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The Future is Youth

My name is Jacundo Ramos. I am 23 years old and I currently reside in San Antonio, Texas. I am Co-chair of the Health Justice Youth Council and Youth Community Outreach Specialist for Ryan White Part D.



Come with an open mind

Youth engagement is critical in ending the HIV epidemic we are facing because they are a demographic that is currently being affected. Many organizations are complacent and stagnant with their outreach. What they did for the last 10+ years has worked; however, we need to touch a population that has a completely opposite mindset to what these ASOs are used to. Not only must we use informal and non-traditional outreach, but we need to bring minorities and hard-to-reach populations – such as the immigrant and transgender populations – to the forefront of all engagement.

Young people have a low perception of risk that they will get HIV and may not feel the need to protect themselves. In order for us to reach them, they must see a face similar

to themselves. Similar faces resonate more with our youth population. When they see someone who is close in age, from a similar background, and identifies as they do, they see someone who “gets it.” The many youth I have spoken to say that they are more likely to listen to someone young and knowledgeable versus someone older and knowledgeable telling them what they need to do or that what they are doing is wrong.

The youth population is hard to reach because many organizations have a programmatic mindset, which is normal when working in a structured environment. Youth, however, are risqué; youth are outgoing; youth are open-minded. Institutions need to leave what they know at the door and come in with an open mind.

The San Antonio Health Justice Youth Council

In 2018, the San Antonio End Stigma End HIV Alliance ran a Youth Listening Tour. The objective was to meet and engage youth in San Antonio with the purpose of learning more about them. The Health Justice Youth Council (HYJC) started in July 2018 as a branch of End Stigma End HIV Alliance of San Antonio (ESEHA). It was a way to continue engagement for young people, to give youth a platform, and to provide support for ideas for youth peers to take action in the community on issues that impact youth. We focus especially on HIV, sexual health, and mental health.

We are a group of youth and adult allies who meet every other week to plan events and outreach. HJYC aims to build our membership with a lens of equity by recruiting diverse youth and adult allies to volunteer together. The HYJC youth come from organizations like Ryan White, Beat AIDS, Fiesta Youth, Planned Parenthood, Health Collaborative, Healthy Futures, and more. We meet biweekly to discuss new engagement ideas and events for the community.

Doing things differently

Young people don’t read pamphlets. Social media is the best outlet to reach the youth population because it is quickly accessible and most youth spend a majority of their day accessing Facebook, Instagram, Twitter, and Snapchat.

Here are some of the non-traditional ways HJYC is engaging youth in fun and entertaining ways that are still educational:

- HJYC had their first youth-centered Art & Activism event on October 20, 2018. The event weaved art, music, HIV, and stigma at Say Si and had 44 people attend.
- In 2018, the Youth Listening Tour reached 198 people in 23 groups.
- The Youth Listening Tour 2.0 started in January 2019 and is still going on.
- HJYC created a data sheet with a scannable QR code that is available at our tabling events. This gives students and youth access to information on where to get tested, PrEP info, mental health resources and more.
- “CUM as You Are” Trivia is our next event on May 28 at The Block SA. We are partnering with Texas Wears Condoms and LUCHA, as well as sororities and fraternities from UT-San Antonio who will be doing a stepping show and participating in all activities.
- HJYC is revamping our social media to be more structured and consistent. Moving forward, all our marketing will be done via social media.
- We are contacting the resident advisors (RAs) of college dorms, school radios and newspapers, and local radio stations, as well as the venues we book to get

the word out to their followers.

We are straying away from testing at these events. Many youth feel pressured or embarrassed to get tested in public or in a space around their peers. We want them to come to the events and become educated. We give them the tools to access the resources on their own, like the QR code resource.

Success never came from a comfort zone

There is no perfect or structured way to engage youth or to perform informal or non-traditional outreach. You must stray away from what you know and step outside of the box. Success never came from a comfort zone. If we stay comfortable we will not reach the success we need to end the HIV epidemic. My population is much different than what many organizations are used to; however, instead of figuring out how to reach them, try to bring young individuals to the table who are already doing the work. These individuals, if given the platform, can shape a change not yet seen in the youth demographic we are trying to reach.

We are the face and the future of our communities, so why not give us the opportunity and the platform to continue the change we want to see for the future? As an individual living with HIV, it is not only empowering to see a young, diverse group of individuals coming together to passionately shape a community. It resonates louder with me because we are minorities, we are different, but we are successful and we are powerful. That is exactly what our youth need to see.

Featured in videos: Tristan Garcia + Jacundo Ramos



Project STYLE (Strength Through Youth Livin' Empowered) Young MSM of Color

Highlights from the Special Projects of National Significance (SPNS) Program



This fact sheet contains highlights from the University of North Carolina at Chapel Hill's *Project STYLE* Intervention, launched in response to rising HIV rates within young men who have sex with men (YMSM) of color. Project STYLE was designed to reach HIV-positive Black and Latino YMSM at college and university campuses through a social marketing campaign and linking them into care.

Setting: North Carolina

Target Population: Black and Latino young men (ages 17–24) who have sex with men

Background

Young (aged 13–24) MSM (YMSM) are a population with specific risk factors for HIV infection and if infected, have greater likelihood of poorer health outcomes than older populations living with HIV. Several factors can pose as barriers to effective HIV prevention approaches among YMSM, including: inadequate reach of HIV prevention education to YMSM, low levels of awareness and perception of risk among young people, risky sexual behavior due to substance and/or alcohol use, and social issues commonly faced by sexual minority youth such as stigma, sexual violence, social and family isolation.¹ In addition, racial/ethnic differences are associated with different diagnoses trends among YMSM. Project STYLE is an innovative model of care designed to engage, link, and retain HIV-positive Black and Latino YMSM, ages 17–24 into HIV primary care. YMSM have been disparately impacted by HIV since the start of the HIV epidemic in the U.S., and encompass groups historically unaware of their HIV status and/or not connected to care. These include underserved youth, racial/ethnic minorities, and sexual and gender minorities.²

Unmet Needs

In 2014, the CDC estimated that MSM accounted for 80% of youth ages 13–24 diagnosed with HIV.³ These trends have translated into heavy HIV burdens among older populations of Black and Latino YMSM. Of these newly diagnosed YMSM, 55% were Black and 23% were Latino. In 2015, the CDC estimated that Black MSM have a 1 in 2 lifetime risk of HIV infection, while Latino MSM have a 1 in 4 lifetime risk.⁴

Intervention Objectives

The objectives of *Project STYLE* were to reach HIV-positive Black and Latino YMSM at college and university campuses through a social marketing campaign and link them into care.

