

# INVISIBLE PEOPLE

A RETROSPECTIVE REPORT ON  
THE IMPACTS OF COVID & HIV  
IN THE UNITED STATES



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# INTRODUCTION

GLAAD’s mission to ensure accurate and inclusive LGBTQ representation across media has never been more urgent, especially in the story that has dominated all of our lives these last two and a half years, the COVID-19 pandemic. LGBTQ people and queer people of color are disproportionately affected in the pandemic, yet data collection didn’t begin for months to help guide responses and resources, and our voices were vastly underreported across the media. These are painful parallels to the early days of HIV/AIDS, when GLAAD was formed to fight inaccuracy and invisibility. Combined with systemic intolerance and indifference, it led to incalculable loss.

Racism, discrimination and lack of access and resources remain challenges that undermine health and safety, evidenced again this year as monkeypox virus surfaced, with early data showing a threat to gay, bisexual and queer men of color. Stigma about illness and identity, inequity, and lack of visibility, are comorbidities across epidemics and generations.

Remarkably this is the first report to examine academic data, and deliver personal stories about the compounding effects of the COVID-19 pandemic and the HIV epidemic in the United States. Through our qualitative work, we heard from people living with HIV who say they felt even more forgotten as the world focused on COVID-19; how messages that can save lives, including information about prevention tools like PrEP, were swamped by COVID-19 coverage. People living with HIV and providers describe astonishment at the rapid development of COVID vaccines and boosters, advances that have yet to be achieved for HIV more than 40 years after the first cases.

On the plus side, clients and providers tell us in their own words how they survived disruption in care, coped with isolation, and discovered new ways to connect. Advocates pivoted to new approaches to improve access to care. Their creativity and resiliency in the face of unprecedented challenges must be rewarded with more resources to continue to innovate for patient care and all public health.

This research offers a clear path forward: media must uplift stories of people living with HIV, who need to be seen and heard in the healthcare system and the world at large, for HIV to be understood as preventable, treatable and untransmittable. Communities, industries and government must continue to innovate together to create and implement solutions, to better prepare for all challenges to health and safety.

Above all, this research reinforces GLAAD’s core work to accelerate acceptance for LGBTQ people, and for people living with HIV. It centers key voices and elevates understanding. We must remove all barriers to end the HIV epidemic, and prepare for new crises, so all can live the life they love.





## STATEMENT FROM ADEDOTUN A. OGUNBAJO, PHD, MPH, MHS

The COVID pandemic is personal, very personal. On March 11, 2020, the World Health Organization declared the novel coronavirus a global pandemic. Three weeks later, I successfully defended my doctoral dissertation in public health. Exactly a week after that, a phone call from my father at an odd time signaled trouble. He was calling to let me know my mother’s COVID symptoms had significantly worsened, and the ambulance was on its way to our house. I listened helplessly as my mother gasped for air that her lungs couldn’t find. The three weeks that followed consisted of anguish, anxiety, and angst as her life hung in a balance, aided by a ventilator and the prayers of friends and family, both near and far. While my mother was one of the lucky ones to pull through, the death of over 6 million people globally is a sobering reminder of the lasting impact of this pandemic. As a behavioral scientist whose research centers the lived experiences of Black LGBTQ folks, I am acutely aware of how structural inequality, prejudice, and discrimination drive health inequity and outcomes in the United States and across the globe. The HIV epidemic and COVID pandemic are real life embodiments of this maddening phenomenon. My hope is that this report serves as a catalyst for real conversations and actions that aim to undo the work of racism, homophobia, and all forms of discrimination.

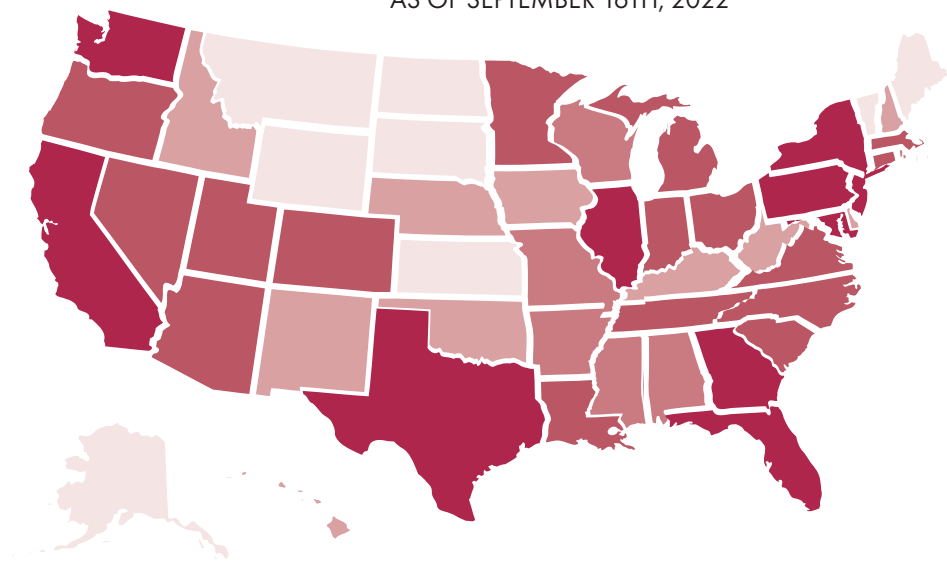
## ADDENDUM ABOUT MONKEYPOX (MPX) AND THIS REPORT:

This report was conceptualized and developed prior to the onset of the recent monkeypox (MPX) outbreak in the U.S. Currently, an overwhelming majority of MPX cases in the U.S. is among Black and Latino sexual minority men [1], mirroring the HIV epidemic. Additionally, preliminary data suggests that MPX disproportionately affects people living with HIV [2]. While vaccinations for MPX are beginning to be rolled out nationwide, there is still a shortage of vaccines and vaccine eligibility criteria differ by state and localities. The parallels between HIV, COVID-19, and MPX in the U.S. cannot be overstated. They all disproportionately affect racial and sexual minority communities, which are groups that have been historically marginalized throughout U.S. history. While these are inherently different viruses, are transmitted differently, and have different clinical severity, they share a common thread. Social inequalities and disproportionate access to healthcare services are the major driving forces of these public health emergencies. This is especially salient in the uneven distribution of testing sites, hospitals, and availability of other healthcare mitigation services in affluent and often White communities. Additionally, stigma has presented itself an insurmountable barrier to adequately address these health issues. Specifically, the generally held but less spoken belief that people who become infected with any of these viruses were acting irresponsibly and are therefore personally responsible for any health consequences might dissuade testing and disclosure of infection. Additionally, it is also important to name the inherent homophobia that precipitated the naming of HIV as a “gay disease” in the early days of the epidemic, which has also been repeated during this recent MPX outbreak due to most cases being among sexual minority men. The convergence of the COVID-19 pandemic, HIV epidemic, and MPX outbreak marks a critical period for the public health infrastructure in the U.S.. To achieve any tangible progress in curbing these pressing health issues, we must adequately address the root causes which are rooted in the unequal distribution and prioritization of the resources to design and implement long-lasting and sustainable solutions. Without this, we are merely spinning our wheels as the next global health crisis looms.

[1] <https://www.cdc.gov/poxvirus/monkeypox/clinicians/technical-report.html#summary>  
[2] <https://www.nejm.org/doi/full/10.1056/NEJMoa2207323>

### 23,499 TOTAL CONFIRMED MONKEYPOX/ORTHOPOXVIRUS CASES

AS OF SEPTEMBER 16TH, 2022



#### CASE RANGE

- 1 to 10
- 11 to 50
- 51 to 100
- 101 to 500
- >500

# COVID-19 & HIV:

## INTERSECTIONS & LESSONS LEARNED

### KEY FINDINGS

This report brings an academic and personal voice of the impact that the COVID-19 pandemic has had to-date on the fight to end the HIV epidemic, while also providing recommendations/needs from people at community-based organizations (CBOs) who serve and support the community. We underscore the disruption in access to HIV prevention and care services due to mitigation measures imposed in the early days of the COVID-19 pandemic, which will have implications for many years to come. We also highlight innovation to HIV service delivery that provided an important bridge between healthcare professionals and clients in an unprecedented time. Our recommendations will help sustain the fight against HIV in the United States in the midst of this pandemic, and future health emergencies

### ANNUAL COST FOR HIV PREVENTION & CARE

**20 BILLION**

PEOPLE LIVING WITH HIV

**1.2 MILLION**

NEW HIV DIAGNOSES

**36,801**

NEW CASES OF HIV OVER THE NEXT DECADE

**400,000**

HIV DIAGNOSES THAT ARE MEN WHO HAVE SEX WITH MEN (MSM)

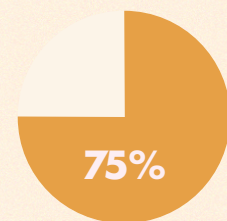
**69%**

### PRE-PANDEMIC STATE OF HIV IN THE US

In 2019, 1.2 million people were living with HIV in the U.S. and there were 36,801 new HIV diagnoses. Given the new cases of HIV annually it is estimated that without intervention nearly 400,000 more Americans will be newly diagnosed over the next 10 years despite the availability of tools to prevent transmissions. Sexual minority men (SMM) including gay, bisexual, and other men who have sex with men made up 69% of all new HIV diagnoses in 2019. The U.S. government spends \$20 billion in annual direct health expenditures for HIV prevention and care. There is a real risk of an HIV resurgence due to several factors, including trends in injection and other drug use; HIV-related stigma; homophobia and transphobia; lack of access to HIV prevention, testing, and treatment; and a lack of awareness that HIV remains a significant public health threat.

### PRE-PANDEMIC EHE HIV PREVENTION GOAL:

Ending the HIV Epidemic (EHE) Initiative focuses resources on areas where HIV transmission occurs most frequently, which funds communities to design and implement local programs to: Diagnose, Treat, Prevent, and Respond. The goal of the EHE is to reduce new HIV infections by 75% in five years and by 90% in ten years.



Reduction in new HIV by 2025



Reduction by 2030

### DISPROPORTIONATE IMPACT OF COVID-19 IN THE U.S.

**97,481,146**

COVID-19 Cases

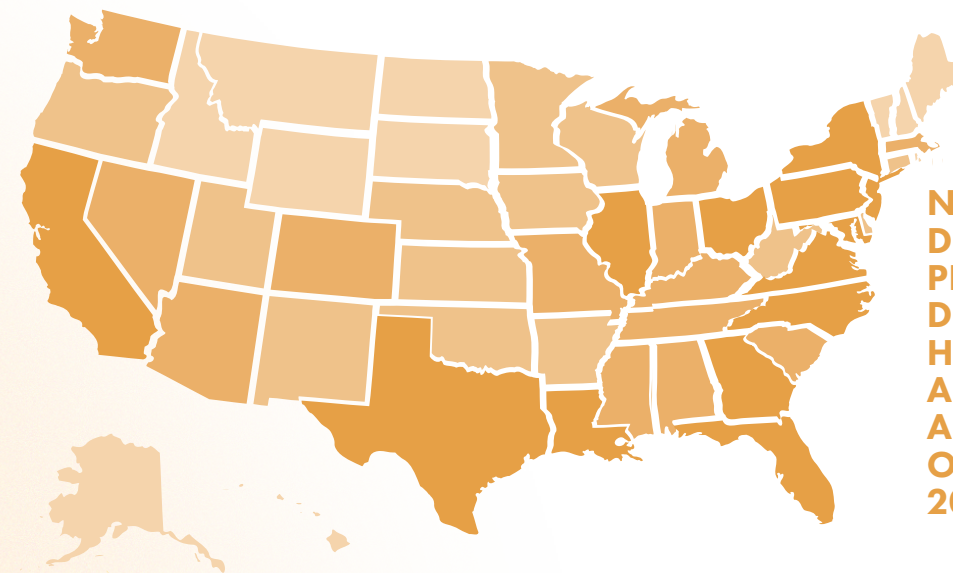
**1,078,457**

COVID-19 deaths

According to the CDC, racial minority communities in the U.S are 2-3 times more likely to be hospitalized and die due to COVID-19 complications compared to White, non-hispanic Americans.

