

# HIV Specialist

## Let's Talk About STIGMA

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## Addressing Stigma

**A**T THE CDC PREVENTION CONFERENCE in Atlanta in March, the most animated discussions seemed to revolve around the Administration's "End the Epidemic" plan, particularly the sociological problem of stigma, since—as we know—those who feel most stigmatized typically lose trust in the larger systems and fall out of care. Participants at that CDC conference persistently stressed the need to “quantify” stigma, with an eye towards *reducing* stigma in a measurable way as the path towards eventual elimination. The social factors that hamper care and treatment presumably can be measured and calculated; therefore, we should be able to statistically predict and measure impact on health. And yet, stigma by its own essence is so deeply personal.

Being a white cis-gendered hetero male, the pervasive endemic sense of feeling stigmatized for who I am is not something I share with marginalized groups. Many HCPs who treat patients with and at risk for HIV also express dismay for not being able to innately feel more connected. But all providers of care, regardless of their own demographics, have to understand and approach each patient personally, to listen much better, to make themselves available more often and to strive to understand individual struggles.

No one can ever feel someone else's pain, nor should they try to co-opt that pain and endeavor to feel it for someone else. Still, we must each consistently strive to understand and get a sense of what the lives of others are like, what it's like to be *them*, while also keeping an eye on what structural factors may be affecting that patient's trust and comfort in his or her healthcare environment. As Dr. Tonia Poteat points out in her blockbuster lead article for this issue, “structural level stigma is so much a part of our everyday lives that it requires conscious effort and close attention by each individual, in order to disrupt it.” This is the key message on stigma from my reading: Just being aware that social determinants of health and issues around stigma affect patient outcomes will not solve the problem; these factors must instead be actively perturbed on an individual level.

All of which is perhaps why I've never met a group of healthcare professionals so willing to question their own assumptions and experience on social issues as those who work in HIV. Even being on the front lines every day with



marginalized patients of color, economically disadvantaged patients, LGBTQ+ patients and so on, I have never encountered from members of AAHIVM any mien of being the undisputed “experts” on stigma and intersectional and structural inequalities. They will read the research articles, go to the workshops, avail themselves of the resources and pass along their real world experience to the next generation of providers in this space. The expert knowledge here is that, as long as stigma exists, there is always room to improve how we provide individualized care and

make a difference in patients' lives.

There is a place in this conversation too for technology and improved care and prevention systems that address some of these structural concerns. Every year, AAHIVM has issued an award for outstanding and novel technology in the delivery of HIV care, treatment, and prevention. In the pages that follow, we feature RipplePHX, our 2019 award winners, who created a mobile prevention kiosk that dispenses information on HIV risk, prevention, PrEP and other supportive services in the community. Meeting people with risk where they are with critical prevention information is another way that we can continue to address stigma around HIV and its risk factors.

As always, I'm personally inspired by the attention, hard work, innovation, investment, and passion demonstrated by all of the technology award applicants, as well as in our constituency of credentialed providers and AAHIVM members and others working in this space and fighting the effects of stigma every day.

HIV





# In the NEWS

## PrEP gets an A from the U.S. Preventive Services Task Force— Could Increase Uptake

**O**N JUNE 11, JAMA Network announced that the “U.S. Preventive Services Task Force (USPSTF) issued its strongest strategy yet for preventing HIV” by giving PrEP an “A” grade, its highest rating. They based their assessment on their “review of 14 randomized clinical trials, eight observational studies, and seven studies of diagnostic accuracy, which demonstrated that PrEP was associated with decreased risk of infection after four months to four years.”

The USPSTF, established by Congress in 1984 and supported by the Department of Health and Human Services staff, is made up of 16 volunteer members, most of them practicing clinicians.

At present, 1.2 million people in the U.S. are at relatively high risk of acquiring HIV infection but fewer than one-third of them are taking PrEP. Cost and access are inhibiting factors given that PrEP is expensive in the U.S. in the absence of insurance coverage or a copay assistance plan. The Affordable Care Act (ACA) requires that most private insurance plans and Medicaid expansion programs cover

the entire cost of medications that have a USPSTF A and B rating, with no ancillary cost sharing paid by the consumer. This new USPSTF rating, therefore, should facilitate much improved PrEP access for those enrolled in ACA plans and in those Medicaid expansion states.

Long-lasting PrEP injectables and implants are now being developed for people who prefer not to take daily pills. Uptake of generic PrEP (not available in the U.S.) is rising in countries where it is available at relatively low prices. The USPSTF rating can, we hope, promote access here by compelling more payers/insurers to cover PrEP without patient co-pays.

We also hope it will increase PrEP awareness among health care providers and address the concerns of those still reluctant to prescribe PrEP. In the words of Dr. Diane Havlir, a professor at UCSF and co-creator of the San Francisco Public Health Department’s “Getting to Zero San Francisco” Program, “I hope that with this recommendation we can garner momentum to bend the curve for new HIV infections in the U.S.”

## Connecticut to Make PrEP Available to Minors without Parental Consent

**C**ONNECTICUT’S GENERAL ASSEMBLY and Senate recently passed HB 6540 entitled “An Act Concerning the Prevention of HIV.” The bill allows Connecticut health providers to prescribe PrEP without parental consent to minors who disclose that they are at risk of HIV exposure and want PrEP for protection.

The state’s Health Department data show that 34% of people living with HIV in the state were young people and that HIV diagnoses in the state rose by 4% in 2017 (most recent data available). In testimony before the legislature’s Public Health

Committee, Health Commissioner Raul Pino said that the bill would, “increase access for minors to preventive care.” He also noted that, in 2004, the FDA had approved PrEP for all ages.

Last March, AAHIVM wrote to the CT Public Health Committee in support of the bill. We noted that, “HB 6540 essentially parallels the provision of contraceptive pills and emergency contraception to minors without parental consent. In both cases, youth seeking to protect their health are allowed to obtain and use the protection they need without parental

involvement, if necessary.”

Academy member Gary Spinner and his colleague, Dr. Kristyn Wagner, alerted us to this bill. Spinner wrote in his letter to the Committee that, “of the last 12 newly infected patients who have seen me, nearly all are young men of color who have sex with men.” They needed to be “able to discuss their sexuality with a health-care provider where they would not feel shame and to have access to sound HIV prevention education and access to PrEP.”

Connecticut Governor Ned Lamont is expected to sign the Bill into law soon.

# In the NEWS



## Making Trans Women Count in HIV Vaccine Trials

**A**N ANALYSIS CONDUCTED BY THE HIV VACCINE TRIALS NETWORK (HVTN) observed an overall increase in the proportion of racial and ethnic minorities enrolled in Phase 1 and Phase 2A preventive HIV vaccine clinical trials in the United States between 2002 and 2016 compared to 1988 to 2002. The findings were published on December 5, 2018 in *Public Health Reports*.

Among the 3,469 study participants enrolled from 2002 to 2016, 33 percent identified as a racial and/or ethnic minority compared with 17 percent among 3,731 participants enrolled during the period 1988 to 2002, a two-fold increase overall.

<https://www.hvtn.org/en/media-room/news-releases/mind-the-gap.html>—release dated Feb 2019 but bodypro covered it last month.

## Medicare Part D “Protected Classes” Receive Reprieve from Proposed Changes

**A**AHIVM CELEBRATED THE RECENT DECISION by the Centers for Medicare and Medicaid Services (CMS) regarding Medicare Prescription Drug Plan (Part D). CMS retracted its proposal to introduce changes that would have created barriers to accessing critical HIV drug therapies. Nearly 25% of people living with HIV in the U.S. rely on Medicare as their medical insurer.

According to CMS’s announcement, the Department of Health and Human Services (DHHS) will continue to require that Medicare Part D plans cover all (or virtually all) HIV antiretroviral drugs without prior authorization and step therapy. Retraction of these two barriers will apply to all Medicare patients living with HIV, including new, treatment-naïve patients.



## San Francisco Leads the Way in Safe Injection Sites

**L**AST MONTH, THE CALIFORNIA STATE ASSEMBLY passed (by 44-26) legislation to allow San Francisco to open a Safe Injection Site (SIS), despite the federal Justice Department's contention that such facilities are illegal. The Mayors of both San Francisco and Oakland (where the state's first SIS will likely be located) strongly support the bill and Governor Newsom is committed to signing it if it passes in the state Senate. State Senator Scott Weiner observed to the press on May 25th that, "California legislators tend not to be intimidated by the Trump administration."

Earlier this year, the Academy's Board of Directors decided to support SIS as a legitimate tool for HIV and hepatitis C prevention. We agreed, on the basis of evidence, that SIS clearly reduce overdose deaths, help to improve users' health and encourage people with substance use disorder to consider treatment. Despite this, the Department of Justice strongly opposes their legalization.

Nevertheless, several U.S. cities are moving toward SIS, including Ithaca (New York), New York City, Denver and Seattle. Philadelphia has been leading the way for the last two years with a project called Safehouse. Over 3,000 people died of opioid overdose in Philadelphia in the last three years, the highest number of any city in the U.S. The opening of Safehouse is a goal supported by the Mayor, the District Attorney, the City Council, the City Health Department and numerous community, public health and religious organizations.

Last year, the federal Department of Justice sued Safehouse to block its opening. U.S. Attorney William McSwain argued that the existence of Safehouse would violate the 1986 law against maintaining a place for the use of controlled substances and could result in up to 20 years imprisonment.

Ronda Goldfein, Executive Director of the AIDS Law Project of Pennsylvania and Vice President of the Safehouse board, responded to this last September by applying for a tax-exempt status from the Internal Revenue Service. She described Safehouse as "formed to mitigate a national health crisis which is hitting residents of the city of Philadelphia particularly hard." Last week, the non-profit status was awarded by the IRS.

This not only enables Safehouse to solicit tax-exempt donations from supporters but also puts two sectors of the federal government at odds with each other. Safehouse contends that it will provide overdose prevention and harm reduction services—all of which are legal. The IRS has validated this definition by recognizing Safehouse as a legitimate non-profit organization.

While this legal dispute drags on, Safehouse is also addressing the problem of Philadelphians who appreciate the value of SIS but do not want such a service in their neighborhoods. One possible response under consideration is the conversion of vans into mobile clinics—as is done during blood donation drives. SIS is already being provided via vans in other countries including Germany, Spain and Canada. As the Philadelphia Inquirer wrote on its editorial page, "If a brick and mortar site is what's standing in the way of allowing a supervised injection site to save lives, we should instead put it on wheels."



By TONIA POTEAT, PhD, MPH, PA-C, AAHIVS and  
LINDA WESP, PhD, RN, FNP-C, AAHIVS

**M**ARIA HAS BEEN A PATIENT AT YOUR CLINIC FOR TWO YEARS and has never missed a visit. Thirty minutes after her appointment time, you notice that she has not yet checked in, and you begin to worry. You approach the medical assistant who lets you know that she called “Brian’s” name, but no one responded, so she marked “him” as a no-show. You point out the tiny area on the EMR screen that indicates that the patient’s chosen name is Maria. The medical assistant feels terrible that she missed this and immediately goes back to the waiting room to call the patient by her chosen name. However, no one responds. When you telephone Maria to follow-up, she is quite upset. She reports being present for her appointment and being so horrified when she heard her “dead name” being called out, that she left in shame. She doesn’t understand how this could have happened and hesitates to reschedule her appointment, stating she no longer feels safe at the clinic. Maria has challenges finding an affirming clinic environment and eventually falls out of care altogether.