Key Considerations for Replication

- **Ensure staff possess the skills and cultural competency** necessary to delivery and/or provide linkage to HIV care and ancillary services to HIV-positive Black and Latino YMSM.
- **Create partnerships and linkages** with agencies in your area already working with HIV-positive Black and Latino YMSM
- **Create a social marketing campaign** that reflects input from Black and Latino YMSM, as well as community stakeholders and current/potential service partners



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who have access to the target populations. (*Materials should raise HIV awareness, speak directly to Black and Latino YMSM, and be disseminated through print and online outlets*)

- **Establish an Advisory Board** to help oversee and provide input during the ongoing creation and roll out the intervention.
- **Supplement social marketing efforts** with intensified in-person outreach, such as HIV informational town halls or HIV testing at venues and events (i.e. health fairs, dance clubs, and college campuses, frequented by Black and Latino YMSM).
- **Obtain referrals of HIV-positive Black and Latino YMSM** from aligned entities including local and state health departments, HIV studies, clinics, faith- and community-based organizations (FBOs/CBOs), and AIDS service organizations (ASOs).
- **Link HIV-positive Black and Latino YMSM** into a tightly integrated medical and social support network. This should be a warm handoff, with an HIV Outreach Worker linking newly diagnosed/re-engaged YMSM with a case manager and a medical appointment within 72-hours of identification.
- **Ensure medical and support staff work together** to stay connected with HIV-positive Black and Latino YMSM and support retention in care.

Intervention Staff Requirements

To replicate the University of North Carolina at Chapel Hill's *Project Style* intervention, the following positions and capacity are necessary.

- **Peer Outreach Workers**—serve as the public face of the intervention; facilitate HIV education and testing events.
- **Case Managers**—coordinate with Peer Outreach Workers to schedule initial medical appointment.
- **HIV Primary Care Providers**—An infectious disease board-certified physician with expertise delivering HIV primary care.
- **Research Support Panel**—collects, tracks, and analyzes study data.
- **Advisory Board**—An interagency/community comprised of community members and stakeholders, current/potential service partners, and Black and Latino YMSM representatives.

RESOURCES

This fact sheet is part of the *Improving Health Outcomes: Moving Patients Along the HIV Care Continuum and Beyond* resources from the Integrating HIV Innovative Practices (IHIP) project.

- **Integrating HIV Innovative Practices (IHIP). Engaging Hard-to-Reach Populations: Outreach. (Webinar). April 18, 2013. Available at: <https://careacttarget.org/library/engaging-hard-reach-Populations-outreach>.**
- **Integrating HIV Innovative Practices (IHIP). Innovative Approaches to Engaging Hard-to-Reach Populations Living with HIV/AIDS into Care: Tools from the Integrating HIV Innovative Practices Program Training Manual and Curriculum. 2012. Available at: <https://careacttarget.org/ihip/engagement>.**
- **Outreach, Care, and Prevention to Engage HIV Seropositive Young MSM of Color Initiative. Available at: <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/spns-initiative-outreach-care-and-prevention-engage-hiv-seropositive-young-msm-color-2004-2009>**

Notes

¹ U.S. Centers for Disease Control and Prevention. HIV and Young Men Who Have Sex with Men. https://www.cdc.gov/healthyouth/sexualbehaviors/pdf/hiv_factsheet_ymsm.pdf

² NIMHD. *Sexual and Gender Minorities Formally Designated as a Health Disparity Population for Research Purposes*. October 6, 2016. <https://www.nimhd.nih.gov/about/directors-corner/message.html>.

³ CDC. *HIV Surveillance Report 2014*. 2015; 26.

⁴ 2016 Conference on Retroviruses and Opportunistic Infections (CROI). *Gay and Bisexual Men of Color Face Greatest Risk of HIV*. Boston, MA. February 2016. <http://www.cdc.gov/nchhstp/newsroom/2016/croi-2016.html>.



Millennials and Social Media: Engaging, Mobilizing, and Learning for HIV Outreach

By: [Pavni Guharoy, Communications Director, AIDS.gov](#) | **Published:** December 16, 2014

Topics

[Communities of Color](#) [Social Media](#) [Youth](#)



According to the Centers for Disease Control and Prevention (CDC), about 50,000 Americans are newly infected with HIV each year. Of those, one in four (26%) is 13-24 years old. In 2012, the highest rate of new diagnoses of HIV infection occurred among people aged 20-24 years. In response to these rates, government agencies, youth-focused community organizations, and youth advocates are finding innovative outreach methods to engage young people about their HIV risk.

Today we are spotlighting four initiatives that prioritize youth engagement and work to empower youth. Each initiative is leveraging social media tools to amplify youth voices, as well as to showcase the ways in which millennials are uniting in their efforts to create an AIDS-free generation. **National Minority AIDS Council: Youth Scholar Program** Each year, the [National Minority AIDS Council \(NMAC\)](#) assembles a group of Youth Scholars by recruiting advocates from across the U.S. to represent the voices of young people in the epidemic. NMAC provides the Scholars a platform to learn about policies, other HIV programs, and leadership.

At NMAC's annual U.S. Conference on AIDS (USCA 2014), [HIV.gov offered a pre-conference workshop entitled "Utilizing Social Media"](#) during the NMAC Youth Scholar orientation. The session offered an opportunity for HIV.gov to learn from, and interact with, over 20 Youth Scholars who are working as community advocates for local HIV organizations, or who are self-made local advocates working to mobilize communities across the nation through their personal networks. As an added highlight, we welcomed one of the [NMAC Youth Scholars, Kahlil Barton](#), as our newest blogger for the [HIV.gov Black Voices Blog](#).

Kaiser Family Foundation: Greater Than AIDS #speakoutHIV This fall, the the Kaiser Family Foundation's (KFF) Greater Than AIDS campaign launched #SpeakOutHIV - a visual storytelling project featuring the personal experiences of 25 young gay and bisexual men who are age 25 and younger (approximately one-third are HIV-positive). "Despite the continued impact of HIV, gay and bisexual men are not talking about HIV even with those closest to them," noted Tina Hoff, KFF's Senior Vice President and Director of Health Communication and Media Partnerships. "#SpeakOutHIV is about promoting a more open dialogue about HIV in all aspects of life, in relationships, with healthcare providers, and within the community generally."

#SpeakOutHIV challenges people to post their own stories about HIV on YouTube and share through Twitter, Facebook, and other social media platforms as part of a collective effort to promote more open discussion about the issue.

Viiv Healthcare Youth Summit #YouthHIVManifesto It is a sign of the times that in its 16th year, the Viiv Annual Community Summit expanded its focus to host its first Youth Summit. Held during the weekend of October 24-25, the Viiv Youth Summit featured young community leaders like Lawrence Stallworth II, a member of the Presidential Advisory Council on HIV/AIDS, as well as two HIV.gov Black Voices bloggers - Patrick Ingram, and Anthony Roberts, Jr. You can read and watch a video on Anthony's blog from the Viiv Summit, where he shares lessons he learned from his new mentor, Mr. Jeff Berry. The day's workshops focused on outreach strategies, utilizing social media, using digital storytelling, and preparing appropriate audience-centric messages.

Centers for Disease Control and Prevention: Act Against AIDS Launched in 2009, Act Against AIDS (AAA) is a five-year national campaign launched by CDC and the White House to combat complacency about HIV and AIDS in the United States. *Act Against AIDS* focuses on raising awareness among all Americans and reducing the risk of infection among the hardest-hit populations – gay and bisexual men, African Americans, Latinos, and other communities at increased risk. *Act Against AIDS* consists of several concurrent HIV-prevention campaigns and uses mass media (TV, radio, newspapers, magazines, and the Internet) to deliver important HIV prevention messages.