### CAUSES OF DISPROPORTIONATE IMPACT

- Structural Racism
- Underlying health comorbidities
- Living in high density neighborhoods
- Employment in public-facing occupations
- Societal inequities such as limited access to COVID testing
- Disparities in COVID vaccination rates

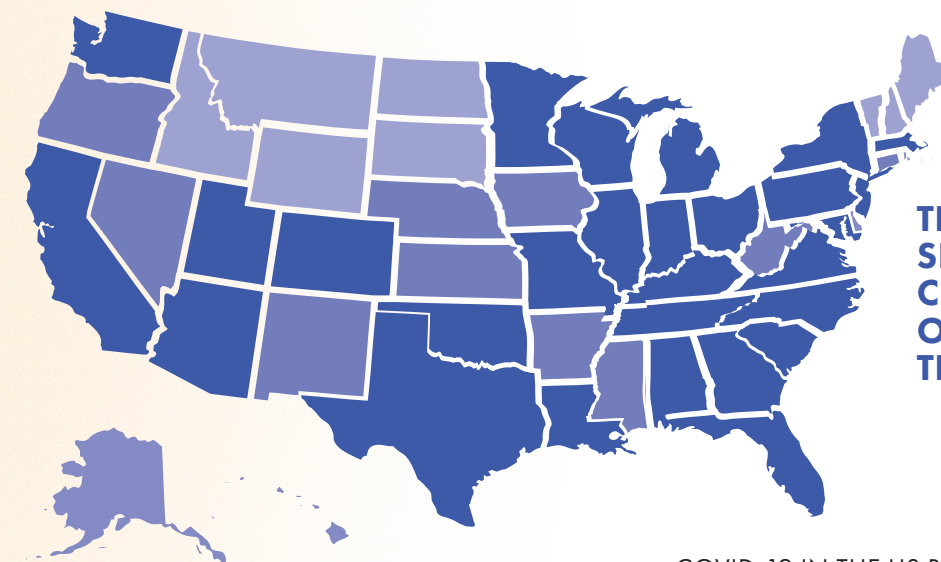


NEW HIV DIAGNOSES AND PEOPLE WITH DIAGNOSED HIV IN THE US AND DEPENDENT AREAS BY AREA OF RESIDENCE, 2020\*

### LEGEND

NEW HIV DIAGNOSES

- 0
- 2 - 72
- 81 - 320
- 326-773
- 881-4,378



TRACKING THE SPREAD OF THE CORONAVIRUS OUTBREAK IN THE US

### LEGEND

COVID-19 IN THE US BY STATE & TERRITORY

- 1 - 99,999
- 100,000 - 499,999
- 500,000 - 999,999
- 1 MILLION OR MORE

### EFFECTS OF COVID ON HIV

#### TESTING

- 68 - 97% reduction in HIV testing
- 17% decrease in HIV diagnosis

#### PREVENTION

- Surge of public information on COVID overshadowed other topics and health issues like prevention of HIV transmissions
- Client services were greatly reduced (or eliminated)
- 72% decrease in new PrEP initiation

#### CARE

- Detrimental impact on mental health
- Increased anxiety and depression
- Support services shuttered or not as utilized in a virtual environment
- Telemedicine - while an important bridge - wasn't as optimal as in-person

# INVISIBLE NO MORE: IN THEIR OWN WORDS

## PART 1

So, that's my take from my experience living with HIV during the COVID pandemic..., I became an invisible person by the medical community.

**- Person Living With HIV (PLWH), 32y, Western US**

Clients were not able to participate in support groups and therefore felt alone. Because they needed to have some sort of interactions with each other, support each other through this process. So, it was definitely difficult for them.

**— Community Based Organizer (CBO) Staff**

I had a friend who didn't get vaccinated and then caught COVID and they didn't want to tell me...the stigma of people not wanting to share their truth about whether they are vaccinated or not is similar to those people who are fearful of sharing their HIV status.

**— Gay Black Male, 40y, Western US**

Some people came in for HIV testing, but the numbers were definitely impacted for us and other agencies in the area. People were still concerned about COVID so they were hesitant to come in for testing. All testing [HIV/STIs] went down by 60%.

**— Community Based Organizer (CBO) Staff**

I did try telemedicine once or twice, but it was pointless ... they can't really examine you and they are hesitant to writing a prescription ... I just didn't find a good doctor. I have been with them for six months and I have changed doctors a lot ... and that is incredibly problematic.

**— Person Living With HIV (PLWH), Gay Black Male, 41y, Mid-Atlantic US**

Isolation became my enemy... with that came depression and anxiety and confusion about what was going to happen.

**— Person Living With HIV(PLWH), Gay Black Male, 36y, Southern US**

## ACKNOWLEDGEMENT OF LANGUAGE AND COMMUNITIES

A note on the term Hispanic: While not necessarily the term used by people of Latin American or Indigenous descent living in the U.S., it is the term sometimes used by entities conducting scientific and academic research, and thus referenced in this report.