The case scenario above illustrates how institutional systems can foster stigma and present barriers to providing quality care, despite the good intentions of individuals within those systems.

### What is stigma?

Stigma is the process, both intentional and unintentional, by which certain groups are devalued through the exercise of power.<sup>1,2</sup> Stigma can be complex for people living with HIV who deal with HIV-related stigma in the context of *structural* and *intersectional* stigmas.<sup>3</sup> *Structural stigma* refers to the ways in which stigma operates at the societal level (such as cultural norms, laws, policies, or procedures) that limit opportunities and have a negative impact on wellbeing.<sup>4</sup> *Intersectional stigma* describes how multiple, interconnected stigmas mutually reinforce one another to limit opportunities for some while maintaining privilege for others. For example, people may experience stigma based on HIV status, race/ethnicity, and gender identity all at the same time.<sup>5,6</sup>

While HIV care providers may be most familiar with the consequences of HIV-related stigma, other forms of stigma are also an insidious component of our society. These forms of stigma can result in health-care experiences that do not feel safe for people seeking HIV care. As illustrated in the scenario above, a common procedure, like the use of an electronic medical record (EMR) that does not provide clear documentation of chosen name and pronouns, may result in transgender individuals feeling unsafe and disengaging from care. Awareness of the ways stigma can impact safety within the healthcare encounter requires an understanding about how these structural factors impact our care.

*Culturally safe care* is when we make a conscious effort to make health-care safe from harm by becoming aware of our own individual biases and assumptions, as well as understanding the structural and intersectional

# The HIV Care Provider’s Role in Reducing

How to challenge  
institutional norms  
to improve care for  
patients living  
with HIV





STIGMA

stigmas that perpetuate inequalities in healthcare.<sup>7,8</sup> For example, transgender people experience discrimination from friends and family, but also face multiple barriers at the larger societal level, such as difficulty accessing public facilities and discrimination in employment.<sup>9,10,11</sup>

Another example is how people of color face commonplace racial indignities (i.e. microaggressions), which can result in ongoing chronic stress and inequities in care provision.<sup>12,13</sup> Understanding the ways that multiple layers of stigma exist is important, so we can avoid unintentionally perpetuating these harms when marginalized groups are accessing healthcare.

As demonstrated in the case scenario above with Maria, healthcare environments can be unsafe for transgender people because systems, policies, and procedures have been implemented without an awareness about gender diversity.<sup>14</sup> In other scenarios, it may be unconscious racism that is impacting provider decisions about who may be “at risk” for certain conditions or appropriate for certain interventions because of the color of their patients’ skin.<sup>15</sup>

For example, as illustrated in the case scenario above, healthcare providers are operating within a system that assumes everyone is cisgender. Thus, the field for chosen name is very small and off to the side of the patient chart or EMR. As the medical assistant in the case scenario found out, following the habitual approach to calling the patient, e.g. going along with what the system expected (using the name in large font at the top of the chart) actually was incorrect and had long lasting negative consequences.

Another example might be to question how and why we include certain information in our medical charting, such as patient pronouns or a patient’s race/ethnicity. Many electronic medical records pre-populate the clinical note with pronouns that are automatically attached to the legal gender marker in the system, which can lead to an entire note with the incorrect pronouns. Additionally, many providers were taught to chart chief complaints such as, “African-American female presents with a sore throat.” Research has demonstrated providers’ unconscious bias based on a patient’s skin color, such as



**Truly reducing stigma within HIV care settings requires consideration of how structural stigma works to impact our interpersonal interactions. Maintaining vigilant awareness about personal implicit biases and prejudices is an important place to start because without self-awareness, it is difficult to even name and notice the larger power dynamics at play.**

As Young suggests in *Responsibility for Justice*, interrupting stigma requires self-reflection about how our individual actions might be reflecting the larger societal norms and perpetuating marginalization (even when our actions are intending to help and not harm).<sup>16</sup> Structural level stigma is so much a part of our everyday lives that it requires conscious effort and close attention by each individual, in order to disrupt it.

HIV disproportionately impacts communities facing structural and intersectional stigmas.<sup>17-19</sup> These same communities face ongoing structural barriers to accessing HIV testing, linkage to care, and treatment.<sup>20,21</sup> It is our responsibility as healthcare providers to ensure experiences within healthcare are as safe and free from structural harms as possible. To do this, we can examine our reactions and interactions with individuals from marginalized populations. We can examine the technology we use and our institutional policies and procedures. We can pay attention to the ways our own actions and the systems that we work within may create a power dynamic that adversely impacts people who are already marginalized. Once we notice the ways potential marginalization can occur, we can begin to change them.

presuming that people of color have a higher pain tolerance and thus providing less pain medication or underdiagnosing serious illnesses.<sup>15,22</sup> We can ask why we might be including this person’s gender or race in the chief complaint section of this acute care visit. How do these facets of a person’s identity impact this visit or the workup for this chief complaint?

### **How does stigma impact health of people living with HIV?**

A recent meta-analysis looked at relationships between HIV stigma and health outcomes among studies of people living with HIV.<sup>23</sup> Sixty-four studies were included with a total sample size of over 20,000 participants. HIV-related stigma was associated with poorer mental health, including depression; lower quality of life, lower levels of social support; and poorer self-rated general health.

In addition, people who experienced HIV-related stigma were 21% less likely to access or use health and social services and were 32% less likely to adhere to antiretroviral therapy. This study provided an important synthesis of the impact of HIV stigma; however, it did not disaggregate the impact of



provider and/or institutional stigma nor address intersectional stigma.

A qualitative synthesis of 55 studies among people living with HIV illustrated ways in which institutional practices can be stigmatizing, even if this was not the intent.<sup>24</sup> Behaviors that may seem benign to the medical staff may be experienced as stigma, particularly if the actions mirror discrimination experienced in larger society. HIV-related stigma frequently intersects with other forms of marginalization. A quote from the qualitative synthesis illustrates this point well: “The hospital treats you bad. There are attitudes and gestures toward me being black, HIV positive, gay and a recovering drug user.” (African-American Male quoted in Cain (2001), p. 301).<sup>24</sup>

The healthcare environment is an institutional structure where larger social values and dynamics of power play out. Consequently, stigma against people living with HIV manifests through individuals and systems to whom people with HIV are expected to entrust their health. Experiences of stigma within healthcare environments deter care utilization, leading individuals to avoid the clinic or hospital that stigmatized them or to stay away from healthcare environments altogether. As Nyblade and Stockton so eloquently state in their stigma review, “stigma in health facilities is particularly egregious, negatively affecting people seeking health services at a time when they are at their most vulnerable.”<sup>25</sup>

### What can HIV care providers do about it?

Compassionate healthcare providers are an essential component of the support systems of people with HIV. Non-judgmental attitudes from healthcare workers are fundamental to creating a safe space for people with HIV. Supportive attitudes facilitate care seeking behaviors, motivate adherence, encourage communication, and decrease social isolation and exclusion.<sup>24</sup> In addition to informing the development and evaluation of training and interventions in healthcare settings, provider stigma and/or microaggression assessment scales delivered routinely can encourage regular self-evaluation of stigmatizing attitudes and behaviors among healthcare providers.<sup>26,27</sup>

Truly reducing stigma within HIV care settings requires consideration of how structural stigma works to impact our interpersonal interactions. Maintaining vigilant awareness about personal implicit biases and prejudices is an important place to start because without self-awareness, it is difficult to even name and notice the larger power dynamics at play. Devine and colleagues have created an intervention geared specifically to reduce unconscious racial bias, which has shown through randomized controlled trials to reduce implicit bias over time.<sup>28</sup> More information about the intervention can be found at <https://breakthe prejudicehabit.com/>.

Similarly, our research found that due to social and institutional stigma, healthcare providers often receive little or no training about transgender people and their health concerns.<sup>29</sup> This leads to ambivalence and uncertainty when transgender people present for medical care, upsetting the

normal balance of power within the provider-patient encounter.

When providers were uncertain and ambivalent, they were more likely to act in stigmatizing ways towards transgender patients, perpetuating the cycle of systemic and interpersonal stigma. A growing body of educational materials are available for healthcare providers to increase awareness about the diversity of human gender experiences and improve our ability to provide evidence-based and high-quality care for transgender patients. The World Professional Association for Transgender Health (<https://www.wpath.org>) and the UCSF Center of Excellence for Transgender Health (<http://transhealth.ucsf.edu>) both provide training opportunities and guidelines for healthcare providers.

Another important resource is *TransLine*, a transgender medical consultation service <https://transline.zendesk.com/hc/en-us>. This program provides a warehouse of information about all aspects of gender affirming and primary care for transgender patients, including the ability to submit a request directly through the website, where experts reply to requests for consultation about specific patient scenarios.

Addressing stigma at the institutional level can seem challenging. However, scientific evidence supports the efficacy of multiple stigma reduction interventions. A recent systematic review identified studies of 42 unique interventions tested in the prior five years addressing HIV, mental illness, and/or substance use stigma.<sup>25</sup> Key strategies included information provision, skills-building, participatory learning, contact with the stigmatized group, empowerment of the stigmatized group, and structural/policy change.

Another recent systematic review focused solely on HIV stigma, identified eight studies, and found some evidence for information-based interventions, structural interventions, biomedical interventions (e.g. universal versus targeted HIV testing), skills building and contact strategies.<sup>30</sup>

As we saw with the case of Maria, a lack of awareness about the ways that our systems are defaulted to creating stigmatizing interactions means we may not know about the problems until a patient has been harmed. Understanding how stigma is rooted in larger societal ideologies and



permeates our institutions is a start. HIV providers can begin to analyze the reasons why our healthcare systems may be inadvertently perpetuating harm. Creating culturally safe environments, through self-reflection and taking action at the larger institutional level, can disrupt these experiences of stigma within our healthcare system.

### Where can I find tools/resources?

Below are a select set of tools and resources that healthcare providers can use to address stigma at the individual as well as institutional levels.

- Reducing Implicit Bias: <http://www.ihl.org/communities/blogs/how-to-reduce-implicit-bias>
- Creating Equitable Health Systems: <http://www.ihl.org/resources/Pages/IIHWhitePapers/Achieving-Health-Equity.aspx>
- Training materials to reduce HIV stigma among health facility staff:<sup>31</sup> <https://www.healthpolicyproject.com/index.cfm?id=stigmapackage>
- Training materials to reduce gender and sexual diversity stigma:<sup>32</sup> <http://www.healthpolicyproject.com/index.cfm?id=GSDTraining>

<http://www.ihl.org/communities/blogs/how-to-reduce-implicit-bias>

- Strategies to improve racial equity: <http://www.racialequitytools.org/act/strategies/training-and-popular-education>

HIV



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# PrEPFacts and PleasePrEPMe

## Clinicians' Partners in Eradicating PrEP Stigma

By DAMON L. JACOBS, LMFT, LAURA LAZAR, MPH, and CHARLIE ROMERO

**S**TIGMA ABOUT PREP USE is well-documented at both the social and provider level.<sup>1-3</sup> This stigma is a barrier to potential PrEP users being aware of, starting, and adhering to this safe and highly effective HIV prevention method.<sup>4,5</sup> With the proven biomedical tools to end the epidemic already in our hands, all health advocates—providers included—must take a conscious role in stemming the flow of misinformation and shame experienced by people attempting to invest in their own sexual health and wellbeing.