At HIV.gov we continue to engage with, and learn from, organizations and youth advocates who are using social media to drive change to curb the epidemic in their own communities. Subscribe to the HIV.gov Blog so you can stay abreast of more updates on youth initiatives. Share with us what youth in your community are doing to be HIV advocates.

Protocol

Promising Approaches for Engaging Youth and Young Adults Living with HIV in HIV Primary Care Using Social Media and Mobile Technology Interventions: Protocol for the SPNS Social Media Initiative

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Abstract

Background: In the United States, disparities in the rates of HIV care among youth and young adults result from the intersections of factors that include stigma, substance use, homelessness or marginal housing, institutional neglect, and mental health issues. Novel interventions are needed that are geared to youth and young adults.

Objective: In this paper, we aim to describe the interventions used by participating sites for Using Social Media initiative, the process for classifying the intervention components, and the methods for conducting a comprehensive evaluation of the interventions.

Methods: In 2015, the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau, Special Projects of National Significance (SPNS) funded the Evaluation and Technical Assistance Center (ETAC) at the University of California, Los Angeles and 10 demonstration projects at sites across the United States that incorporated innovative approaches using a variety of social media and mobile technology strategies designed specifically for youth and young adults living with HIV. The ETAC developed a typology, or a classification system, that systematically summarizes the principal components of the interventions into broader groups and developed a multisite, mixed-methods approach to evaluate them based on the Department of Health and Human Services HIV health outcomes along the HIV care continuum. The mixed-methods approach is key to remove potential biases in assessing the effectiveness of demonstration projects.

Results: This SPNS project was funded in September 2015, and enrollment was completed on May 31, 2018. A total of 984 participants have been enrolled in the multisite evaluation. Data collection will continue until August 2019. However, data analysis is currently underway, and the first results are expected to be submitted for publication in 2019.

Conclusions: This HRSA-funded initiative seeks to increase engagement in HIV medical care, improve health outcomes for people living with HIV, and reduce HIV-related health disparities and health inequities that affect HIV-positive youth and young adults.

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KEYWORDS

HIV; health outcomes; mobile technology; social media; youth; young adult; mobile phone

Introduction**Background**

In the United States, HIV-positive youth and young adults have disproportionately lower rates of HIV care engagement, retention, medication adherence, and viral suppression compared with older HIV-positive populations. Zanoni and Mayer [1] estimate that only 25% of HIV-positive youth and young adults in the United States are linked to care, 11% retained in care, and 6% virally suppressed. Data on HIV clinical outcomes among youth are limited, but their retention-in-care rates suggest that they are less likely to be meaningfully engaged in care and to achieve viral suppression [2-4]. Although current antiretroviral therapy regimes are less toxic and simpler, factors that are more likely to be present in younger populations are also associated with suboptimal adherence [2,5,6]. HIV-positive youth and young adults face HIV-related health disparities resulting from the intersections of multiple and concurrent stigmas (eg, homophobia, race or ethnicity, and HIV), substance use, homelessness or marginal housing, institutional neglect, mental health issues, and other challenges [2,5,6].

The largest percentage of HIV-positive youth and young adults are men who have sex with men (MSM). Among Ryan White HIV/AIDS Program (RWHAP) clients aged 13-30, male-to-male sexual contact was the transmission category for 60% of HIV infections, with African Americans (54%) and Latinos (22%) being the largest racial or ethnic groups affected [7]. The RWHAP is a federally funded program, authorized by title XXVI of the Public Health Service Act, which provides a comprehensive system of care—primary medical care and support services—for people living with HIV who are uninsured or underinsured. Challenges to engagement in HIV care and viral suppression for young MSM include substance use disorders, mental health issues, stigma, discrimination, and marginalization [8]. Stigma resulting from an HIV-diagnosis and fear of familial, peer, and community rejection profoundly impact youth and young adults [9] and is associated with higher rates of depression, anxiety, and social isolation [10-12]. Aspects of the health care environment exacerbate care engagement challenges because medical providers often reproduce and communicate larger social homophobia and HIV-related stigma [13,14]. Furthermore, there are structural barriers that limit access to HIV care, such as limited health care insurance and lack of transportation, especially among those with a low income and racial or ethnic minorities [14-16].

Most interventions that address barriers to HIV care have been developed for adults [1] and have not been tailored to youth struggling with a variety of unique issues including identity formation, economic hardship, and unstable housing among other daily survival issues [1,7]. A recent randomized control trial attests the importance of tailoring medication adherence interventions to an increasingly young HIV-infected population [17]. However, one promising new strategy with the potential to help young people overcome these challenges is the use of

mobile technology. The type of technology use among youth is constantly increasing, and new forms of communication technology and Web-based social networking offer opportunities to reach and engage young people for health promotion [18-20].

Mobile Technology and Social Media

Significant gains can be made to improve the health outcomes of HIV-infected youth and young adults using mobile technology and social media for engagement and retention in HIV medical care. Media and technology that facilitate social interaction (ie, social media) are preferred among young adults, who spend more time with social media and mobile technology than any other activity [21,22]. The science and practice of leveraging social media and mobile apps to support youth in accessing care hold great promise for better patient outcomes. A growing body of evidence suggests that mobile app interventions and social media can help in achieving HIV care program priorities, including linkage to care, engagement and retention in care, and adherence to HIV medications [23-26]. Significant advantages to using mobile technologies and social media apps for engagement and retention in HIV primary care include convenience to the user, reaching larger numbers of people, consistency in delivery, real-time exchange, and potential privacy protections [17,27]. Smartphones have revolutionized the mobile communications markets, and mobile phone health interventions are increasingly being used for the care and prevention of HIV and other sexually transmitted diseases [28-31]. Over 95% of all Americans own a cell phone [32], and over 3-quarters (77%) own a smartphone; the majority (92%) of smartphone owners are between the ages of 18 and 29 years [32].

Overview of the Special Projects of National Significance Social Media Initiative

To harness and test the potential of social media in the interest of better HIV care engagement for youth, the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau, Special Projects of National Significance (SPNS) program launched the Using Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum initiative (SMI) in 2015. The 4-year initiative includes ten demonstration projects in HIV care sites (n=5), health departments (n=2), and community-based organizations (n=3) located throughout the United States. An Evaluation and Technical Assistance Center (ETAC) was awarded to the Department of Family Medicine at the University of California, Los Angeles (UCLA) to provide technical assistance to the demonstration projects and to develop and implement a rigorous multisite evaluation. Demonstration projects developed mobile technology and social media interventions for linking, retaining, and supporting HIV-positive, underserved, underinsured, hard-to-reach youth (ages 13-24 years) and young adults (ages 25-34 years) in HIV primary care and supportive services. The overarching goal of this initiative is to create a system change—improvements in policies and procedures using social

media and mobile technologies—that results in improved HIV health outcomes for HIV-positive youth and young adults.