## A NOTE ON BLACK COMMUNITIES FOR THIS REPORT

Identifying the race or ethnicity of a person or group of participants, along with other sociodemographic variables, may provide information about participants included in a study and the potential generalizability of the results of a study and may identify important disparities and inequities. The term "Black" refers to people of the African diaspora, no matter their nationality. While sometimes "African American" refers to people who were born in the United States and have African ancestry. While many people use the terms interchangeably. Black and African American are not always interchangeable. African American was typically used to refer to descendants of people from Africa who were enslaved. Some people may identify as African, Afro-Caribbean, Afro-Latino and many other races and ethnicities. Some people prefer the term Black because they do not identify as African and/or American, because they can't trace their lineage back to Africa or because being Black isn't just about race, it's an entire culture. Some still identify as Black and African American and use the terms interchangeably for themselves, depending on the situation.

## THE DISPROPORTIONATE IMPACT OF THE COVID-19 PANDEMIC

More than two years into the coronavirus (COVID-19) pandemic, the United States (U.S.) has recorded over 83.6 million cases, 4.7 million hospital admissions, and over 1 million lives lost (CDC, 2022). Various studies have shown a significantly higher rate of COVID-19 hospitalization and death among racial minorities in the U.S. [1-3]. According to the Centers for Disease Control and Prevention (CDC), racial minority communities (Black, Hispanic, and American Indian/Alaska Natives) in the U.S. are 2-3 times more likely to be hospitalized and die due to COVID-19 complications compared to White Americans. These outcomes are the result of structural racism limiting access to healthcare, and underlying health conditions (which include diabetes, asthma, hypertension, obesity, etc.) among racial minority communities in the

U.S., which are significantly associated with COVID-19 related hospitalization [4-6] and death [6-8]. Additionally, societal inequities such as limited access to COVID-19 testing [9], living in more crowded conditions and high density neighborhoods [10], being employed in public-facing occupations (e.g. restaurants, grocery stores, and transportation services) that prevent adequate physical distancing [10], amongst other factors, intensify observed racial disparity in COVID-19 health outcomes in the U.S. Additionally, there is a disparity in COVID-19 vaccination rates, with 87% of Asian, 67% of Hispanic, and 64% of White people having received at least one COVID-19 vaccine dose, higher than the rate for Black people (59%) as of July 11, 2022. (KFF, 2022)

### RISK FOR COVID-19 INFECTION, HOSPITALIZATION, AND DEATH BY RACE/ETHNICITY

Rate ratios compared to White, Non-Hispanic persons	American Indian or Alaska Native, Non-Hispanic persons	Asian, Non-Hispanic persons	Black or African American, Non-Hispanic persons	Hispanic or Latino persons
Cases <sup>1</sup>	1.5x	0.8x	1.1x	1.5x
Hospitalizations <sup>2</sup>	2.8x	0.8x	2.2x	2.1x
Death <sup>3,4</sup>	2.1x	0.8x	1.7x	1.8x



## THE PRE-PANDEMIC STATE OF HIV IN THE UNITED STATES

In 2019, before the start of the COVID-19 pandemic, there were 1.2 million people living with HIV (PLWH) in the U.S. with 36,801 new diagnoses that year. Sexual minority men (SMM) including gay, bisexual and other men who have sex with men are disproportionately affected by HIV, making up 69% of all new HIV diagnoses in 2019 [CDC]. Black SMM have a 1 in 2 lifetime risk of HIV diagnosis compared to 1 in 5 among Hispanic/Latino SMM and 1 in 11 among White SMM [11]. Additionally, a vast majority of the states with the highest lifetime risk of getting HIV were in the southern region of the U.S. [11]. There have been significant advancements in biomedical approaches to HIV prevention, treatment, and care including pre-exposure prophylaxis (PrEP) for affected communities, and antiretroviral medications for PLWH, which has helped slow the transmission of HIV, bringing us closer to achieving an HIV-free generation [12]. Also, in 2019, the U.S. Department of Health and Human Services launched the Ending the HIV Epidemic in the U.S. (EHE) initiative, which aims to reduce new HIV cases in the U.S. by 90% by 2030 by scaling up key HIV prevention, care, and treatment strategies. On World AIDS Day 2021, President Joe Biden announced a new strategy developed by the reestablished White House Office of National AIDS Policy, which places a particular emphasis on addressing racial (declaring racism a ‘public health threat’) and gender disparities in our health system, to ensure the HIV/AIDS response is truly equitable and meeting the needs of those most affected.

## NATIONAL HIV/AIDS STRATEGY TO END THE HIV EPIDEMIC IN THE UNITED STATES BY 2030:

- Incorporates the latest data on HIV incidence, prevalence and trends
- Expands the focus on addressing the social determinants of health that influence an individual’s HIV risk or outcomes
- Encourages reform of state HIV criminalization laws
- Adds a new focus on opportunities to engage the private sector in novel and important ways in the nation’s work to end the HIV epidemic

Source: <https://www.whitehouse.gov/briefing-room/statements-releases/2021/12/01/fact-sheet-the-biden-%E2%81%A0harris-administration-marks-world-aids-day-2021-with-renewed-commitments-to-ending-the-hiv-aids-epidemic-by-2030/>



