the following: Participants reporting a lower score on negative self-image stigma score and were more likely to have discussed U=U with their doctors (No didn't talk to doctor: .6086, Yes did talk with doctor: .56). (t = 2.507, 294, p = .013).

Participants with lower scores on the disclosure stigma score were more likely to have discussed U =U with their friends (Yes discussed with friends: .6604 vs .7159 did not). (t = 3.244, 294, p = .001).

Participants with lower scores on the negative self-image stigma score were more likely to have discussed U =U with their friends (Yes discussed with friends: .5636 vs .6076 did not). (t = 2.266, 294, p = .024). Participants with higher scores on disclosure stigma scale, negative self-image scale, and the public attitudes subscale were significantly more likely to have discussed U=U with their sexual hookups.

There was no relationship between race and having heard about U=U when examined using a chi-square test.

Conducting ANOVAs

ANOVA tests were run to explore age and Stigma Scores (for the Everyday Discrimination or HIV Stigma scale and subscales).

Current health: Scores on the overall HIV stigma scale and the four subscales were found to be statistically different related to the participant's reported current health. With the higher likelihood of a participant's report of feeling excellent or good, the lower the scores on the scales.

Health quality: It was determined that having a lower overall health rating, the participants had a significantly higher stigma score (overall, public attitudes, negative self-image, disclosure stigma, personalized stigma).

Conclusions and Recommendations

This survey and report examined questions and concerns around discrimination and stigma for people living with HIV (PLWH). The convenience sample was conducted during the spring of 2019 and yielded 296 responses from PLWH in the Phoenix and Maricopa County, Arizona area.

Interestingly, for many of the individual stigma questions examined, approximately half of the respondents reported strongly agree or agree with the statement, and about half reported disagree or strongly disagree. This showed a diversity of opinions and experiences across the respondents.

Several specific themes emerged from these findings. These areas might be addressed by prevention and/or intervention strategies, policies and regulations, media campaigns, and other stigma reduction strategies.

Social isolation and its role in relationships may be a concern for this group. Of respondents, 69.9% were single/never married, 45.6% lived alone, and 54% stopped socializing with some people. Over half reported that in many areas of their life, no one knew they had HIV and they worked hard to keep it a secret, behaviors that may result in social isolation in some situations. Indeed, almost half indicated they felt set apart and isolated from the rest of the world.

Join the movement to help end HIV.

Find resources at:
www.hivaz.org
www.phoenix.gov/hivphx

The content of this campaign was developed with scientific, editorial and financial support provided by ViiV Healthcare.
Credit: Cronkite PR Lab in association with SIRC
Stock photos posed by models and are a depiction of individuals with HIV.

Disclosure was the most negative of the Stigma subscales. Of respondents, 68.9% reported that telling someone was risky, 83.5% were very careful about whom they tell, and 80.7% worried that people may judge them. Over half of respondents indicated that they had been hurt by telling, but fewer than half of respondents felt that telling others had been a mistake. These varying responses showed a high degree of recognition that telling others had to be very intentional as to the person and situation in which disclosure took place.

Discrimination was a worry for 69.9% of respondents. Specifically, the Everyday Stigma and Discrimination Scale identified negative interactions about 30% to 40% of the time. Whether this discrimination is from knowing one’s HIV status and/or the roles that socio-economic or ethnic status plays in these interactions is unclear, but experiencing stigmatization and discrimination was common for many PLWH. While only 20% of respondents indicated it was acceptable to identify a PLWH as dirty, this is undoubtedly a stigmatizing view. Many respondents identified different risks from situations in which others knew their status, making the public stigma and discrimination concerns familiar and very real for PLWH.

U=U is a message still unknown to almost 30% of the PLWH. Indeed only about half of the respondents have talked with a friend or doctor about U=U. This is an important medical management issue for HIV-positive people who should receive this information. Research shows that HIV stigma experienced by PLWH reduces their likelihood of achieving viral suppression, resulting in increased risk for illness and virus proliferation.

Identity as defined by race, ethnicity, and LGBTQ status were examined. There were no significant differences on the Everyday Discrimination or HIV Stigma scale and subscales for those who identified as LGBTQ or Latino; initial analysis also showed no differences for African-Americans. However, qualitative information has identified some influences of stigma and its impact on people of color that may warrant additional investigation of these quantitative data.

Indeed, other sources show some specific identity factors that are worth noting. “Black gay and bisexual men use condoms more, have less sexual partners, and use drugs less than White gay and bisexual men. However, they are infected with HIV more and faster… racial biases and stigma keep Black Americans from seeking healthcare services and from testing for HIV, a critical first step in HIV prevention” (Stojanovski, King, & Geronimus, 2019, para. 5 & 6). In Arizona, “rates among Non-Hispanic Blacks have increased from 22 per 100,000 in 2010 to 36.3 per 100,000 in 2017. This difference is even more evident in Non-Hispanic Black females. In 2017, Non-Hispanic Black females had an incidence rate of 23.3 new infections per 100,000 individuals, almost 4x higher than any other female racial/ethnic group in Arizona” (Arizona Department of Health Services, 2018a, p. 5). Moreover, identifying as belonging to cultural, ethnic and social groups often impacts identity and reactions. Thus any strategies, policies, and messages should be tailored with cultural, social and ethnic sensitivities in mind.

Overall, stigma conversations are difficult but necessary. For PLWH, discussions with health providers can – and often are – a matter of life and death. Yet too often these conversations are not initiated by either the individual and importantly, too often not by the doctor or provider; less than half of survey respondents had discussed U=U with their doctor. Since U=U and PrEP can be life-saving, these conversations need to take place.

Further, research has shown that “HIV stigma was associated with an indicator of better physical health and well-being” (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013, p. 1791) demonstrating the importance of maintaining a positive self-identity. The existence of stigma in the environment has harmful and unhealthy effects on PLWH. Procedures and policies within various health departments, community and governmental agencies, and provider organizations should encourage these discussions around stigma, HIV prevention and treatment, and living healthy and stigma-free lifestyles.

Marketing campaigns can help push forward discussions at all levels and raise awareness of issues such as stigma that need to be addressed. These campaigns can be both general as well as for targeted populations and groups in order to provide specific messages as determined. Few if any initiatives target stigma and its range of concerns, but the impact will be truly meaningful in the lives of Arizonans.

The Phoenix Fast Track Cities Ad Hoc Committee and its subcommittees will use the information from this survey in planning and setting objectives for upcoming years. Among the activities will be further data collection on HIV Stigma as perceived by health providers and the general public. Strategies will be put in place to inform stigma reduction efforts that can increase advances and decrease discrimination in medical care, social services, and the breadth of interactions and experiences that permeate the lives of PLWH.

> “While it is difficult to incorporate the lived experiences of stigma into policy and practice, it is an essential step in ending the HIV epidemic by 2030.”
>
> - Stojanovski, King, & Geronimus, 2019, para. 10

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