In this paper, we describe the interventions used by participating sites for this initiative, the process for classifying the intervention components, and the methods for conducting a comprehensive evaluation of the interventions.

Methods

Demonstration Sites

Through a competitive proposal process, HRSA selected demonstration sites using innovative mobile technology and social media strategies deployed via the internet or mobile apps designed to improve engagement and retention in care, medication adherence, and to help achieve viral load suppression among youth and young adults living with HIV (see [Multimedia Appendix 1](#) for a more detailed description of the interventions). The ten demonstration sites are located in Los Angeles, California; San Francisco, California; Chicago, Illinois; St Louis, Missouri; Winston-Salem, North Carolina; New York, New York; Cleveland, Ohio; Hershey, Pennsylvania; Philadelphia, Pennsylvania; and Corpus Christi, Texas. Each demonstration site used its own outreach, linkage, and retention strategies tailored to their local target populations. They all used youth advisory boards either to modify and tailor existing intervention approaches or to develop new intervention approaches for the populations they are serving.

Target Population

The initiative focuses on youth and young adults. HRSA defined youth as persons between the ages of 13 and 24 years and young adults as persons between the ages of 25 and 34 years. The sites focused on the age ranges of their target population based on the groups most affected by HIV in their local communities. The SMI includes all genders, races or ethnicities, and sexual orientations. Nonetheless, some interventions focus on specific populations, such as transgender women, MSM, or MSM within specific racial or ethnic groups such as African American or Latino. Demonstration sites classified and described the respective target population for their intervention by setting, age, gender, race or ethnicity, and sexual orientation.

Youth Involvement

An important component of this initiative is the involvement of youth advisory groups providing input in the design of intervention and outreach strategies, typically via focus group discussions. Engaging the target population to guide intervention design is important in developing an intervention that resonates with them and ensures cultural and linguistic appropriateness crucial to the development of messaging in social media-based components [33]. Across the demonstration sites, youth and young adults have been engaged in multiple ways such as guiding the process and design of messages that market the interventions to potential users and providing feedback on the content of intervention messaging and informing app feature priorities and functions. Demonstration site staff typically recruited youth to attend regular meetings to ensure young people had consistent opportunities to provide input in developing components of the intervention and to gather

feedback about the effectiveness of implemented strategies. Youth advisory groups give voice to young adults' own lived experiences from different regions in the United States, serving as an important step forward in understanding the connection between social media and technology use and young adult health behaviors [33]. Thus, the involvement of youth in the project design is critical for sustainability and meaningful, long-term impact.

Social Media Initiative Interventions Typology

The UCLA ETAC reviewed each of the funded proposals and their intervention descriptions to establish a classification system that systematically summarizes the main components of the interventions into a typology. We chose this approach because the use of typologies has proved more useful than hierarchies of evidence (systematic reviews, meta-analyses, randomized controlled trials, cohort studies, etc) in conceptualizing the strengths and weaknesses of different methodological approaches [34]. In other words, hierarchies of evidence misrepresent the interplay between the question being asked and the type of approach most suited to answering it. Typologies systematically indicate the relative contributions that different kinds of methods can make to different kinds of research or, in this case, evaluation questions [35]. The typology developed includes a description of the target population, inclusion criteria, intervention components and functions, and how these correspond to the HIV health outcomes along the HIV care continuum. The typology provided a framework to develop the multisite evaluation of these interventions, discussed below.

[Table 1](#) includes information on the respective target populations by setting, age, gender, race or ethnicity, and sexual orientation for each demonstration site. Most sites target similar populations, with few exceptions. There is one demonstration site that is a community research site, two are Departments of Health, one is a hospital system, and the rest are clinics in either a community or a university setting. There are 6 sites that target participants under the age of 18, while the others focused on ages 18-34 years. There is one site where the intervention is designed specifically for transgender women and another specifically for men, while half are designed for all genders and sexual orientations.

Inclusion Criteria for Enrollment in the Multisite Evaluation

HIV medical eligibility criteria for enrollment in the multisite evaluation is based on the US Department of Health and Human Services (HHS) common core indicators for monitoring HHS-funded HIV care services [36] and include (1) being newly diagnosed, which is defined as testing HIV positive for the first time within the last 12 months prior to enrollment; (2) not being linked to HIV medical care, including participants who are aware of their HIV infection status but have never engaged in care (never having an HIV medical visit after being diagnosed with HIV); (3) being out of care or not fully retained in care, which includes participants diagnosed with HIV more than 12 months prior to enrollment who had a gap in their HIV care that was >6 months, within the last 24 months; or (4) not being virally suppressed, defined as having a viral load of ≥ 200 copies/mL at their last lab test.

Table 1. Target populations for the Using Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum initiative (SMI).

Demonstration site	Setting	Age (years)	Gender	Race or ethnicity	Sexual orientation
Coastal Bend Wellness, Corpus Christi, Texas	Community clinic	13-34	Male and female	All (focus on African American and Latino)	All
Friends Research Institute, Los Angeles, California	Community research site	18-34	Transwomen	All	All
Howard Brown Health Center, Chicago, Illinois	Community clinic	13-34	Male and transwomen	All	MSM ^a and heterosexual
MetroHealth System, Cleveland, Ohio	Hospital system	13-34	All	All	All
New York State Department of AIDS, New York, New York	Health department	18-34	All	All	All
Pennsylvania State University Medical Center, Hershey, Pennsylvania	Community and university clinic	13-34	All	All	All (primarily MSM ^a)
Philadelphia FIGHT and Children's Hospital of Philadelphia, Philadelphia, Pennsylvania	Community clinic	14-29	All	All	All
San Francisco Department of Public Health, San Francisco, California	Health department	18-34	All	All	All (primarily MSM ^a)
Wake Forest University, Winston-Salem, North Carolina	University clinic	13-34	Male	All	MSM ^a
Washington University St Louis, St Louis, Missouri	University clinic	18-29	Male and female	All (primarily African American)	MSM ^a and heterosexual

^aMSM: men who have sex with men.

Additional eligibility criteria included (1) being between the ages of 13 and 34 years; (2) meeting at least one of the above medical criteria determined from tests or medical records; (3) providing informed consent (if 18 years or older) or providing informed assent (if 13-17 years) and, if required by state laws and regulations, obtaining consent from a parent or legal guardian; and (4) meeting any demonstration site-specific criteria (eg, smartphone ownership or being a patient at the site's clinic) as necessary.

Technology Platforms

While each demonstration site's intervention is unique, there are general commonalities listed in the typology framework (Table 2). For example, all ten demonstration sites include a text messaging service component, three of which use text messaging services exclusively. Text messaging is done through short message service (SMS) or private messaging apps such as WhatsApp [37] or Kik [38], while private messaging also functions in mobile Web apps or social media apps and sites. There are six sites that developed new mobile apps specifically for their intervention, while one site has adapted an existing mobile app. The different technology platforms used in each intervention are described in Table 2.