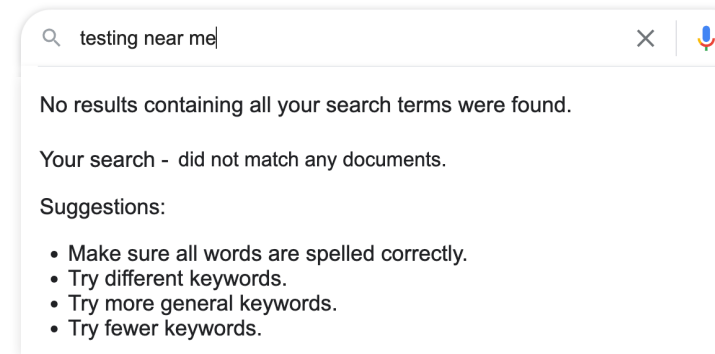
## THE INTERSECTION OF COVID-19 & HIV

The intersection between the HIV epidemic and COVID-19 pandemic, especially as it relates to communities that are most vulnerable to transmission and death, cannot be overstated. The HIV epidemic in the U.S. has disproportionately affected marginalized communities including racial/ethnic minorities, young people, sexual minorities (specifically gay and bisexual cisgender men and transgender women), and people who inject drugs. The same societal-level systems of oppression and marginalization that increase vulnerability to HIV such as racism, stigma, economic disenfranchisement, and neighborhood disadvantage have been implicated in the disproportionate impact of the COVID-19 pandemic [13]. For example, a study conducted in Wisconsin found that African Americans and those impacted by poverty were more likely to be hospitalized due to COVID-19 [14]. Another study conducted among patients admitted to the hospital with COVID-19 in Michigan found that neighborhood disadvantage (i.e. poverty rate, median income, and access to healthy foods), which is closely associated with race, is a predictor of poor clinical outcomes in COVID-19 (i.e. intensive care unit admissions and need for invasive mechanical ventilation) [15]. Additionally, studies found racial minority and poorer communities were less able to engage in the necessary COVID-19 mitigation strategies such as social distancing [16],

quarantining [17], and remote work [18]. Lastly, while the COVID-19 response, especially the rapid development of the COVID-19 vaccine, leveraged advances made within the field of HIV research and programming, there is still no viable HIV vaccine. All in all, the COVID-19 pandemic coupled with the existing HIV epidemic has disproportionately affected already marginalized communities, fueled by institutionalized structures of oppression that propagate inequity on the basis of race, gender identity, sexual orientation, socioeconomic status and also minoritized identities.

## EFFECTS OF COVID-19 ON HIV

The most recent CDC annual HIV surveillance report showed a 17% decrease in HIV diagnoses in 2020 compared to 2019 [CDC]. This downward trend was attributed to disruptions in HIV testing and clinical operations caused by the COVID-19 pandemic. Dr. Demetre Daskalakis, the director of the CDC Division of HIV/AIDS Prevention, described 2020 as 'a lost year' for the fight towards ending the HIV epidemic and added that "We don't really know where HIV transmission is going to land, but it's something that we obviously are concerned about." [NBC News]. The COVID-19 pandemic has upended the delivery of HIV testing, treatment, and care services, with consequences that will likely be felt for decades.



## TESTING

Testing is the first step in HIV prevention [19], as knowledge of one's status facilitates engagement in HIV prevention services for those who are negative and linkage to treatment services for people living with HIV. It also prevents the spread of HIV among people who are unaware of their status. Various studies have reported significant decreases in HIV testing rates across the U.S. [20-22] as a result of the pandemic. Specifically, a study conducted in four geographically diverse regions found between a 68-97% reduction in HIV testing rates during the stay-at-home order period compared to early 2020 (pre stay-at-home order period) [20]. In response to a decline in traditional, in-person HIV testing, HIV home-based self-testing programs were implemented by several health departments, CBOs, and health systems across the country [23-25], which showed high acceptability and utilization of these programs by affected communities [24, 25]. However, one major challenge of implementing home-based self-testing has been the collection and documentation of test results. While the COVID-19 pandemic has drastically affected HIV testing rates, self-testing both for HIV and other sexually transmitted diseases (i.e. syphilis, gonorrhea, & chlamydia) will provide a safe and convenient way of continued engagement in this major pillar of the HIV prevention continuum.

A study conducted in four geographically diverse regions found between a

**68-97%**

reduction in HIV testing rates during the stay-at-home order period compared to early 2020 (pre stay-at-home order period)

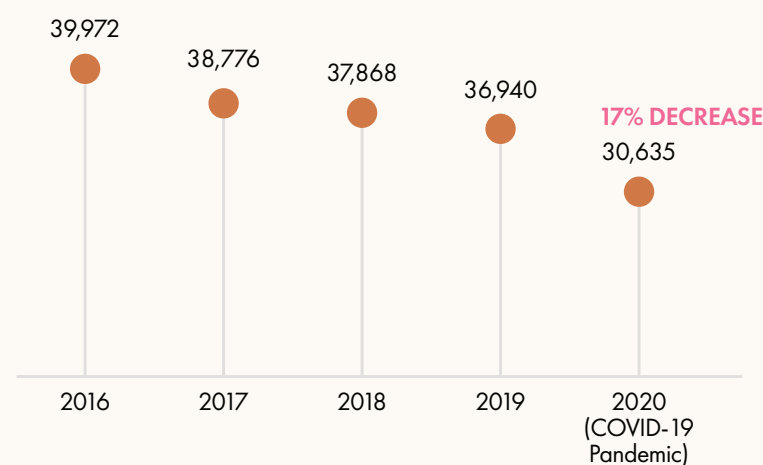
Source: Moitra, E., et al., Impact of the COVID-19 pandemic on HIV testing rates across four geographically diverse urban centres in the United States: An observational study. The Lancet Regional Health-Americas, 2022. 7: p. 100159

### HIV Diagnoses in the United States and Dependent Areas Over Time

likely due to disruptions in clinical care services, hesitancy in accessing health care services, and shortages in materials for HIV tests during the COVID-19 pandemic

Data for 2020 should be interpreted with caution due to the impact of the COVID-19 pandemic. For more information, view the report commentary section.

\* Among people aged 13 and older



Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2020. HIV Surveillance Report 2021;33.

## PREVENTION

The best approach to HIV prevention is a combination of condom distribution, health education, syringe exchange services, and initiation of and continued adherence to pre-exposure prophylaxis (PrEP; HIV prevention medication). Prior to the pandemic, these services were delivered primarily in person through clinics, hospitals, community centers, and outreach events in social spaces frequented by the target population (clubs, bars, bookstores, etc). Stay-at-home orders and widespread closings of social spaces due to the COVID-19 pandemic significantly affected access to HIV prevention services, and face-to-face client interactions were suddenly halted and transitioned to virtual spaces. These transitions, while seamless for some, have been difficult for others.