Increasingly, people of all races, notably Black and Latinx Americans, are seeking such health information online.<sup>6,7</sup> PleasePrEPMe.org and the “PrEP Facts: Rethinking HIV Prevention and Sex” Facebook group (PrEPFacts) are two services utilizing online platforms to address some of the confusion, barriers, and stigma surrounding PrEP use.\*

PleasePrEPMe links PrEP/PEP seekers with evidence-based information and resources through English and Spanish online chat with a trained navigator. The navigator provides support and guides consumers through the complicated insurance and healthcare systems to help facilitate access to PrEP services. This person-centered chat service offers a space that can be as anonymous as the visitor prefers. No major identifying information is required to chat. PleasePrEPMe also works with the state of California's PrEP assistance program (CA PrEP-AP) and is able to assist people with a variety of complex payor systems and other coverage needs.

Since 2013, PrEPFacts has utilized social media networking to crowd-source evidence-based, sex-positive information as well as compassionate peer-to-peer support surrounding PrEP use, side effects, and access. Currently receiving an average of 5,000 visits per day, the PrEPFacts Facebook group offers a unique opportunity to share members' experiences with PrEP in their daily lives and receive ample emotional support and encouragement from peers. Members frequently post screenshots from hurtful online conversations. Painful interactions with misinformed or

unsupportive healthcare providers are also reported.

At PleasePrEPMe, chat visitors often report hesitation to speak with their primary providers about PrEP, predominantly for fear of being judged for their sexual activity and/or sexual orientation. Some have been told by providers that they don't need PrEP, based on the providers' assumptions about their sexual practices. One visitor reported their doctor counseled them to “just take PEP” should an emergency situation occur. Still others have erroneously been given referrals to clinics that only serve people living with HIV.

These anecdotal experiences highlight that providers are not immune to the effects of implicit bias.<sup>8,9</sup> This may result in providers inadvertently expressing their personal morals and attitudes about their patients' sexual behavior (whether it is “risky” or “not risky enough,” and what specific acts make it so<sup>3</sup>) and making empirically incorrect assumptions about risk compensation.<sup>10</sup> Research has shown that when compared by race, Black patients are rated as more likely to engage in risk compensation than White patients.<sup>11</sup> Misinformation about PrEP, HIV prevention, and sexual health contributes to the many barriers PrEP candidates face in trying to avoid HIV infection.<sup>3</sup>

Oppressive attitudes towards sex, pleasure, and HIV are deeply entrenched (and even celebrated in the current political climate). With PrEP, providers have a unique opportunity to support and guide patients as they take charge of their sexual health and engage them in ongoing medical care—perhaps for the first time. PrEP care encourages a collaborative relationship grounded in a patient's ability to prevent a chronic

\*The authors recognize that PrEP stigma, while often abusive, painful, and grounded in ignorance and misunderstanding, is not the same as the stigma imposed on people living with HIV and is not compounded by the same extensive, systemic limitations.<sup>12</sup>

illness and proactively take steps toward maintaining health and wellness.

A growing community of well-informed and compassionate healthcare providers is seeking to empower their clients' sexual health choices through a whole-person approach to PrEP care that starts the minute their staff answer the phone. All providers in the PleasePrEPMe directory were voluntarily added by clinic staff, which speaks to this community's eagerness to facilitate greater PrEP access.

Services like PleasePrEPMe and PrEPFacts strive to lift up and support the daily work of those on the front lines. Up to 40% of PleasePrEPMe's chat visitors are clinic workers—22% of whom are clinicians—who visit the web site seeking educational materials and trainings to help them alleviate PrEP access issues for their clients. PleasePrEPMe aims to support providers by developing and hosting a wealth of resources for clinic staff of all levels. Their staff also conduct regular one-on-one outreaches to clinics to offer support and link to capacity-building resources.

Through the PrEPFacts community, members learn tips for communicating about PrEP successfully with friends and partners, gain emotional support when they have been attacked online or on hookup apps for disclosing their PrEP usage, and learn how to address concerns with medical providers. Members are also able to share positive experiences they have had with providers which have facilitated long-lasting, trusting relationships. Examples include, "They don't make assumptions about what my life looks like or what I do or don't do;" "They appear to genuinely appreciate seeing me. They accept me as a partner in my care;" "There is a lack of judgment and not issuing moral prerogatives;" and "Not demanding I use condoms 100% while normalizing STIs as a normal part of sexual behavior."

The services PleasePrEPMe and PrEPFacts offer to providers and PrEP candidates can function as a bridge, providing support in the time between PrEP contemplation and initiation. By educating potential PrEP users about HIV prevention options and linking them with services, PleasePrEPMe and PrEPFacts help providers transition consumers along the continuum of PrEP care, and also contribute to an informed "head start" before PrEP seekers even set foot in the clinic.

While providers, PrEP navigators, and advocates continue to work together toward systemic change in attitudes and access to sexual wellness, the safe spaces that services like PleasePrEPMe and PrEPFacts offer allow

confidential access to scientifically sound information and vetted resources. In these spaces, visitors do not need to fear being shamed for who they are, the sex they choose to have, and the questions they want to ask. It is our hope that these supportive attitudes continue to become common offline, in health care settings, as well as in the online realm.

The goal of ending the HIV epidemic is within reach, but stigma continues to impede our progress. It is essential that providers at all levels serve as trusted allies and champions of their clients' sexual health and HIV prevention needs—and services like PrEPFacts and PleasePrEPMe are here to help.

**HIV**



#### ABOUT THE AUTHORS

**Damon L. Jacobs** is a New York-based Licensed Marriage and Family Therapist and HIV prevention specialist who focuses his work on sexual wellness, relationships, and harm-reduction. He is best known for championing the use of pre-exposure prophylaxis (PrEP) in *The New York Times*, *USA Today*, *MSNBC*, *NPR*, *Vice News*, and more. He has presented on clinical approaches to PrEP and Harm Reduction at The U.S. Conference on AIDS, CROI, The NMAC Biomedical Prevention Summit, Creating Change, Harm Reduction Coalition Conference, The CDC National HIV Prevention Conference (NHPC), The International AIDS Society Conference (IAS), and more.



**Laura Lazar** has been Coordinator at [PleasePrEPMe.org](http://PleasePrEPMe.org) since Feb 2017. Prior to PleasePrEPMe she was the Program Coordinator for Research and Data Analytics at AVAC in New York and completed a policy fellowship with amfAR in Washington, DC. She graduated with an MPH from Columbia Mailman School of Public Health in 2015.

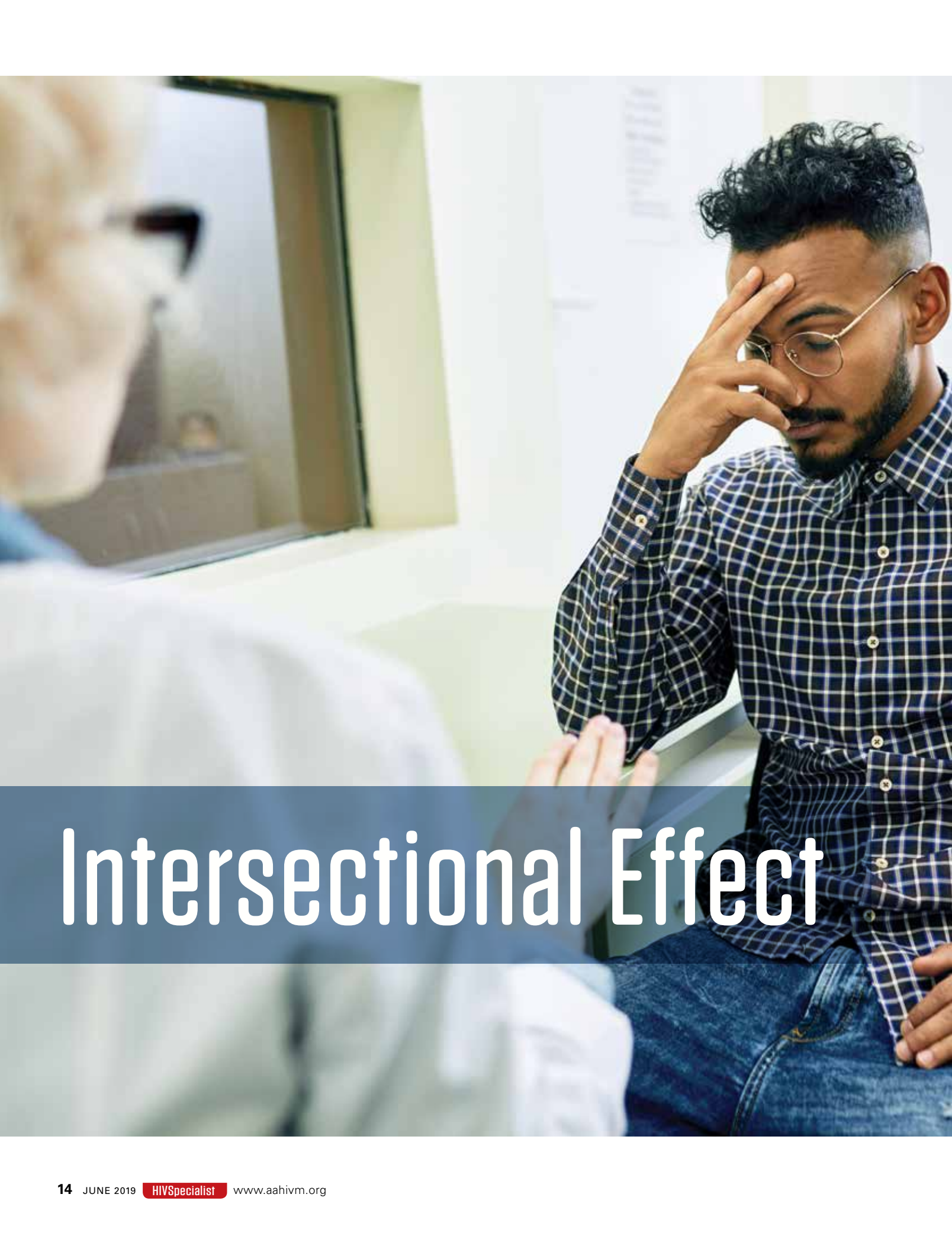


**Charlie Romero** is a PrEP Navigator at PleasePrEPMe.org, offering virtual support and guidance to people seeking PrEP services throughout the state of California. This includes sexual health education, HIV prevention and financial assistance in English and Spanish. His career in prevention began in the early 2000's providing LGBTQ youth HIV education/ counseling and support group facilitation for people living and affected by HIV at the largest Latinx focused HIV prevention organization in the nation. He then became a national certified phlebotomist at one of the top Children's Hospitals in the U.S., where he continued providing prevention services as well as PrEP and PEP navigation services till 2016. Now at PleasePrEPMe.org, he is committed to providing education through non-traditional settings.