For outreach and recruitment, almost all (n=9) of the sites use social networking sites or apps and other social media platforms (Table 2). Of these, seven have corresponding websites, with three using apps optimized for mobile devices to support the promotion of their interventions. There is one site that uses

YouTube, Twitter, and Instagram as platforms for their graphic serial.

Functions of the Interventions

The interventions offer a range of functions, as represented in Table 3. Most interventions have seven to nine functions (an average of seven functions). There is one intervention that has only one function, namely, automated information delivered through SMS, and one other intervention contains all ten functions. The most common components of the interventions are communication, information, social support or networking, and reminders for HIV medical care appointments, HIV medication, and non-HIV care-related issues. The least common components are the skills building and gaming components. In general, youth advisory groups across the ten demonstration sites communicated in focus groups during formative research that medical appointment reminders and support for medication adherence were most important, followed by receiving lab results for HIV viral load. As a result, most interventions focus on helping participants to develop good habits relating to retention in medical care, medication adherence, and monitoring viral load. Developing skills and gaming are functions of interventions that target younger youth (13-24 years of age). The idea of gaming includes interactive games, quizzes, and puzzles and a points system for the use of the mobile app in achieving appointment, adherence, and viral suppression milestones. There is one site where the mobile app offers immediate feedback and incentives while using avatars to be more attractive to their target population.

Table 2. Technology platforms for the Using Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum initiative (SMI).

Demonstration site	Text messaging	Mobile apps	Social network- ing sites or apps	Social Media ^a	Website
Coastal Bend Wellness, Corpus Christi, Texas	All types	— ^b	✓	✓	✓ ^c
Friends Research Institute, Los Angeles, California	Automated, unidirectional	—	✓	✓	—
Howard Brown Health Center, Chicago, Illinois	Automated	✓ (adapted) ^d	—	—	✓
MetroHealth System, Cleveland, Ohio	Automated	✓ (new)	—	✓	✓
New York State Department of AIDS, New York, New York	All types	✓ (new)	✓	✓	✓ ^c
Pennsylvania State University Medical Center, Hershey, Pennsylvania	All types	✓ (new)	✓	✓	✓ ^c
Philadelphia FIGHT and Children's Hospital of Philadelphia, Philadelphia, Pennsylvania	All types	✓ (new)	✓	✓	✓
San Francisco Department of Public Health, San Francisco, California	Live, bidirectional	✓ (new)	✓	✓	✓
Wake Forest University, Winston-Salem, North Carolina	Live, bidirectional	—	✓	✓	—
Washington University St Louis, St Louis, Missouri	All types	✓ (new)	—	✓	—

^aFacebook, Instagram, Twitter, Snapchat, and YouTube.^bNot applicable.^cMobile optimized.^dAdapted apps signify that institutions have existing mobile apps that they have adapted for this intervention and target population.**Table 3.** Intervention functions of the Using Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum initiative (SMI).

Function	Definition	Interventions (N=10)
Communication	Interactive communication between participants and service providers.	9
Education	Interactive teaching of information or content.	6
Gaming	Rewards, incentives, or a points system embedded in the social media/mobile digital tool that may or may not include competition between peers.	2
Information	One-way or “push” of content to inform participants (eg, tips, referral resources)	9
Skills building	Social media tools specifically designed to build skills through demonstration and practice.	3
Social support or social networking	Provides participants with opportunities to receive social support from peers, family, service providers, or others.	9
General reminder	Reminders other than for HIV care appointments or HIV adherence.	9
Medical appointment reminder	Appointment reminders for HIV medical care, delivered via the social media intervention tool (can be automated).	9
Medication adherence reminder	Antiretroviral medication reminder that can be automated, live, or both.	8
Monitoring or tracking reminder	Participants record or report information via the social media tools (ie self-monitoring, logging, self-tracking)	7

Table 4. Data collection tools for the Using Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum initiative (SMI).

Methods	Time frame
Audio Computer-Assisted Self-interview Surveys	Baseline and 6, 12, and 18 months
Cost assessments	Annually
Intervention exposure	Monthly or every encounter
Back-end data	Weekly
Medical chart data	Every 6 months

Comprehensive Evaluation Strategy

In order to determine the relative effectiveness of the interventions taking part in this initiative, the ETAC is conducting a rigorous, multisite evaluation of the demonstration sites' interventions. The evaluation plan assesses the outcomes, processes, and cost of using social media- and technology-based interventions to ensure that they have maximum impact on engagement, retention, adherence, and health outcomes of HIV-infected youth and young adults. The design of the quantitative multisite evaluation is informed by the components of each site's interventions and the type of data the components capture (eg, intervention exposure such as back-end data or person-to-person contact by intervention staff) as well as engagement and outcomes of care measures approved by HHS for funded HIV care services [39]. The demonstration sites recruited a convenience sample of 984 participants across a 20 month period from October 2016 through May 2018 (see Inclusion Criteria above). Intervention participant data is being collected using audio computer-assisted self-interview (ACASI) survey software to increase privacy and confidentiality in the data collection process. Table 4 provides a list of the data collection tools being used in the multisite evaluation. All data are submitted to the ETAC through a Web-based secure portal at UCLA for data management and analysis.

Audio Computer-Assisted Self-Interview Surveys

ACASI surveys are conducted at baseline enrollment and repeated at 6-, 12-, and 18-month intervals. The five primary domains of the ACASI surveys are: (1) sociodemographic characteristics (eg, age, education, housing stability, and incarceration); (2) biomedical health, linkage, engagement, and retention in care; (3) intervention exposure; (4) barriers to care; and (5) media technology usage and attitudes. In addition, the surveys collect information on the popularity, adoption, and usability of social media-based interventions among participants. Surveys also gather information on the broader barriers and facilitators of engagement and retention in medical care.

Cost Assessments

Cost assessments are being conducted annually to determine the cost of implementing each intervention. Sites use standard microcosting techniques (incremental time required for each intervention) combined with direct costs to obtain an estimate of total incremental recurring costs. Development and ongoing maintenance costs of the studies are collected through a cost assessment tool that captures personnel information, recurring goods and services, capital equipment, and facility costs. The

costs of developing new mobile apps are captured in the recurring costs reported by the five sites developing them. Cost assessments also indicate successful strategies for labor and programmatic costs for each intervention in this SPNS initiative to inform future replication.

Intervention Exposure: Back-End Data and Person-to-Person

Intervention exposure collected weekly helps identify which components of the interventions contribute to desired outcomes. There are two forms of exposure data being captured in the SMI: person-to-person and back-end data. Person-to-person exposure is defined as any type of contact between participants and intervention staff in person, by phone, by text, or by other mobile messaging services. Back-end data include participants' activities on mobile apps, private Facebook pages, or other social media platforms used in this intervention. Back-end data will be used to measure intervention exposure in the multisite evaluation. Some sites have used real-time measures of back-end data to adjust their intervention. For example, one demonstration intervention removed the gamification component of their mobile app due to lack of use.

Medical Data

Data about participants' HIV health outcomes (medical data) are collected every 6 months to assess changes in health outcomes over time. Sites use either the administrative data associated with the receipt of RWHAP funds or abstracted data collected from medical records by hand. Participants' identification is coded to protect their identities before sites submit data to the ETAC. Information from medical data includes: core service visits for HIV care, substance abuse, mental health, CD4 cell count testing, viral load testing, the first date of antiretroviral prescription, and any breaks in the use of highly active antiretroviral therapy.