For example, a community- and primary care-based HIV prevention program for sexual minority men in New York went from servicing 2000 patients/day in person visits to under 100 through May 2020 [26]. During this time, telemedicine visits became and remains the norm for seeing clients. There were mixed results in how the COVID-19 pandemic has impacted engagement in HIV prevention services.

**Use of PrEP has been steadily building among men who sleep with men, a trend that began before the pandemic and continues to climb.**

**—Community Based Organizer (CBO) Staff**

A study conducted in three states found an increase in male PrEP visits during the pandemic compared to pre-pandemic period, a vast majority of them being telehealth visits [27]. Another study of a community-based clinic in Boston, MA found a 72% decrease in new PrEP initiations and 3-fold increase in lapses in PrEP refills among existing PrEP patients since the beginning of the pandemic [28].

**72%**  
**DECREASE IN NEW PrEP INITIATIONS**

**SOURCE:** Krakower, D., et al., Impact of COVID-19 on HIV preexposure prophylaxis care at a Boston community health center. *Journal of the International Aids Society*, 2020: p. 176-177

In our interviews, we heard the surge of public health information around COVID-19 overshadowed other important topics and health issues, including prevention of HIV transmission. Comparatively, people we spoke to in our qualitative interviews remarked that PrEP messaging directed at affected communities decreased as COVID-19 messages filled the public discourse.

These findings underscore the immense effects of the COVID-19 pandemic on access to HIV prevention services and the implications for those with limited access to these services pre-pandemic. Ensuring funding to keep PrEP low cost or free to patients is a long-term need. Without it, prevention of new HIV transmission could be in jeopardy. And, continued education about access to preventative medication like PrEP is needed, and could be incorporated into public health messages about COVID-19.

## CARE

Engagement in comprehensive HIV care services including adherence to antiretroviral medications, doctor visits, psychosocial services, and support groups is necessary to living and thriving with HIV. The COVID-19 pandemic has upended the ability for PLWH to adequately engage with these vital services. There is evidence about PLWH being more vulnerable to getting COVID-19. A systematic review examining the epidemiology of COVID-19 rates and mortality among PLWH found that PLWH had significantly higher risk of getting COVID-19 and mortality from COVID-19 compared to HIV-negative individuals [29]. Given that risk for severe COVID-19 (hospitalization, intensive care, ventilation, and death) is higher among people who are immunocompromised, continued engagement in HIV care services among PLWH is important amidst this pandemic.

**COVID actually made me be better about taking my HIV medications. I had never had a pill regimen before, so taking a pill every day wasn't something I was used to. But once the pandemic hit, I knew that I needed my immune system to be as strong as possible.**

**— Newly Diagnosed Person Living With HIV (PLWH), Gay Black Male, 25y, Southern US**

The pandemic surfaced many new or previously unacknowledged issues that required social or emotional support, including healthcare and wellness needs. In our interviews, many clients reported a heightened need for mental health services and support, particularly in-person, but lacked the resources (e.g. time, money, knowledge) to do so. The overall uncertainty of information about COVID-19 magnified health challenges, and caused increased anxiety and depression compounded by the isolation of working from home and the elimination of in-person social interactions. Some clients we spoke to found it difficult to establish relationships with new mental healthcare providers virtually, and even those that were already connected to support (e.g. therapists, 12-step programs) prior to March 2020 experienced an abrupt shift to virtual, which did not provide the same overall benefit as in-person.

**I used to attend support groups meetings for my 12 step programs a few times a week and, once the pandemic hit, they all stopped doing (them) so it was pretty difficult for me because they were my primary support system ... one later started to do video meetings, but it was just not the same.**

**— Person Living With HIV (PLWH), Gay Black + Latinx Male, 56y, Western US**

Lockdown and stay-at-home orders significantly affected access to HIV care services. A study of PLWH in an urban HIV clinic in the southeastern U.S. found a decrease in the number of outpatient medical encounters and new patient appointments but an increase in mental health encounters during the initial wave of the pandemic [30].

In our interviews, CBO staff mentioned that in-person support groups were difficult to replicate virtually, heightening the isolation and lack of support felt by clients.

Overall, focusing on funding and support for mental health services for PLWH and affected communities is critical. The compounding effect that the pandemic has had on mental health for PLWH and affected communities has created a need for more resources for CBOs and options to connect people to life-saving outreach and support.

Similar to HIV prevention services, there was an almost immediate pivot to telemedicine for the delivery of HIV care services [31]. While the transition from in-person to telemedicine delivery model for HIV care was found to be highly acceptable among PLWH [32-34], there were still concerns about lack of physical examination by a healthcare provider, privacy, technical issues, digital literacy [32, 33, 35]. In our qualitative interviews we found that people living with HIV and affected communities that entered the pandemic with established and trusted health care provider (HCP) relationships were better positioned to weather ensuing changes the pandemic caused. Clients we spoke to largely showed more resilience if they had strong sources of support from their medical team in place prior to March 2020, and shifting to virtual medicine may have been easier for clients who already had strong connections with their provider.

**I was diagnosed with HIV in November 2019, so I was just getting used to my medications when the pandemic came. I didn't have any interruptions in my care, though. I have a good relationship with my doctor. It wasn't hard to pivot to telehealth appointments when we had to**

**— Person Living With HIV (PLWH), Bisexual Black Male, 33y, Western US**

On the other hand, those without established supportive medical care relationships expressed a destabilization of support, exacerbated by having to engage in a virtual environment.