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# Intersectional Effect





# HIV-related Stigma as a Determinant of Health Among Sexual and Gender Minority Latinxs

By OMAR MARTINEZ, JD, MPH, MS

**S**EXUAL AND GENDER MINORITY LATINXS (SGML) continue to be disproportionately impacted by HIV. While new HIV diagnoses stabilized for gay and bisexual men from 2012-2016, they increased by 12% during this period for Latinx gay and bisexual men.<sup>1</sup> According to U.S. epidemiological data, Latinx transgender individuals are also disproportionately impacted by HIV.<sup>2-5</sup> These disparities among SGML are the products of, and exacerbated by, social and structural conditions, including poverty, HIV-related stigma, discrimination, documentation status, lack of access to healthcare, and anti-immigration rhetoric.<sup>6-9</sup>

Among these conditions, HIV-related stigma serves as a determinant of health among SGML.<sup>10, 11</sup> HIV-related stigma includes negative attitudes and beliefs directed at people living with HIV (PLWH) and/or associated with PLWH. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable.<sup>12, 13</sup> Given the pervasive impact of HIV-related stigma on overall health, we urge researchers, clinicians, health and social service providers, policy makers, and multi-sectoral community stakeholders to implement programs and interventions that address HIV-related stigma and disparities in HIV/AIDS.

## Intersectional Stigma

A discussion on HIV-related stigma should be framed within an intersectional approach. The concept of intersectional stigma examines the juncture of multiple stigmatized identities that fall across categories, such as co-occurring health conditions (HIV, mental illness and substance use); sociodemographic characteristics (racial, ethnic, gender, sexual orientation and immigration status); and behaviors/experiences (substance use, sex work, and pre-and-post migration experience).<sup>14, 15</sup>

Through syndemics theory, research has documented that pervasive psychosocial (depression, substance use,

experiences of childhood sexual abuse) and structural/social conditions (discrimination, HIV-related stigma, violence, history of incarceration) exist among SGML, and that the interplay of these conditions exacerbate HIV risk and HIV transmission.<sup>2, 6, 7</sup> Syndemics theory posits that multiple risk factors interact synergistically to increase vulnerability; diseases and social conditions not only co-occur, but also interact with one another, making the cumulative impact of co-occurring conditions greater than the impact of each condition alone.<sup>16</sup>

A participant from one of our studies mentioned, *“As trans individuals, we are constantly challenged by discrimination, stigma, violence, homelessness, and lack of comprehensive trans care. Support is needed to navigate through legal and medical systems, like name change and access to hormones and affirmation surgery”* (Laritza, Latinx, 30). Another participant further expanded on the role of stigma amongst healthcare providers *“When I changed my name, a nurse insisted on calling me ‘he’ when that made me uncomfortable. I consider myself a woman”* (Jen, Latinx, 26).

In particular, our research has documented the detrimental impact of the processes of immigration on health and wellness.<sup>17-19</sup> For sexual and gender minority immigrants, anti-immigration rhetoric is often linked with HIV acquisition and transmission, delays

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in HIV prevention and treatment, substance use, negative mental health outcomes, and isolation. One participant commented “Many people won’t go and seek out services because they are afraid it will affect their immigration status...for fear of being found out as undocumented individuals, they don’t seek help” (Alex, Latinx, 45).

### Programs, Interventions and Initiatives to Address HIV-Related Stigma

Several programs and interventions have proven to be feasible and acceptable, efficacious and/or effective at reducing HIV-related stigma and disparities in HIV/AIDS among SGML. Some of the programs and interventions include *Contacto*, *Connecting Latinos en Pareja*, SOMOS, *Trans Equity Project* and *HOLA en Grupo*.

*Contacto* is an individual-level HIV stigma reduction intervention for SGML living with HIV in Puerto Rico. Delivered by a trained health educator using motivational interviewing techniques, this intervention helps participants manage the negative impact of stigma related to HIV-status and/or sexual orientation. The intervention also helps participants identify challenges and create a plan to overcome the negative impact of stigma when accessing healthcare services. More information about the intervention can be found at: <https://apha.confex.com/apha/143am/webprogram/Paper331684.html>.

*Connecting Latinos en Parejas* is a couple-based bio-behavioral HIV prevention and treatment intervention for Latino men and their same-sex partners.<sup>20</sup> *Connecting Latinos en Pareja* consists of four sessions with content, scenarios, and examples that adapt to each couple’s unique circumstances and HIV status. It incorporates biomedical prevention methods such as pre-exposure prophylaxes (PrEP); promotes engagement in care, adherence to HIV treatment regimens,

“When I changed my name, a nurse insisted on calling me ‘he’ when that made me uncomfortable. I consider myself a woman.”



and viral suppression; and encourages routine HIV testing as indicated by the couple’s serostatus.

SOMOS is a three-component, theory-based HIV prevention intervention targeting Latino gay men that includes: group sessions, social marketing, and community presentations.<sup>21</sup> The group sessions consist of five meetings which address family dynamics, gay identity, homophobia, body image, and sexual health. The social marketing campaigns consist of testimonials that mirror participants’ learning during the sessions. Community presentation topics emerge from the group sessions, these range from community activism to sexual health.

*Trans Equity Project* is a homegrown, community-level HIV prevention and treatment intervention for transgender men and women.<sup>22</sup> *Trans Equity Project* consists of six peer-led hybrid individual- and group-based intervention sessions that emphasize leadership, social and structural interventions, and HIV risk reduction using evidence-based practices for HIV prevention and care. Trans Equity Project’s peer-led model

includes peer activities ranging from peer service delivery (such as peer-led rapid HIV testing or referral to peer-led needle and syringe program) to peer health promotion (such as peer-developed and peer-implemented stigma reduction campaigns or community development, including the Trans March in Philadelphia) and peer leadership (such as peers taking leadership roles in their community, their sector, or participating in policy and law reform).

*HOLA en Grupo* is a Spanish-language, group-level HIV prevention intervention for Latino gay, bisexual and other men who have sex with men.<sup>23</sup> Module 1 introduces





the intervention purpose, describes the impacts of HIV and STIs on Hispanic/Latino MSM, and summarizes HIV and STI facts, including transmission, prevention strategies, HIV testing, and healthcare access. Module 2 includes activities that teach participants HIV and STIs prevention/protection methods, including negotiating condom use and correct condom use. It concludes with a homework activity in which participants are given different brands and types of male condoms and an internal condom (also known as a female condom) and asked to examine them on their own to determine their preferences. Module 3 explores Latino cultural values and their impact on sexual health. Module 4 reviews all previously covered concepts. This last module includes a DVD developed by the partnership that uses a testimonial from Latino men with HIV to begin a discussion about the experience of living with HIV.

In order to address HIV-related stigma and disparities in HIV/AIDS among SGML, it is critical to increase the rates of implementation for existing interventions and programs. An implementation science framework could guide the uptake of effective HIV programs and interventions. Implementation science is a multidisciplinary scientific field that seeks generalizable knowledge about the magnitude of, determinants of, and strategies to close the gap between evidence and

routine practice for health in real-world settings.<sup>24</sup> Special attention should be given to facilitating and encouraging academic-community partnerships as platforms for implementation science projects to reduce HIV-related stigma and disparities. Community-based organizations are also critically important to reduce stigma and ensure long-term success of these programs, interventions, and initiatives.**HIV**



#### ABOUT THE AUTHOR

**Omar Martinez, JD, MPH, MS** is an Assistant Professor at Temple University's School of Social Work. He completed his MPH in Health Policy and JD in Health Law at Indiana University-Bloomington. He later went on to obtain an MS in Clinical Research Methods at Columbia University. Mr. Martinez completed his postdoctoral research fellowship in Behavioral Science Research and HIV Prevention at Columbia University. His research interests lie in addressing health disparities affecting Latinxs, people living with HIV, immigrants, and sexual and gender minorities. His past and current research has pertained to syndemic factors and HIV risk among sexual and gender minorities, development and implementation of HIV prevention and treatment interventions, and health inequalities research. He is currently developing and testing several interventions, including couples-based and peer-led interventions, to reduce HIV/STI risk and psychosocial and social-structural vulnerability among sexual and gender minorities.

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# Causing an HIV Awareness Ripple

## Technology Award Winners Educate with Ariel

By AMBER McCracken, AAHIVM

**J**EREMY BRIGHT has been volunteering in the HIV community since 1998. Inspired by a friend's HIV diagnosis, Jeremy did everything from stuffing envelopes to condom distribution in bars and night clubs to try to make an impact in HIV awareness and education. But it wasn't until 2012 that HIV truly hit home. After suffering from a persistent sore throat, Jeremy's partner of two months, Jason Jones, was diagnosed with HIV. Jeremy remained negative.

Jason immediately sought treatment and Jeremy began the newly-approved PrEP regimen. Additionally, the two searched to find other people in their community who were similarly in a mixed-status relationship for peer support... and they found nothing.

Jeremy decided to ramp-up his involvement in HIV awareness and education by leveraging his marketing and advertising background to go from a Design Studio Director at an international corporation, to a Manager of HIV Testing and Outreach at a Phoenix-based nonprofit. His goal was to normalize the conversations around HIV and to help people find the resources that he and his partner needed at the time of Jason's diagnosis.

In 2018, frustrated with funding that limited his ability to effectively address HIV stigma in his community, Jeremy and Jason decided to serve as those voices in their community and co-founded a new, back-to-grassroots nonprofit, RipplePHX. Jason and Jeremy gathered friends who were living with HIV, taking PrEP, a Family Nurse Practitioner, and other champions of HIV awareness in their community to form their initial Board of Directors and to establish their mission of creating ripples of HIV awareness, prevention and testing from the trenches in their community.



Working from their two-bedroom apartment, they've rolled their innovative mobile outreach unit—nicknamed Ariel. The mobile HIV prevention kiosk targets thousands of Phoenix-based at-risk individuals that were not actively engaged or being reached for HIV care or prevention services. In 2018 RipplePHX launched the mobile Ariel outreach units to motivate those individuals to educate themselves about HIV transmission risk and to seek out direct clinical services and referrals for supportive services.

And it's working! Due to their unrepresented success in their first year, this technology is the winner of the 2019 AAHIVM/Institute for Technology in Health Care HIV Practice Award. The RipplePHX team received \$25,000 in recognition of their unique approach to engaging the community by leveraging innovative technology to reach those living with HIV and those most at-risk.



The mobile HIV prevention kiosk is a round, rolling, wireless outreach unit that brightly glows through frosted plexiglass designed to capture the attention of people who may be at high-risk for HIV. Ariel communicates easy-to-adopt methods to reduce the spread of HIV specifically by offering its interfacing subjects targeted prevention and treatment information.

“High-risk LGBTQ+ Millennials often don’t travel in exclusive LGBTQ+ social circles as the Baby Boomers and Gen X populations once did, creating an important shift in where HIV organizations must recruit young at-risk individuals to adopt a method of prevention or to engage in treatment,” stated Bright. “Also, HIV stigma remains present among Baby Boomers and Gen X populations, often making it shameful for those groups to engage in HIV-related services.”

According to the RipplePHX award application, Ariel is the centerpiece at nightclubs, colleges, bathhouses, and other community-based locations. Each kiosk has four tablets loaded with exciting quizzes and activities that encourage socially-connected individuals to talk openly about HIV. Tablets also email lists of providers for HIV, prevention services, and/or Transgender resources. Ariel also acts as an EMR where participants can register for free HIV Testing through HIPAA Compliant Web Forms. The Tester is electronically notified of the registration and can digitally page the person to the testing area. Ariel’s tablets also work to qualify participants to instantly receive an At-Home HIV Test Kit. All services are available in English and Spanish.