Qualitative Methodology

Qualitative analysis will document the effective implementation of these interventions. Data is being collected by ETAC investigators during years three and four of the initiative through key informant interviews with participants and providers and tracking reports and forms kept by demonstration sites. Qualitative research methodologies are valuable for understanding factors that facilitate or inhibit the implementation and the effectiveness of the intervention, thus providing context and informing quantitative HIV health outcome data. In addition, qualitative methods afford a better understanding of participants' experiences with social media and mobile

technology to link, engage, and keep them in HIV medical care. It also provides a means to capture any unanticipated themes that may emerge from the data regarding intervention implementation and acceptability.

Multisite Evaluation

The multisite evaluation is assessing engagement in care, health outcomes associated with participation in the social media and mobile technology-based interventions, and individual-level factors that influence the effectiveness of these interventions.

The quantitative evaluation primarily looks at associations between intervention type and exposure and changes in HIV care continuum outcomes and related health outcomes over time. Statistically significant changes in outcomes over time will be indicative of a possible intervention effect; we are cautious against using more causal language in the absence of a control group. We will conduct subgroup analyses for data from each of the ten demonstration sites as well as in aggregate to evaluate differential intervention effects across sites. Random effects will be included for each study participant to account for correlations between outcome observations on the same study participant and properly adjust SEs that will be estimated by the regression models. Most of the analyses will be conducted on nonnormally distributed outcomes and will use random effects generalized linear models with appropriate outcome link functions.

The qualitative evaluation will document the barriers and facilitators to the effective implementation of interventions. Qualitative data sources include individual, semistructured interviews with participants or clients and key informants (site staff implementing the social media interventions), review of secondary sources of information (eg, demonstration site grant proposals, notes from ETAC site liaisons, and ETAC site visit reports) and site presentations at grantee meetings, and observations of project operations at intervention sites. Interview transcripts will be iteratively coded, sorted, and analyzed using a thematic analysis process [40]. Themes will be selected based on their prevalence across the dataset and importance in assessing barriers and facilitators to implementation and acceptability among participants.

This mixed-methods approach will be important in removing potential bias in establishing the effectiveness of demonstration projects. The findings from the evaluation will provide insight for the future use of social media and mobile technology to improve health outcomes for HIV-positive youth and young adults. The results will include best practices from the demonstration sites, lessons learned, and implications for system change or system integration of social media and mobile technology.

Privacy, Confidentiality, and Security

Privacy, confidentiality, and security are paramount in designing an intervention that uses social media or mobile technology for engaging and retaining HIV-infected persons in medical care. In addition to firewalls and information technology security procedures required by the Health Insurance Portability and Accountability Act (HIPAA) regulations, unintentional disclosures can result in stigma, discrimination, and prejudice, particularly for HIV-positive patients. Participants in the SMI are trained in device security, such as using passwords to access phones, added layers of password protection to access specific apps, how to clear text message logs, etc, by SPNS staff at the demonstration sites. Awareness of current privacy concerns associated with each technology has helped alleviate participant concerns. HIPAA requirements must be adhered to when using mobile technologies and social media connected to patients' personal health information.

Results

This SPNS project was funded in September 2015, and enrollment was completed on May 31, 2018. A total of 984 participants have been enrolled in the multisite evaluation. Data collection will continue until August 2019. However, data analysis is currently underway, and the first results are expected to be submitted for publication in 2019.

Discussion

The Social Media Initiative is an HRSA SPNS initiative that emphasizes the primary goals for HIV prevention and care outlined in the US National HIV/AIDS Strategy: to reduce new infections, increase access to care, improve health outcomes for people living with HIV, and reduce HIV-related health disparities and health inequities that HIV-positive youth and young adults face. The innovative interventions included in this initiative have the potential to improve the health outcomes of youth and young adults who are living with HIV.

The ETAC at UCLA aims to complete the analysis and dissemination of findings, best practices, and lessons learned from using social media and mobile technology to support the engagement of HIV-positive youth and young adults in medical care by the end of 2019. The ETAC hopes that the findings will serve to inform future policy and practices for programs seeking to use ever-changing and improving social media platforms and mobile technology in the delivery of high quality, culturally appropriate HIV primary health care interventions. Successful scale-up of these types of interventions will require understanding how and why youth and young adults use social media and emerging mobile technologies for personal health.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Demonstration site interventions.

[[PDF File \(Adobe PDF File\), 34KB - resprot_v8ile10681_app1.pdf](#)]

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Abbreviations

ACASI: audio computer-assisted self-interview

ETAC: Evaluation and Technical Assistance Center

HHS: Health and Human Services

HIPAA: Health Insurance Portability and Accountability Act

HRSA: Health Resources and Services Administration

MSM: men who have sex with men

RWHAP: Ryan White HIV/AIDS Program

SMI: Using Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum initiative

SMS: short message services

SPNS: Special Projects of National Significance

UCLA: University of California, Los Angeles

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Original Paper

A Gamified Smartphone App to Support Engagement in Care and Medication Adherence for HIV-Positive Young Men Who Have Sex With Men (AllyQuest): Development and Pilot Study

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Abstract

Background: HIV disproportionately impacts young men who have sex with men (YMSM) who experience disparities across the HIV care continuum. Addressing antiretroviral therapy (ART) adherence among YMSM is an urgent public health priority. Technology-based interventions—particularly mobile health platforms—can provide tailored adherence interventions and allow YMSM to engage and connect with others.

Objective: The objective of this study was to describe the development of *AllyQuest*, a novel, theoretically-based, smartphone app designed to improve engagement in care and ART adherence and social support among HIV-positive YMSM.

Methods: *AllyQuest* was built on an established platform for patient engagement that embeds social networking and fundamental game mechanics, such as challenges, points, and rewards. A medication tracker provides reminders to promote ART adherence via personalized adherence strategies that are user and context specific; a calendar allows for reflection on adherence over time. After iterative development with input from two youth advisory boards, usability testing was conducted to assess app functionality, comprehension of the educational content, use of intervention features, and overall impressions of app relevance and appeal. A 28-day pilot trial was conducted with 20 HIV+ YMSM to evaluate intervention feasibility and acceptability.

Results: Mean age of participants was 21.8 years (range 19-24), and 95% (19/20) of the participants were nonwhite. The mean time of app use was 158.4 min (SD 114.1), with a range of 13 to 441 min. There was a mean of 21.2 days of use (out of a total possible 28 days). There were 222 posts to the daily discussion social wall. Feasibility and acceptability ratings were high. Overall, participants found the app easy to use and navigate, not intrusive, and had few reported technical issues. Higher levels of app usage were positively correlated with HIV self-management outcomes, and there was a statistically significant ($P<.05$) positive association between the number of days logged into the app and knowledge and confidence in ability to reliably take HIV medications.