# INVISIBLE NO MORE: IN THEIR OWN WORDS

## PART 2

It's been very difficult to find a doctor and healthcare team that's supportive of my transition. I went through a lot of bad doctors before I started seeing one who was open to me and open to listening to me. I had to move back in with my parents. I've been purchasing HRT online since then, but it's very expensive. I really want to go back to my medical team

—**Trans Fem & NonBinary, Androphilic, Latinx, 25y, Southern US**

So definitely have a one-stop shop and have the medical provider on site. There are many aspects of getting somebody connected to care - we're going into PrEP, we have a case manager or, PrEP nurse and pharmacy, you know, all those things will really just make it better

—**Person Living With HIV (PLWH), Gay Black Male, 36y, Southern US**

I just realized now that you asked me this that for 6 to 9 months, I did not get tested at all, while I could not see my doctor. But I was never worried about it because my viral load had always been really low

—**Person Living With HIV (PLWH), Gay Black + Latinx Male, 56y, Western US**

I think that one thing I can say is that with all the advancement during COVID it has taken the focus off of taking PrEP for prevention

—**Person Living With HIV (PLWH), Gay Black Male, 36y, Southern US**

Once we got the mask mandate, I started my blood work again. I skipped during lockdown for 6 months, Luckily my numbers were in a good place

—**Person Living With HIV (PLWH), Gay Black Male, 36y, Southern US**

I started online counseling after I took a depression assessment through work, but it wasn't a great resource for me. I didn't feel like they "got" me, they weren't present in the way I needed them to be through the screen. I'm now looking for an in-person therapist I can go to, but it's difficult to schedule and connect with a therapist who has availability for new patients in my area.

—**Person Living With HIV (PLWH), Gay Male, 41y, Mid-Atlantic US**

For me I prefer to go to my doctor... it's part of my routine, the people are nice. I can honestly say my HCPs are like my family.... telehealth now is a backup

—**Person Living With HIV (PLWH), Gay Black Male, 32y, Western US**

The negative has just been the unknown...we didn't know anything about it...it kind of felt like we were being guinea pigs...I snapped into survival mode...I would do anything to stay alive....I don't have the leisure of not trusting a vaccine...it has to work for me

—**Person Living With HIV (PLWH), Gay Black Male, 36y, Southern US**

Understand that people were dying, and they had to slow COVID down somehow, but the focus went to COVID research and took away focus on things like cancer, HIV, diabetes

—**Community Based Organizer (CBO) Staff**

If they didn't go to work, they lost their jobs, but their jobs exposed them to COVID and because of the health disparities that you have with this population you had more deaths.

—**Community Based Organizer (CBO) Staff**

Initially I lost my job and they kept us on insurance a bit but then we had to pay, you would have to pay to keep the insurance going. It was very expensive and not enough with just unemployment. I only paid for a month and then it was too hard. A social worker helped with Ryan White funds to help pay some of the insurance. I don't have that same level of support in 2022. There are some funds for trans care, my hormones are covered by some grants. My therapist went virtual, still saw my infectious disease doctor in person but never met my Psych in person, only virtual. I prefer in-person but one of my mental issues makes it hard to have interpersonal relationships. I need you to be trusting and want my psychiatrist to confirm with the rest of my medical team.

—**Person Living With HIV (PLWH), Black Transgender Female, 28y, Midwest US**

## IMPACT ON COMMUNITY BASED ORGANIZATIONS

The role of HIV CBOs during the COVID-19 pandemic is of the utmost importance. Almost overnight, CBOs were forced to adapt the delivery of HIV-related services as a result of an unprecedented global event. Additionally, many organizations broadened their service offerings to include COVID-19 testing, distribution of food and other personal care items, and psychosocial health services, while dealing with staff shortage and budgetary restrictions [36]. The pandemic severely impacted how CBOs interface with their existing and new clients, with a pivot from in-person to more virtual channels of interactions [37]. While many shifted to remote work - or a rotation of remote and in-person schedules - this affected the availability of medical providers. One CBO we spoke to provided smartphone-type devices to clients that allowed HCPs to share medical information and connected clients to medical care without interruption.

**We provide Sano devices to [clients] – a phone they can specifically use for medical or emergency services. So we got those out to our clients. It was a small program before COVID and we expanded with COVID so that they could still meet with their doctor**

**– Community Based Organizer (CBO) Staff**

There was also a decline in the utilization of HIV testing and care services due to inability to conduct traditional community outreach and engagement events. However, as noted above, a pivot to telemedicine and social media allowed for continued engagement with clients.

## A FEW OBSERVED PARALLELS IN STIGMA

GLAAD conducts annual research around HIV stigma, to better understand how much stigma still exists, the challenges we must overcome to end HIV-related stigma, and what the impact is on those living with HIV. In our research we have found that less than half (48%) of Americans feel knowledgeable about HIV, and there is still unfounded fear about people living with HIV, even though those receiving proper medical treatment cannot transmit HIV. For more information on our HIV Stigma work please reference GLAAD's State of HIV Stigma Study at <https://www.glaad.org/endhivstigma>.

Through our qualitative interviews we heard people mention a few similarities between COVID-19 and HIV as it relates to the stigma that both viruses carry, much of it centered around an initial lack of education, and fear of transmission. People we spoke with referenced that both viruses carry some shame with people being judgmental of others and their choices, but in different ways.

Both COVID-19 and HIV are often incorrectly associated with behavioral decisions which result in blaming the individual for contracting the virus. And both can involve denial and a mentality that it can't happen to them, even among those communities that are most affected by COVID-19, as well as those most affected by HIV.

With COVID-19 the stigma has most often been associated with the unvaccinated, or those refusing to take precautions to avoid exposure.

Other parallels echoed in our interviews reference the initial government response to both viruses, the feeling that COVID-19 was ignored by leadership. This was a familiar feeling to those who experienced the early years of the HIV epidemic. Also, changing messages from leaders and experts regarding COVID-19 was a striking similarity, and led to further confusion, misunderstanding, and likely stigma in both cases. Recent mishandling of COVID-19 could also be a cause of further mistrust in the most impacted communities regarding government responses.

## COVID-19 VACCINE DEVELOPMENT

Through our interviews we heard that the development and approval of the COVID-19 felt "too quick". This caused hesitancy, distrust, and delay, particularly early on among Black clients, who recalled prior studies with a racist history.