“Since Ariel is wireless, mobile, and fits through most doorways, she shifts traditional outreach methods from workers standing behind a table, to an outreach table that travels directly to the people—filled with exciting HIV-related activities,” says Jones. “The kiosk is designed to be attractive and engaging to a wide audience, but specifically tailored to engage high-risk individuals who aren’t engaged with HIV-related education or services or who may feel embarrassed about engaging.”

In her first seven months, Ariel distributed over 10,000 quick-start educational materials to people at 76 outreach events. Those interactions are expected to number more than 25,000 in 2019. The focus of each outreach event is different based on the audience and location.



“We know we have the prevention and treatment tools to end the HIV epidemic in this country,” said Bruce Packett, AAHIVM executive director. “The challenge is getting education about HIV to those that need it, while at the same time defusing stigma around the issue. Ariel effectively tackles both challenges. We are very pleased to present our award to RipplePHX and hope the funds will extend their reach to an even larger population.”

In its eighth year, the AAHIVM/Institute for Technology in Healthcare HIV Practice Award seeks to acknowledge those who have created, adapted and/or used innovative technology in their HIV practice and to share that technological knowledge with others in the practice of HIV medicine to improve patient care.

**HIV**



#### ABOUT THE AUTHOR

**Amber McCracken** is director of marketing and communications at AAHIVM.

# HIV-





# ASSIST

By NICKY MEHTANI, MANOJ MADDALI and MAUNANK SHAH

## JD WAS TRANSFERRED TO OUR HOSPITAL

from a regional medical center where he had been diagnosed with pulmonary tuberculosis. His care had been complicated by volume overload from dilated cardiomyopathy, chronic kidney disease and a deep vein thrombosis. When his HIV test returned positive, the added complexity sparked rigorous discussion among several members of the care team about the optimal choice of antiretroviral therapy (ART) when considering drug-drug interactions and comorbidities. When discussing the multiple aspects of his clinical care, it came as a surprise when JD responded to the team's 'new' diagnosis of HIV with a shrug of his shoulders: "I've known about that for years..."

While advances in pharmaceutical science have dramatically expanded HIV treatment options over the past two decades—making the disease easier to treat than ever before—JD's situation remains far from unique. He is just one of many Americans with HIV infection who remain out of care or unsuppressed, and whose clinical approach requires consideration of many different factors.<sup>1</sup> This percentage may grow if we do not also acknowledge the declining number of providers trained in HIV medicine, or the need to support HIV clinicians in a rapidly changing field.<sup>2-4</sup>

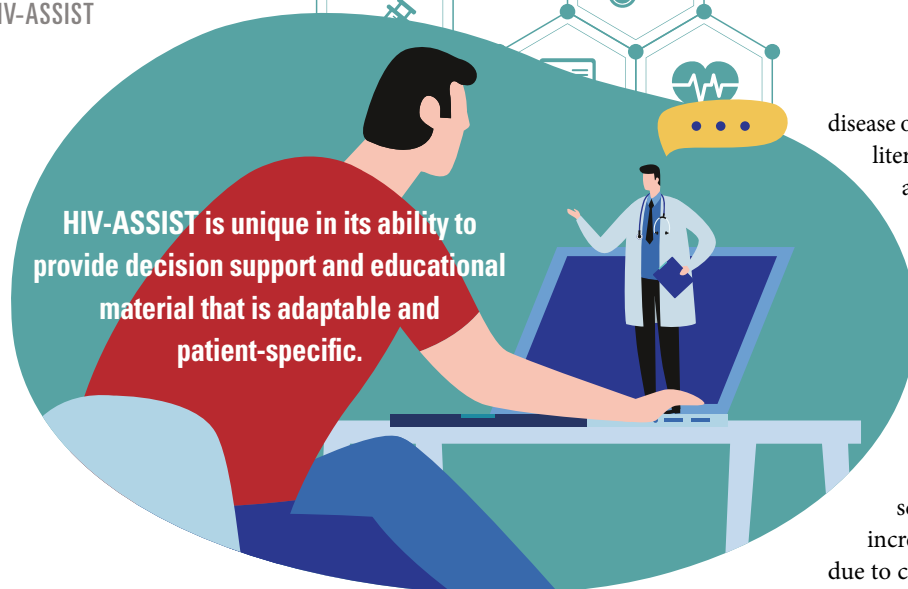
The landscape of HIV medicine has evolved at a furious pace, offering better-tolerated and potent treatment options. In addition to the 30+ antiretroviral drugs in seven different mechanistic classes currently approved by the U.S. Food and Drug Administration (FDA), there is also a growing repertoire of fixed-dose combination pills.<sup>5</sup> With continual changes in clinical guidelines and an aging HIV patient population with increasing numbers of comorbidities, treatment

experience, and co-medications, deciding on the best ART regimens is far from simple for even the most experienced providers. The selection of an optimal regimen is ultimately a nuanced medical decision, with guidelines advocating for individualized therapy that accounts for multiple patient and viral characteristics.<sup>6,7</sup>

Drawing upon these personal experiences and challenges caring for people living with HIV, Drs. Manoj Maddali and Maunank Shah at Johns Hopkins University set about creating HIV-ASSIST (<https://www.hivassist.com>)—a free, online educational tool coupled to real-time decision support to help guide ARV selection for providers caring for patients with HIV.<sup>8</sup>

Designed for providers of all levels of expertise, HIV-ASSIST implements an objective, quantifiable approach to ART selection that weighs numerous different clinical factors simultaneously and presents relevant clinical information in a transparent manner to assist clinicians in making treatment decisions. The tool's online interface allows users to input

.....  
*An online clinical  
decision support  
tool to guide  
patient-centered  
ARV selection*



**HIV-ASSIST is unique in its ability to provide decision support and educational material that is adaptable and patient-specific.**

de-identified patient-specific attributes pertinent to medication selection—including HIV viral load, genotype mutations, viral tropism, HLA-B5701 status, CD4 count, co-morbidities (e.g. renal function, cardiovascular disease), co-medications, treatment history, and factors related to adherence and patient preference.

The tool's algorithms—a complex multi-attribute utility function that draws upon existing literature, expert opinion, and published guidelines from the International Antiviral Society (IAS) and Department of Health & Human Services (DHHS)—then measures and ranks all potential multi-drug ART regimens in relation to the composite objective of achieving viral suppression while maximizing tolerability and adherence. The potential regimens are then presented to users, along with dosing guidelines, and interactions with co-morbidities and co-medications.

Recognizing that each patient situation is unique, HIV-ASSIST provides an explanation or 'rationale' for all decision-making steps associated with a given recommended regimen. The program allows clinicians to evaluate appropriateness of the recommendations based on their own judgement and clinical scenario. The tool provides summaries of current guidelines and associated clinical trial data for each regimen, to provide further tailored educational support while simultaneously aiding clinical care.

While there are several existing HIV educational resources, HIV-ASSIST is unique in its ability to provide decision support and educational material that is adaptable and patient-specific. Current treatment guidelines are comprehensive but—at nearly 200-pages in length—can also be time-consuming to navigate and challenging to apply during a short office visit.<sup>6,7</sup> For example, when selecting a regimen for HIV treatment initiation or modification of an existing regimen, many patients do not fall neatly into categories that have been explicitly studied. While data may be available related to risks associated with some comorbidities, resistance mutations, or co-medications individually (e.g., cardiovascular

disease or drug resistance to some ARV classes), there is less literature available on how to integrate these attributes and comprehensively approach patients with more than one such modifying factor. HIV-ASSIST transparently weighs and presents information on each of these factors to assist clinicians in making such decisions.

Data from the CDC shows that less than half of people living with HIV in the United States are virally suppressed.<sup>1</sup> Given this and current rates of retention in care in the U.S., providers will face increasingly complex treatment scenarios—not only due to an aging population with increased co-morbidities and co-medications, but also due to complicated mutation profiles from exposure to a greater number of prior antiretroviral drugs.

To that extent, HIV-ASSIST offers even highly experienced HIV clinicians an opportunity to examine their treatment selections objectively when competing factors are at play. In an effort to simplify access and help curb the HIV epidemic, HIV-ASSIST is completely free to use and does not require a login. However, users who do opt to create a free login account have the ability to participate in user discussion boards to connect with other clinicians and to discuss complex patient cases.

Recognizing that the utility of such a tool is dependent on ensuring validity and acceptability of the recommendations, the developers recently conducted several research studies. After allowing clinicians at Johns Hopkins to use the tool over the span of a year, a mixed methods evaluation including quantitative surveys and focus groups among users of HIV-ASSIST demonstrated high user satisfaction rates.<sup>9</sup> In particular, clinicians have found the tool useful in its ability to consolidate the capabilities of several other valuable resources—such as the HIV drug interaction checkers and the Stanford HIV Drug Resistance Database (mutation penalty scores for HIV-ASSIST algorithms draw directly from this resource)—into a single comprehensive tool. Clinicians also noted the utility of HIV-ASSIST in providing relevant scientific literature as well as its efficacy as an educational tool to understand guidelines, drug dosing, drug interactions, and resistance mutations.

Subsequently a prospective validation study was performed across multiple academic institutions in which HIV expert clinicians and pharmacists were asked to provide their ART preferences across a wide range of clinical scenarios. The study demonstrated that HIV-ASSIST has a high-degree of concordance with ART selection by expert HIV providers—approaching 100% for scenarios involving ART-naïve patients with and without various comorbidities and co-medications.<sup>8,10</sup>

The study also found heterogeneity among HIV experts in their preferred ART selections for experienced patients



and complex patient scenarios; nonetheless, the study found that for all presented cases, HIV-ASSIST recommendations were consistent and highly concordant with experienced HIV providers. It thus may be a particularly robust resource to aid clinical decision-making among primary care providers, who have variable degrees of expertise in HIV medicine but generally serve as a patient's first—and sometimes only—point of contact with the healthcare system.

While an abundance of dedicated research, pharmaceutical investment, and specialized funding support from the Ryan White Care Act helped transform HIV into a chronic disease, data from the CDC and patient narratives like JD's demonstrate that such efforts may be of limited consequence if not coupled with the expansion of access to treatment among people living with HIV.<sup>1</sup> This is especially relevant in the South, where the scarcity of Infectious Disease/HIV specialists is likely to be greatest and which now constitutes the epicenter of the nation's HIV epidemic, accounting for 44% of all people living with HIV in the U.S. despite being home to only 37% of the total population.<sup>11</sup>

By bridging the gap between formal HIV training experiences and the need for longitudinal continuing medical education in HIV medicine among primary care providers, HIV-ASSIST has the potential to help expand access to HIV treatment in such areas of the country with otherwise limited access.

Further developments within HIV-ASSIST will include the integration of ART regimen costs to aid in decision support, as well as location-specific contextual factors to help providers choose regimens that are locally available—a feature that will be of particular importance in global health settings. In addition, there are plans to build a network of clinicians to provide feedback and input on algorithms as well as to provide timely clinical updates based on emerging literature for users.