Conclusions: *AllyQuest* represents a new, highly scalable solution that is well-suited to meet the specific prevention and care needs of HIV+ YMSM. The development of this intervention is both timely and vital, given the urgency of the ongoing HIV epidemic among YMSM.

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KEYWORDS

YMSM; antiretroviral adherence; smartphone app; gamification; social networking

Introduction

HIV Infection Among Young Men Who Have Sex With Men in the United States

In the United States, men who have sex with men (MSM) experience the highest rates of new HIV diagnoses, with young MSM (YMSM) and MSM of color continuing to be significantly impacted [1]. Although the number of diagnoses of HIV infection among MSM remained stable, from 2010 to 2014, the number of diagnoses among MSM in the age range of 13 to 24 years increased by 6% [2]. National HIV Behavioral Surveillance data on MSM from 20 cities found that among black MSM in the age range of 18 to 24 years tested in 2014, 26% were HIV positive, compared with 3% of white MSM. This disparity in HIV prevalence between black and white MSM increased from 2008 to 2014, especially among YMSM [3]. Young Hispanic or Latino MSM had a 20% increase in numbers of diagnoses of HIV infection from 2010-2014 [2].

HIV also disproportionately impacts YMSM across the HIV care continuum, with disparities in linkage, retention, antiretroviral therapy (ART) adherence, and viral suppression [4,5]. YMSM have documented low levels of ART adherence, impeding their likelihood of achieving viral suppression [6]. One study among 13 sites in the US Adolescent Trials Network found only 7% of diagnosed youth (81% male, 72% black, and 70% gay or bisexual) achieved viral suppression [5], which was substantially lower than the estimated 50% viral suppression for all age groups [4,5]. Alarming, a recent study of 991 HIV-infected YMSM (aged 15-26 years) found that 69.4% had a detectable viral load; two-thirds of whom (n=458) reported recent condomless anal sex [7].

Barriers to Adherence Among Youth

Individual-level stated barriers to adherence among youth include forgetting, not feeling like taking medication, and not wanting to be reminded of HIV [8]. Additional factors contributing to suboptimal adherence and viral suppression among youth, including YMSM, include low medication adherence self-efficacy [9], psychological distress (depression and anxiety) [10-13], substance use (alcohol, marijuana, and other drugs) [10,13,14], structural barriers (eg, homelessness and health insurance) [15], low social support [11,16], and HIV-related stigma [10,11,17]. Multiple factors are often present, and these *syndemics* are associated with greater likelihood of nonadherence and detectable viral load in a dose-response nature [10,18] that also shows disproportionate impact on minority MSM [18].

There are only a few published interventions focused on supporting ART adherence among YMSM [19,20]. A 2017 systematic review of interventions along the HIV care continuum identified 117 medication adherence interventions. Only 9 (9/117, 8%) focused on adolescents or youth, and only 2 were specifically designed for MSM [19]. A 2014 review of adherence

interventions meeting the Centers for Disease Control and Prevention's criteria for evidence-based interventions found none that exclusively focused on MSM or youth [21]. Due to the often marginalized and stigmatized status that many YMSM living with HIV endure, there is a need for the development of tailored interventions that account for the unique and challenging circumstances they face.

Tailored interventions have been found to produce higher rates of behavior change and maintenance than nontailored programs in a variety of health domains, including HIV [22-24]. Technology-based interventions—particularly mobile health (mHealth) platforms—can provide tailored adherence interventions and allow YMSM to engage and connect with others [25-27]. mHealth tools also offer the capacity to design and deliver tailored content that best meets the specific HIV management challenges faced by YMSM and each individual end user [25]. The fidelity to intervention delivery provided by mHealth and the market saturation of mobile technology ownership across socioeconomic strata [28,30] also provides a high-impact platform that can be taken to scale across and beyond the United States. Daily mobile phone-based contact is acceptable to youth living with HIV and is associated with improved adherence [29]. In this paper, we describe the development, usability evaluation, and subsequent pilot testing of *AllyQuest*, a tailored mobile phone app to increase engagement in HIV care, ART adherence, and social support.

Methods

Intervention Development (September 2015-May 2016)

AllyQuest is a novel, theoretically-based, mobile phone app intervention designed to improve engagement in care and ART adherence and social support among HIV-positive YMSM (target age: 16-24 years). *AllyQuest* development was guided by evidence-based risk reduction and medication adherence interventions [30-32]; health behavior change theories, including social cognitive theory (SCT) [33,34]; narrative communication (eg, storytelling) [35-38]; and the principles of persuasive technology [39]. *AllyQuest* addresses key principles of SCT, including (1) Observational learning by participating in daily activities, (2) Modeling and vicarious experiences (observing and participating in daily discussions, exploration of narrative “choose-your-own-adventure” stories), (3) Self-efficacy and verbal persuasion from expert sources (multimedia knowledge center and tailored messages), and (4) Reinforcements (virtual rewards and achievements) [33,34-40]. Narrative storytelling relies on the modeling of behaviors by similar others and has been shown to foster self-reflection and influence disease self-management [41-43]. The Fogg Behavior Model (FBM) [39] of persuasive technology informed the development of Ayogo's Empower Platform, the operating system on which *AllyQuest* was developed. According to the FBM, the principal factors to promote behavior change using technology include triggers, ability, and motivation. The design of *AllyQuest*

enhances motivation and skills and provides triggers to encourage positive behaviors. App notifications are *triggers* for healthy behaviors. Regular behavioral self-report prompts serve as additional triggers and help participants establish healthy habits. *Ability* is increased through knowledge and by identifying small steps toward target behavioral goals (eg, understanding side effects and knowing how to fill a prescription). Participants also get tips from others who are dealing with similar issues and through narrative stories within the app that reinforce the consequences of healthy and unhealthy behaviors. App *motivators* include social support, rewards, goal setting, and achievements.

Concepts for *AllyQuest* design and overall “look and feel” were informed by research we conducted with HIV-positive YMSM to understand technology utilization, the barriers and facilitators to ART adherence, and the use of an app to assist with adherence [26,44,45]. Gamification elements incorporated into *AllyQuest* included the ability to “level up,” earn and redeem in-app virtual currency, and the ability to unlock app features. Throughout development, we worked closely with two YMSM youth advisory boards, composed of eight HIV-positive YMSM, located in Durham, North Carolina and Chicago, Illinois. Youth advisory board activities included 13 in-person sessions and seven rounds of Web-based surveys.

Usability Testing (June 2016–August 2016)

Usability testing was conducted according to established usability guidelines [46] one-on-one with eight (nonyouth advisory board) HIV-positive YMSM aged 16 to 24 years. Participants were guided through app installation on their personal phones. They were asked to explore the app and complete specified tasks within the app without study staff assistance. While exploring the app, participants were asked to “think aloud” and provide a running commentary of their thought processes while performing the tasks [47]. The concurrent think aloud method was chosen to elicit real-time feedback and emotional responses [46,48,49]. Participants then received a guided tour of all app features. Participants were asked about their initial impressions of the app and completed a posttest survey to assess user experience. Participants were then asked to use the app daily for 1 week to assess ongoing functionality, monitor for any technical issues, ensure content comprehension, evaluate intervention features, and describe overall impressions of app relevance and appeal. To facilitate social connectivity, youth advisory board members also used the app during the usability testing period. A semistructured phone interview was conducted at the end of the 1-week testing period.