**When the vaccine came out the first thing on my mind was Tuskegee, so I waited 8 to 9 months before I decided I needed to get vaccinated. There was a point that I just realized I needed to do it so I could be there to care for those who needed me**

**– Lesbian Black Female, 67y, Northeastern US**

Other reasons given in our qualitative interviews for initial mistrust and delayed vaccine adoption included misinformation from leadership, unclear messaging, and lack of diversity in messaging.

**At first when they came out with the vaccine, they would say 'go get vaccinated, protect yourself' but you looked around and everybody they used to communicate that were White people. They quickly learned and started to then show doctors, healthcare providers and people that looked like us, and that helped people of color, especially Latinos in my area to feel more comfortable**

**- Lesbian Black Female, 67y, Northeastern US**

Also, the initial lack of clear messaging that the vaccine didn't equate to complete prevention caused disappointment and frustration among vaccinated clients we spoke to that became infected with COVID-19.

Conversations with trusted and knowledgeable co-workers, healthcare providers, friends or family, in addition to the passage of time and seeing others get vaccinated, helped to assuage fears and mistrust. In our interviews, people remarked at how quickly the COVID-19 vaccine was discovered and deployed, a marked difference from the 41 year wait, and counting, for a vaccine for HIV. Though, we also heard optimism that the COVID-19 vaccine technology may allow for advancements in an HIV vaccine.

**I majored in biochemistry, so I understood how the COVID vaccines worked pretty well. I'm excited now, because they can start to test a HIV vaccine using the mRNA technology that they were able to use in the COVID vaccines. I know that HIV mutates too fast for traditional vaccines, so it's hard to develop a vaccine**

**– MSM, Latinx, 25y, Southern US**

# RECOMMENDATIONS

## 1. MORE FUNDING, AND UNRESTRICTED FUNDING IS NEEDED

Especially in communities where stigma may inhibit accurate information on risk and prevention.

- Guarantees of long-term funding to continue providing PrEP for free or low-cost remains a key need for CBOs serving affected communities
- CBOs need better access to unrestricted funds that will allow them to be flexible to the shifting needs of clients as a result of global public health crisis
- Increase financial support for minority-led, CBOs and AIDS service organizations that allow client-facing workers to earn a livable wage

## 2. LEVERAGE LESSONS LEARNED DURING THE PANDEMIC TO INNOVATE AND ADVOCATE

- Accommodate clients to prioritize maintaining consistent care, including solutions for internet access or ability to attend in-person appointments (i.e. Sano devices or similar technology to connect clients with HCPs)
- Invest in establishing stable support systems for clients to better protect against unexpected and uncontrolled future events that may shake up the healthcare system
- Support is also needed for client-facing staff who put themselves at risk of COVID-19 while maintaining in-person services to PLWH and affected communities

## 3. ADOPT A DIFFERENTIATED AND PERSON-CENTERED SERVICE APPROACH

- Provide a variety of services in one location (for example, having an onsite medical care provider such as a Nurse Practitioner who can prescribe PrEP and ARTs) to serve clients conveniently and efficiently, rather than direct them to new locations for different services
- Mental health services accessible on-site would likely better meet the demand, especially for individuals who have never utilized mental healthcare providers and would feel more understood and supported at a place they trust

## 4. COMPREHENSIVE PUBLIC HEALTH MESSAGES COULD INCLUDE COVID-19 VACCINATION AND PREP FOR PREVENTION

- The surge in public health information about COVID-19 can expand to help educate about preventing and treating other viruses including HIV
- Include target communities in both the development and dissemination of public health messages to strengthen trust and acceptance

## 5. CLEAR AND SIMPLE MESSAGING FOR FUTURE VACCINE ROLLOUTS

- Rather than focusing on a vaccine as being “new”, focus on how the technology has been utilized to reduce hesitancy and skepticism
- Leverage diversity of the community in message delivery; seeing doctors and leaders that resemble the full diversity of our community increases comfortability

## METHODOLOGY

For this report we conducted a comprehensive analysis of peer-reviewed scientific literature, combined with qualitative interviews of people living with HIV (PLWH), affected communities, and community-based organizations (CBOs) that serve these populations. We conducted 26 individual interviews (20 clients, 6 CBO staff) moderated by Ipsos, a leading market research company. The interviews with clients explored how the COVID-19 pandemic affected their access to HIV-related services, psychosocial services, and other support systems. The interviews with CBOs investigated how the needs of clients and organizations shifted during the pandemic, what impact COVID-19 had on services and program delivery, and explored areas of unmet need required to better support their client base. Each interview was conducted virtually and lasted about an hour. It is important to note that these interviews represent a qualitative perspective on the impact of COVID-19 on HIV testing, prevention, and treatment. The sample of respondents was designed to capture a range of individuals from the demographics most affected by HIV. The qualitative insights are intended to complement the literature review and are directional in nature.



## STATEMENT FROM IPSOS

**BETH BYRON**  
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CONSULTANT, IPSOS

It was a privilege to partner with GLAAD on this important research endeavor as the lead qualitative researcher for the Ipsos team. Our highly skilled group of qualitative researchers approached this collaboration with great interest, empathy and professionalism. The Ipsos team agreed from the outset that this was an incredibly personal topic and would be an appropriate application of our combined experience working in healthcare market research, conducting fieldwork among LGBTQ community members and international research experience on the impact of HIV. The qualitative component of this research engagement helps bring to life the voice of PLWH and affected communities to help us better understand the intersections of the COVID-19 pandemic with the HIV epidemic.

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The GLAAD Media Institute provides training, consultation, and actionable research to develop an army of social justice ambassadors for all marginalized communities to champion acceptance and amplify media impact.

Journalists and media interested in speaking to a GLAAD spokesperson, please inquire at [press@glaad.org](mailto:press@glaad.org). Those interested in learning more about the GLAAD Media Institute and its services including consultation, research and contextualized education, media and cultural competency training and more, please visit [glaad.org/institute](http://glaad.org/institute).

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