The challenges of providing appropriate ART regimens that are effective, but also considers the impact on comorbidities, drug interactions, and an array of other factors are likely to continue to increase in the future. This increasing complexity is what drove the development of HIV-ASSIST. It is important to recognize, however, that HIV-ASSIST is not meant to be a substitute for clinical judgment, but rather an educational tool to aid decision-making. Nonetheless, HIV-ASSIST may provide robust patient-centric support to HIV specialists treating an increasingly complex patient population. And through integration in primary care offices, the tool may have the potential to expand access to evidence-based HIV management in a way that has not previously been possible.

**HIV**



#### ABOUT THE AUTHORS

**Nicky Mehtani** is an addiction medicine fellow in the Division of HIV, Infectious Diseases & Global Medicine at UCSF and a recent graduate of the Osler Internal Medicine Residency at Johns Hopkins Hospital. She is interested in HIV primary care, its

integration with the treatment of addictions, and health systems reform.



**Manoj Maddali, MD**, is Co-founder and Lead Developer of HIV-ASSIST. Dr. Maddali is a third year Internal Medicine resident at UCSF. His interests are at the intersection of clinical medicine and healthcare technology. He hopes to leverage technologies such as decision analysis algorithms and machine learning to find innovative solutions to optimize healthcare delivery and access. After residency, he plans on pursuing a fellowship in Pulmonary/Critical Care Medicine.



**Maunank Shah, MD, PhD**, is Associate Professor in the Division of Infectious Diseases at Johns Hopkins (JH) School of Medicine, and a faculty member of both the JH Center for Clinical Global Health Education and the JH Center for TB Research. He is Medical Director for the Baltimore City Tuberculosis Program, an attending physician at the Johns Hopkins Hospital, and is board certified in infectious diseases and internal medicine.

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# Real-Time HIV Cascades in

By CHRISTINE KERR, MD, AAHIVS, LISA REID, LCSW,  
MICHAEL BIDLACK and IRIS ARZU

**A**S HIV PROGRAMS GROW AND THE POPULATION WE CARE FOR AGES, we have a responsibility to continually assess the quality of our programs and develop new technologies. At Hudson River HealthCare, a network of 49 federally-qualified community health centers with integrated primary and HIV specialty care, we have developed an HIV Care Cascade which gives our team members an immediate understanding of who is retained in care, who is on medication, and who is virally suppressed.

The cascade has a tremendous impact on our patient care across our network, which serves a geographically and ethnically diverse patient population. Because of the direct and instantaneous quality assessment, we are able to work with our staff to target the patients and populations that are struggling with viral load suppression and to more clearly understand the treatment barriers. The importance of engagement into care, starting patients on ART, and making sure their viral load are suppressed results in decreased morbidity, mortality, and transmission of HIV.

Hudson River HealthCare was encouraged to develop this system through our collaboration with the New York State AIDS Institute, who sought ongoing assessment of viral load suppression in a cascade format. We quickly knew we

would have to develop a system to look at the data in the aggregate since chart review was no longer a feasible option. We worked within a team approach, building the platform, using informatics expertise, clinical knowledge, and feedback from staff members and peers who represented end users of the work. This information is extracted from structured data within our EMR into an aggregate reporting platform with a graphic interface developed by Solutions 4 Community Health (S4CH.) Any team member can log into this easy-to-use platform and see the HIV Care Cascade (Figure 1) with real-time, drill-down reporting. With a few clicks, we know which patients need to come in for a visit, which patients need medication, and which patients need adherence counseling. The data can be sorted by site, by year, and by



# Care Community Healthcare

region, making it easy for teams to understand how to best allocate resources and efforts.

We are also able to rapidly determine and monitor health care disparities, filtering by race, ethnicity, gender, age, risk factor, and migrant worker status. In addition, patients can be mapped by ZIP code and viral load suppression status, making it easy to see if we are appropriately reaching those who are most in need and helping us understand barriers to care (Figure 2).

Because we can view by combinations of social determinants, we are able to target subgroups that may need particular help. For example, although we don't see significant disparities by race alone, when we looked by gender, age, and race combined, we found that young men were suppressed at a significantly lower rate than older men and that this difference was particularly pronounced for young, African-American men. This allowed us to target our peer work, our social media outreach, and our visual messages within our health centers to make our health centers more welcoming to this group.

The cascades give a graphic representation of gaps in care that is meaningful and easily understandable and allows comparisons to internal and external benchmarks. This

**FIGURE 1.** 2018 HIV Care Cascade

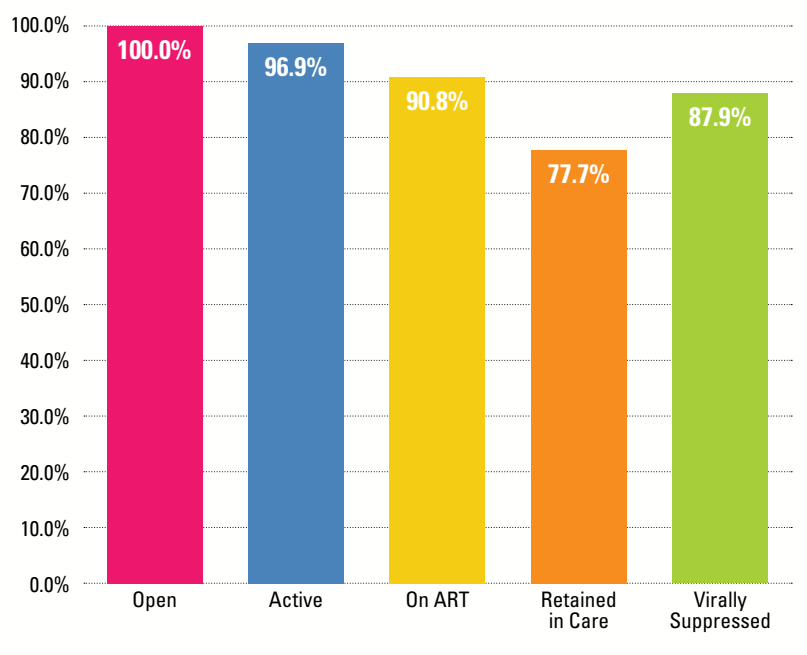
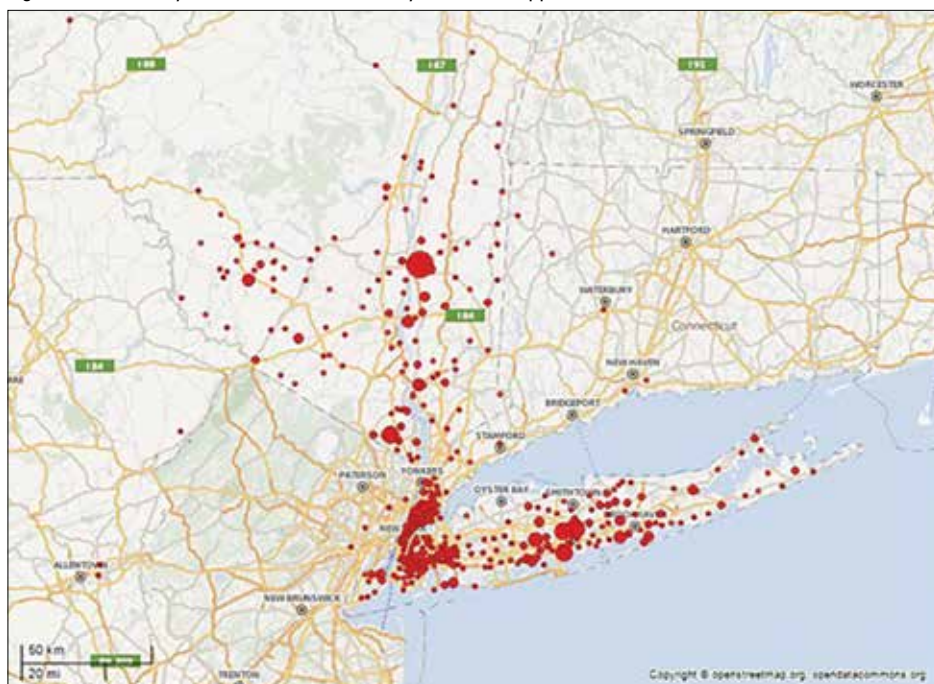




Figure 2: Patients by location. Can be sorted by viral load suppression status as well.



Unique patient count by patient ZIP code. Circle size is determined by volume. The more patients in a ZIP code the bigger the circle.

technology facilitates report writing, appropriate resource allocation, and presentations to board members, auditors, administrators, and others. Because it gives a quick snapshot of how our programs are doing, we can follow longitudinal quality of care issues over time. However, the most innovative and creative uses have been with our patients themselves. Because the visual representation is so clear and effective, our patients have been increasingly involved in the conversation about gaps in care and about creating solutions.

This technology reflects next steps in EMR development, since EMRs have historically been good at patient level data but often struggle with population data. As we work towards ending the HIV epidemic, we will need strong population assessments with the ability to easily drill down to find patients who are not engaged in care or who are not virally suppressed. This technology quickly facilitates that work and gives a strong graphic representation that can easily be shared with consumers and grant funders. We are also immensely proud of the ability to engage patients, because the reports with aggregate data can be easily run and shared with consumer advisory boards and patients themselves, who can identify with case managers and other staff where they fall in the cascade.

As we anticipate needs in HIV care over the next few years, we need to quickly identify patients who are not engaged in care across large population networks. Currently, any patient who touches our system, whether they come in for urgent care, dentistry, or prenatal visit with a diagnosis of HIV, will be included in this cascade, making it easy to identify them and work on bringing them into care if they are not already engaged at our clinical site. Cascade data can be shared with patients to support adherence and the importance of viral load suppression, reinforcing treatment as prevention.

The strength of the real-time visual representation is so compelling that we look forward to expanding to other high-need areas as well. We plan to create a Hepatitis C Testing, Care, and Treatment Cascade and also create a HIV Testing and PrEP Cascade. This will allow us to work within the integrated primary care setting to ensure that we are consistently testing the patients at risk and linking them to either treatment or prevention rapidly. Because the information is accessible to providers across the network, primary care and specialty providers will be able to rapidly assess if their region, their practice, and their providers are meeting testing benchmarks and getting patients into care appropriately. On-going quality assessment is a crucial piece of HIV care. As new systems are developed, we need to make sure that they are accessible and meaningful to our patients. **HIV**



#### ABOUT THE AUTHORS

**Christine Kerr, MD**, AAHIVS is the Medical Director of HIV and Hepatitis Programs for Hudson River HealthCare, Inc. (HRHCare.) Dr. Kerr has been providing direct HIV and Hepatitis care in the Hudson Valley for over 10 years. Dr. Kerr also serves

as the co-chair for the New York State Quality Advisory Committee for the Department of Health's AIDS Institute, is a co-chair of the Johns Hopkins-AIDS Institute Guidelines Committee for Treatment of Hepatitis C and the New York State Task Force for Hepatitis C Elimination, and serves on the Johns Hopkins-AIDS Institute Medical Care Criteria Committee.



**Lisa Reid, LCSW**, is the AVP of Care Management at Hudson River HealthCare. She has over 25 years of experience providing clinical and administrative services with a focus on program development. She currently oversees HRHCare's HIV primary care, HIV, Hepatitis C and Health Home care management and adherence services, PrEP and Medication Assisted Treated Programs throughout the Hudson Valley and Long Island.



**Michael Bidlack** is the Director of Informatics at Hudson River Healthcare and has been a leader in the world of healthcare data analytics for 11 years and counting. Through his experience and knowledge, Michael has driven improved patient experience, increased cash collections, and reduced staff workload. Michael received a Bachelor of Science degree from the Pennsylvania State University's College of Electrical Engineering.

**Iris Arzu** is a Data Analyst for Hudson River HealthCare, Inc. (HRHCare). Iris has over 10 years of progressive experience working in health care, with over five years of experience in quality improvement working directly with HIV patients and five years of experience in data analysis.



# Positive Links

*A Tailored mHealth Platform  
to Support Care and  
Thriving for People  
Living with HIV*

By REBECCA DILLINGHAM, MD, MPH,  
KAREN INGERSOLL, PhD, and  
AVA LENA WALDMAN, MHS, CHES, CCRP

## POVERTY, STIGMA, POOR ACCESS TO TRANSPORTATION, ISOLATION, SUBSTANCE USE, AND MENTAL HEALTH CHALLENGES

are some of the significant barriers to HIV care that face many people living with HIV (PLWH) in rural Virginia.

To address these barriers and to support PLWH working to overcome them, a team of clinician-scientists at the University of Virginia (UVA) Ryan White Clinic worked with clients to explore how mobile technology (mHealth) could provide diverse opportunities to address the challenges to living well with HIV when and where clients want and need it.<sup>1,2</sup>

Based on extensive formative work and with support from AIDS United, the team developed and tested, in partnership with people living with HIV (PLWH) seeking care at the UVA Clinic, a tool called PositiveLinks (PL). PL is a theory-informed, clinic-deployed, smartphone-based platform that provides tools and support to PLWH to improve medication adherence and engagement in care. It includes a patient-facing app, a provider-facing app, and a web portal for providers. (See website here: [www.positivelinks4ric.com](http://www.positivelinks4ric.com)).

The PL app features for PLWH include medication reminders, mood and stress check-ins, educational resources, an anonymous community message board (CMB), secure document upload, and private provider messaging system (Figure 1). PL seeks to shrink physical and psychological distance between patients and care providers. It also expands connections among PLWH in a space that is experienced as safe. It provides important tools that support self-monitoring, care coordination, and social support—all in a secure mobile app.<sup>3</sup>

An initial evaluation of PL's pilot stage assessed baseline characteristics and followed those who enrolled in the program for 12 months. Clinical outcomes measured included viral suppression and engagement in care. Seventy-seven participants enrolled based on referrals from providers.



Figure 1: Menu for PositiveLinks for PLWH



These PLWH were either new to care or returning to care. In addition, they could be referred by providers who felt that they were at risk for falling out of care.

Approximately two-thirds of participants were non-white and 64% were male. This group also faced significant challenges beyond living with HIV with 72% living below the poverty line. About one-fourth of patients were classified as “housing unstable” or homeless. Once enrolled, the participants were provided with a smartphone that had a voice and data plan. They were trained to use the app and asked to use it. There was no minimum usage requirement. We found that participants enjoyed using the app and used it regularly.

For the outcome evaluation, we also found that viral suppression rates and engagement in care increased dramatically and remained robust through 12 months of follow-up. Viral suppression in the cohort at baseline was 51%. It rose to 88% at six months and remained at 81% at 12 months. Recent analyses show that these results persist at 24 months. Engagement in care, as measured by the metric of at least two visits per year separated by at least 90 days, also rose. At baseline, engagement in care was measured at 47%. It rose to 87% at six months and remained at 79% by 12 months. Similarly, the 24 months analysis shows persistence of these positive results.<sup>4,5</sup> (see Figure 2).

The gains made in frequently measured clinical outcomes are impressive, but these clinical outcomes are not the only aspects important to PLWH. Analysis of the messaging on the anonymous CMB revealed that participants engaged frequently with each other relative to key issues like stigma. In fact, there is a signal that discussing issues related to HIV-associated stigma on the CMB is associated with decreased measured

internalized stigma. Opportunities to request and provide social support in a secure, anonymous space were appreciated and frequently taken.<sup>6</sup> As an example, one participant offered this encouragement to another considering disclosure of their status:

“if u want to talk to your friend about your HIV status it’s ok if he is indeed your friend he should understand and it shouldn’t change your friendship and it will make u feel better to talk to someone close to you. I had to do the same it was hard but once I got it out I felt better and he may have questions about just be honest and let him know the facts of being HIV positive”<sup>7</sup>

After the initial demonstration project and based on participant requests, we added a provider-facing app for clinicians, case managers, nurses, and community health workers. The

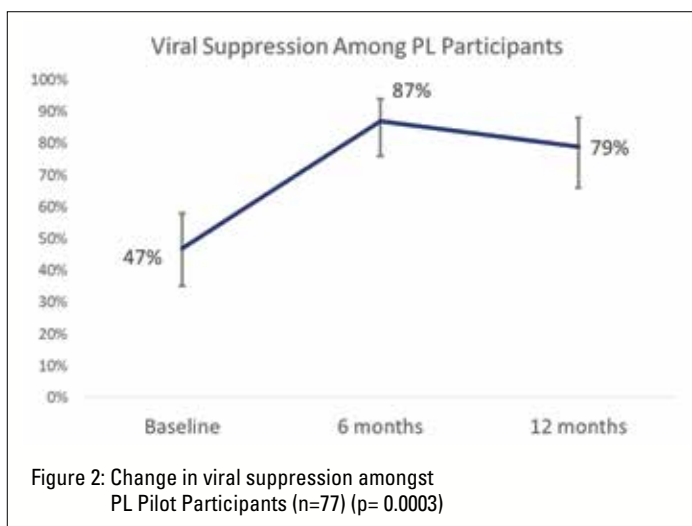
provider-facing PL app and web portal facilitate providers’ ability to monitor patient-reported data about adherence and mood. They also permit “texting”-like messaging in a health system-approved environment that allows for the flexibility and efficiency of texting. While there are always concerns about overwhelming hard-working clinicians and staff with additional tasks or technologies, one clinician described her experience with PL this way:

“...initially I was quite skeptical, but the messaging system ended up being very helpful for me and never made me feel put upon to respond immediately. Perhaps you’re the same, but I’m one of these folks that needs to answer things or complete tasks right away, otherwise I’ll forget about it for weeks. And the notion of “texting” initially terrified me that I would constantly be stressed about someone having direct access to me. But after a few weeks of working with the messaging system I realized that it actually improved handling simple issues, like medication refills or quick questions patients had, and I felt far less pressure to respond immediately since the notifications came through my email. Plus, most of my patients are pretty happy with this method of communication. I even had someone let me know they were stuck in traffic and would be late for their appointment in real time, so I was able to rearrange my morning. Pretty cool!” (Infectious disease specialist)

Another clinician, an experienced HIV-focused psychiatrist, explained how she believes PL supports her delivery of care:

“Despite our best efforts in our clinic, there are still barriers to care. I feel that PositiveLinks has offered our patients an opportunity to be empowered and to have a voice. It allows them the opportunity to ask follow-up questions, to clarify things and to find a way to communicate with us in meaningful ways. ... It offers resources to them and a way to utilize all that the clinic has to





offer. PositiveLinks allows them to access their caregivers and have meaningful communication between visits. ... it has been a method of reassuring patients anxious about the status of various types of paperwork, which is a big source of stress for our patients. They can let me know that something has been sent, I can reassure them that it has been received and attended to, and ask questions as they arise. It has expedited this type of process. It is a great way to have patients follow up and close the loop on activities and their “to do” lists and a great way to give them a vote of confidence and congratulate them on a job well done. It allows patients who remember something after an appointment to not have to wait for the next one to share something with me. It allows me to help them navigate a variety of processes—remove barriers to care—when they might otherwise have been stuck.” (HIV-focused Psychiatrist)

The PL team has also begun to analyze the in-app messaging between participants and providers. Based on the qualitative coding so far, we see that there is an opportunity for instrumental support and navigation, as noted by these two clinicians. In addition, there is a significant component of rapport-building.<sup>8</sup> Given that patient-provider communication is such an important factor in supporting engagement in care and that there are evidence-based strategies to improve verbal communication, we look forward to continuing to refine our understanding of asynchronous, secure electronic communication and to offer recommendations about best practices.

PositiveLinks is now used by three clinics and over 400 PLWH who receive care through the Ryan White program in Virginia. Additional clinics are in the process of adapting it for their context with assistance from the UVA team and support from the Virginia Department of Health (VDH). There are also culturally-adapted pilot projects underway in Russia, Uganda, and South Africa. The PL team remains committed to ongoing rigorous evaluation, iteration based on participant feedback, and attention to the security and sustainability of the platform. More information and contact information is available to interested clinics at the website ([www.positivelinks4ric.com](http://www.positivelinks4ric.com))

HIV



#### ABOUT THE AUTHORS

**Rebecca Dillingham, MD/MPH**, is Co-Founder of PositiveLinks and an HIV clinician. As an infectious disease clinician-researcher with 25 years of experience in HIV prevention and care delivery, Dr Dillingham has partnered with partners and colleagues from different disciplines to develop PositiveLinks as a strategy to extend care beyond the clinic walls, to enhance clinicians’ connection with their patients, and to support patients’ achievement of their health goals.



**Karen Ingersoll, PhD**, is Co-Founder of PositiveLinks and a clinical psychologist. With a background in clinical health psychology, Dr. Ingersoll has focused on helping people live long and well with HIV. She is interested in creating tools that are practical and can help people immediately, because people living with HIV need solutions now!



**Ava Lena Waldman, MHS/CHES/CCRP**, is the PositiveLinks expansion manager. A dedicated public health professional and harm reductionist, Ava Lena has managed a number of HIV/ AIDS prevention and treatment programs with diverse populations in the U.S. She was attracted to PositiveLinks for its use of mobile technology to address challenges to living well with HIV when and where people want and need it.

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## UPDATE



JEFFREY T. KIRCHNER, DO, AAHIVS  
AAHIVM Chief Medical Officer

## FEATURED LITERATURE

**Price JC. Sexually Acquired Hepatitis C Infection in HIV-Uninfected Men Who Have Sex with Men Using Preexposure Prophylaxis Against HIV. *The Journal of Infection Diseases*, May 2019, Volume 219, Issue 9, 1, Pages 1373–1376, <https://doi.org/10.1093/infdis/jiy670>**

Cases of sexually acquired hepatitis C virus (HCV) infection among men who have sex with men (MSM) were first reported about 10 years ago. The number of reported cases of HCV in MSM has increased in recent years and has paralleled the use of PrEP (FTC/TDF) for HIV prevention. This publication describes 15 new cases of HCV infection that occurred among 14 MSM from 2013 through 2018 (including one case of re-infection) who were seen at clinical sites in New York City and San Francisco. All of the men had been taking PrEP for a median of 12 months before their HCV diagnosis. None of them became HIV-infected during this time. Almost all (13/15) were asymptomatic and diagnosed by routine laboratory screening due to elevation in alanine transaminase (ALT) or the presence of HCV antibody.

Their primary hepatitis diagnosis was confirmed by detection of HCV viremia in the setting of HCV antibody seroconversion. Five of the men reported injection drug use with methamphetamine and all 14 engaged in anal receptive intercourse. Six (40%) of the men were concurrently diagnosed with bacterial STIs. Of note, three (20%) spontaneously cleared their HCV infection based on undetectable HCV-RNA levels over 12 weeks from the initial diagnosis. Eight of the men were treated for HCV and cured and treatment is ongoing in three others. The authors encourage incorporation of ALT testing at baseline and for follow-up visits for MSM on PrEP, noting that elevation in ALT is more sensitive than HCV antibody during acute infection. They also acknowledge support for current AASLD/IDSA guidelines that recommend annual HCV antibody screening in MSM using PrEP who report multiple sex partners.

**COMMENTARY:** This paper adds to our data from other cohorts in France and Amsterdam that also reported new cases of HCV in MSM. Baseline HCV screening is currently recommended by the CDC before initiation of PrEP but not as part of the follow-up assessment. It certainly should be considered based on sexual histories obtained at the time of the interval visits for PrEP.

## FEATURED LITERATURE:

**Hyle, EP et al. Clinical impact and cost-effectiveness of genotype testing at HIV diagnosis in the United States. *Clinical Infectious Diseases*, published May 4, 2019. ciz372, <https://doi.org/10.1093/cid/ciz372>**

Current DHHS and IAS guidelines recommended baseline genotype testing for all persons newly diagnosed with HIV infection. This has been standard of care since 2006 and can determine if the patient has acquired drug resistance and thus guide selection of the initial ART regimen. When these recommendations were published, the majority of patients were being treated with a protease inhibitor (PI) or non-nucleoside reverse transcriptase inhibitor (NNRTI) as first line therapy. Current treatment guidelines now recommend an integrase strand inhibitor (INSTI) with a nucleoside/nucleotide reverse transcriptase inhibitor (NRTI) as first-line therapy, thus genotype testing, which routinely does not test for INSTI resistance—only provides information regarding the NRTI. Moreover, even in the face of NRTI resistance, the new INSTIs (bictegravir and dolutegravir) appear to remain very effective in attaining viral suppression. This paper re-evaluated the clinical and economic impact of baseline resistance testing in the U.S. The authors used the Cost-effectiveness of Preventing AIDS Complications (CEPAC) model which is a validated microsimulation model of HIV disease, clinical care, and costs. They compared two strategies: no baseline genotype versus baseline genotype and applied this to four subgroups: no transmitted drug resistance (84%), transmitted NRTI-R (6%), transmitted NNRTI-R (7%), and transmitted PI-R (3%). The authors assumed NO transmitted INSTI resistance which is known to be very rare. This study found that compared to no baseline resistance testing, performing an HIV genotype would result in < 1 additional undiscounted quality-adjusted life day and cost about \$420,000 per quality-adjusted life year. The authors state that for patients starting bictegravir or dolutegravir-based regimens baseline genotype testing offers minimal clinical benefit for persons newly diagnosed with HIV, provides only a very small survival benefit, and even with a cost of \$320 offers poor value relative to other HIV interventions.

**COMMENTARY:** This is a very significant paper and I believe once these data have been fully reviewed and the DHHS guidelines are updated, baseline genotype testing will no longer be recommended. In a 2007 analysis this group determined that baseline INSTI resistance testing was not helpful. In addition, with the growing emphasis on testing and same-day initiation of treatment, the results of genotype testing for newly diagnosed patients offers no practical benefit to most patients or providers.

#### FEATURED LITERATURE:

**Frazier EL et al. Differences by Sex in Cardiovascular Comorbid Conditions Among Older Adults (Aged 50–64 or ≥65 Years) Receiving Care for Human Immunodeficiency Virus Clinical Infectious Diseases. Published May 3, 2019. <https://doi.org/10.1093/cid/ciz126>.**

It is currently estimated that 46% of persons living with HIV (PLWH) in the U.S. are > 50 years of age. Numerous studies have shown an increased risk for cardiovascular disease (CVD), heart failure and stroke in this population. The prevalence of cardiovascular comorbid conditions among (PLWH) aged 50–64 years has not been extensively studied and there is even less data for those ≥65 years of age. This study used data from the CDC's Medical Monitoring Project which is a national cross-sectional sampling of HIV-infected adults. They examined characteristics of the two age groups noted above and also looked at differences based on sex. Comorbid conditions for this study included overweight/obesity (BMI > 25), total cholesterol ≥200 mg/dL, diabetes mellitus, or hypertension. The authors calculated weighted-prevalence estimates and used logistic regression to calculate prevalence differences, (including by sex) for cardiovascular comorbid conditions. The sample size was 7436 with 75% men and 25% women. Approximately 90% were aged 50–64 years and 10% aged ≥65 years. The majority had been diagnosed with HIV infection for at least 10 years, 94% were on ART, and 70% had undetectable viral loads. After adjustment for sociodemographic and behavioral factors, women aged 50–64 years were more likely than men to be obese, hypertensive, or have high cholesterol. Those women ≥65 years had higher prevalence of diabetes mellitus and high total cholesterol levels than men in the age range and nearly 50% of older women compared to 28% of men had > 3 CVD comorbidities. The authors conclude that CVD risk-factors are highly prevalent among older HIV-infected persons in care with women affected more than men, especially in those over age 65. Closer monitoring and risk-reduction strategies for CVD comorbid conditions are warranted for older HIV-infected persons, especially women.

**COMMENTARY:** This study adds to our knowledge of the prevalence of CVD risk factors in the aging HIV population which contribute to but are not the sole reason for the higher prevalence of heart disease and stroke in PLWH. Aggressive screening and appropriate therapeutic interventions (e.g. statin therapy, blood pressure lowering) for men and women are an important aspect of the long-term care of PLWH. Readers are referred to the 2019 Fundamentals of HIV Medicine chapter on Cardiovascular Disease by Dr. David Wohl and myself that discusses current diagnosis and guideline-based management of CVD and associated risk factors in HIV-infected patients.

#### FEATURED LITERATURE:

**Rodger AJ et al. for the PARTNER Study Group Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicenter, prospective, observational study. *Lancet*. Published Online May 2, 2019 [http://dx.doi.org/10.1016/S0140-6736\(19\)30418-0](http://dx.doi.org/10.1016/S0140-6736(19)30418-0)**

There is strong evidence from HPTN 052 and the PARTNER studies confirming a negligible risk of HIV transmission through condomless sex in serodifferent heterosexual couples with the HIV-infected partner having an undetectable viral load while on ART. The PARTNER 1 study included patients from 14 countries who were followed at 75 clinical sites from 2010 to 2014. This recent publication from *The Lancet* includes data from the PARTNER 2 study which recruited and followed only gay couples. The patients were followed through April 2018. A couple of years of follow-up were eligible for inclusion if condomless sex was reported, use of PrEP or PEP was not reported by the HIV-negative partner, and the HIV-positive partner had a viral load of <200 copies per mL at the most recent visit. Data collected at quarterly visits included a sexual behavior questionnaire, HIV testing of the negative partner and viral load testing of the HIV-positive partner. If an HIV seroconversion occurred, anonymous phylogenetic analysis was done to compare HIV-1 pol and env sequences in both partners to determine if this was a linked transmission.

From September 2010 through July 2017, 972 couples were enrolled which provided 1593 follow-up with a median of two years per couple. During eligible years of follow-up, couples reported condomless anal sex a total of 76,088 times. In addition, more than 30% of the HIV-negative men reported condomless sex with outside partners. Within this cohort, there were 15 new HIV infections diagnosed during eligible couple-years of follow-up. NONE of the new infections were phylogenetically linked within-couple transmissions, resulting in an HIV transmission rate of zero. The results of this study provide essentially the same level of evidence on viral suppression and lack of HIV transmission risk for gay men seen for heterosexual couples and suggest that the risk of HIV transmission in this population with condomless sex is effectively zero when HIV viral load is suppressed.

**COMMENTARY:** These data from the PARTNERS studies in addition to evidence for other studies fully support the message of U=U (undetectable equals untransmittable). These results also support and indirectly endorse the benefits of early HIV testing and treatment with ART. U=U is now endorsed by AAHIVM, the CDC and many other groups throughout the world. The web site [www.preventionaccess.org](http://www.preventionaccess.org) is an excellent provider and patient resource for additional information on U=U.

**HIV**



# All of Us

## Creating Precision Medicine for People Living with HIV

**A**AHIVM IS PROUD TO BE A PARTNER of the All of Us Research Program, a historic effort lead by the National Institutes of Health (NIH) to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.

AAHIVM joined the All of Us Research Program to ensure people living with HIV are well represented in the initiative. We look to you, the HIV care team, to make this program known to your patients in hopes they will consider enrolling.

Following is a Q&A provided by the All of Us Research Program to assist healthcare providers with speaking to those that may be interesting in participating:

### What is the All of Us Research Program

The *All of Us* Research Program is an ambitious effort to gather data from one million or more people living in the United States to accelerate research and improve health. The program will be open to people both healthy and sick, from all communities. Unlike a single research study focused on a specific disease or population, *All of Us* will serve as a national resource for thousands of studies, covering a wide variety of health conditions.

### Who can join All of Us?

Initially, enrollment will be open only to those who live in the United States, are 18 years of age and older, are able to

provide consent on their own, and are not currently incarcerated. In the future, we will expand enrollment to include children and other special populations.

### What will my patients be asked to do?

Participants will be asked to complete surveys and share information about their health history, lifestyle habits, and environmental exposures over a number of years. Participants may also be asked to provide access to their electronic health records, and to go to a local enrollment center to have physical measurements taken and to provide blood and urine samples.



### Will my patients have access to results and data from the program?

Participants will have access to their own data along with summarized results from across the *All of Us* Research Program. *All of Us* will not communicate directly with participants' healthcare teams, but participants may choose to share *All of Us* information with their providers.

### How will you protect my patients' privacy?

The program has numerous safeguards in place to minimize potential risks to data security and participant privacy. For example, we encrypt participant data, keep participants' names and other personal identifiers separate from their health information, and test the security of *All of Us* systems on an ongoing basis.

### Who will be able to access the All of Us data?

The data *All of Us* collects will be accessible to researchers in the United States and around the world to accelerate health research and medical breakthroughs. There are strict rules researchers must follow to access the data, to keep participant information private and secure.

To learn more and to enroll, visit [joinallofus.org](http://joinallofus.org).

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- 🗣️ Getting to Zero: Ending the HIV Epidemic
- 🗣️ Early, Sustained Viral Suppression—A Key Disease-Management and Prevention Strategy
- 🗣️ Rapid Antiretroviral Therapy (ART) Initiation: Operationalizing Early Viral Suppression
- 🗣️ Addressing Barriers to Rapid Start
- 🗣️ Manage This Patient: An Interactive Case-Based Activity
- 🗣️ Concluding Comments: Looking Forward—Will You Have a Rapid ART Initiation Protocol in Place in 1 Year?

### TARGET AUDIENCE

This activity is intended for infectious diseases and human immunodeficiency virus (HIV)-specialist physicians and other clinicians and stakeholders involved in the care of patients with HIV infection.

**For additional program and accreditation information, please visit [www.HIVEEMS.com](http://www.HIVEEMS.com).**

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