Intervention Refinement (August 2016–October 2016)

The research team collated all participant feedback into a usability report that was presented to the technological partner. Usability testing revealed several addressable technical bugs and user experience issues that were resolved. Usability participants also provided specific recommendations for content edits and expansion. The research team addressed as many of these suggestions as possible before pilot launch, and the remaining suggestions were prioritized for the next iteration of development.

Pilot Evaluation (October 2016–January 2017)

A 4-week pilot trial was then conducted with 20 HIV-positive YMSM to evaluate intervention feasibility and acceptability. Participants were recruited from a clinic in Chicago that primarily serves impoverished communities. Participants completed a pretest survey and then staff assisted with app download to participants’ phones. After 4 weeks of use, participants completed an online posttest survey and a phone-based qualitative interview.

Pilot Trial Measures

Sociodemographic Items

Sociodemographic items assessed age, race or ethnicity, education, income, homelessness, health insurance, and sexual identity.

Feasibility

Usage data was captured through in-app analytics and included number of times per day or week participants accessed the app and average time spent using app, daily number of activities completed and daily discussion questions answered, content of posts, and number of health-focused daily quests completed.

Acceptability

System Usability Scale (SUS) [50] is a 10-item, 5-point Likert scale of subjective assessments of usability. The SUS provides a global measure of system satisfaction and subscales of usability and learnability. For this trial, 9 of the 10 items were used, as one question was deemed duplicative.

Client Satisfaction Questionnaire-8 (CSQ-8) was used to assess global intervention satisfaction. The CSQ-8 has eight items (quality of app, kind of service received from app, app met needs, recommend app to a friend, amount of help received from app, effectiveness of app for dealing with health problem, overall satisfaction, and willingness to use the app again). These domains are assessed on a 4-point response scale with individually specified anchors. Participant responses are scored from 1 to 4, and thus, the possible total scores range from 8 to 32. Higher scores indicate greater satisfaction. The CSQ-8 has demonstrated high internal consistency across a large number of studies and has been used to evaluate technology-based interventions [51–55].

HIV Self-Management

We developed four questions to assess domains of HIV-specific self-management after versus before the 1-month pilot trial. These included feeling connected to others with HIV, knowledge about HIV, ability to effectively manage HIV, and ability to reliably take ART. All outcomes were measured on a 5-point Likert scale, ranging from 1=“Much less” to 5=“Much more.”

Pilot Trial Analysis

Frequencies and measures of central tendency (means, medians, and SDs) were calculated to describe the sample in terms of sociodemographics and acceptability, feasibility, and 4-week retention. Chi-square tests, *t* tests, and correlations were examined to provide preliminary effect estimates. Exact statistical tests were used where possible to account for the small

sample size. The Spearman rank order correlation coefficient was calculated to assess the magnitude of association between app usage and HIV self-management outcomes, where a value of 0 indicates no correlation, and higher values indicate stronger association between variables [56]. The Spearman rank order correlation is a nonparametric alternative to the Pearson correlation [57] based on ranks instead of absolute values and is less sensitive to outliers and nonnormal variable distributions. Statistical analyses were conducted using SAS (SAS Institute Inc) software version 9.4 for Windows.

Results

Intervention Development

Youth advisory board members provided feedback on (1) Intervention structure and format (eg, organization of the intervention, appropriateness and appeal of language and images, and ease of navigation); (2) Intervention content and activities (eg, comprehension, acceptability, and relevance); and (3) Overall app impressions (eg, utility, interest, and enjoyment). Youth advisory board members' feedback informed content development in all app components (Table 1).

Table 1. *AllyQuest* intervention components and scientific rationale.

Feature description	Scientific rationale
Profile page	
Privacy features: these include avatars, pseudonyms, confidential pin number to open app, app time-out after 5 min of inactivity, and medication tracker that allows participants to choose any name (real or made-up) they want for their medication reminder.	Anonymity and privacy recognized as important for YMSM ^a electronic health. Found in work done by our team and others [58,59].
App progression meter: visual display of current app "level" and in-game currency that is visible to other participants. Participants level up and earn in-game currency based on app use. Redeem currency to unlock narratives and other app features.	Game-based elements (eg, levels and competition) influence intervention engagement and impact [60].
Daily discussion	
Social prompts: (eg, How do you remember your medication?) kick-off daily discussions to foster community, peer sharing, model successful behaviors, and provide reinforcement.	Social support and connection with others are important features for apps for HIV-positive YMSM [61].
Medication tracker	
Medication reminder system: discreet personalized reminders and habit building solutions to promote ART ^b adherence.	Medication reminders improve adherence, but may not be sufficient [62].
Tailored adherence strategies: upon initial set-up, participants enter medication details, including the number of times/day and preferred time of day taken and any food restrictions. The app uses this information to provide suggestions on adherence strategies (eg, Take when I brush my teeth). Participants who are having adherence difficulties will receive tailored feedback on new strategies and adherence tips.	Dynamic tailoring and unique feedback based on frequent assessments effectively promotes behavior change for many conditions, including HIV prevention and ART adherence [61,63].
Brain builders	
Daily quest: actionable routine tasks help users set goals and build knowledge or skills.	Rated highly by usability and pilot participants. Gamification increases intervention engagement and impact [62,60].
Brain games: quizzes and interactive exercises help users check knowledge and skill	
Knowledge center	
Multimedia: presentation of information that includes HIV-related, safer-sex, relationships and general health and wellness. Users prompted with a reflection question after each article to apply the material to their lives. Visual shows progress toward completing each section.	Formative work of our team and others has identified that HIV+ YMSM desire information on both HIV-related issues and general health and wellness [64].
Character-based narratives	
"Choose-your-own adventure" narratives feature HIV+ YMSM navigating common situations that impact care engagement and ART adherence (eg, unstable housing, substance use, and disclosure). Play through story paths allows the user to face hard choices that impact health, practice problem solving, and succeed or fail in a safe space.	Narrative communication through role modeling has been identified as facilitating health behavior change [35-38].

^aYMSM: young men who have sex with men.

^bART: antiretroviral therapy.

Usability Testing

Usability testing revealed several addressable technical bugs and user experience issues. Given the time frame and cost considerations with app development, we prioritized bug fixes and user experience issues. Although users had other suggestions for app improvement (eg, making the daily discussion more like Facebook and using different imagery in the profile area), these changes were deemed by the research team and technical partners to not likely impact pilot trial outcomes in a meaningful

way and given development cost, were prioritized for a later study.

App content was also reviewed by usability participants who provided specific recommendations for areas of the app that could be expanded (brain builders and daily discussion posts) and edited (collection stories and daily quests). The research team worked to address as many of these suggestions as possible before the pilot launch. Figures 1-6 provides screenshots of the fully developed *AllyQuest* app.

Figure 1. Profile page.

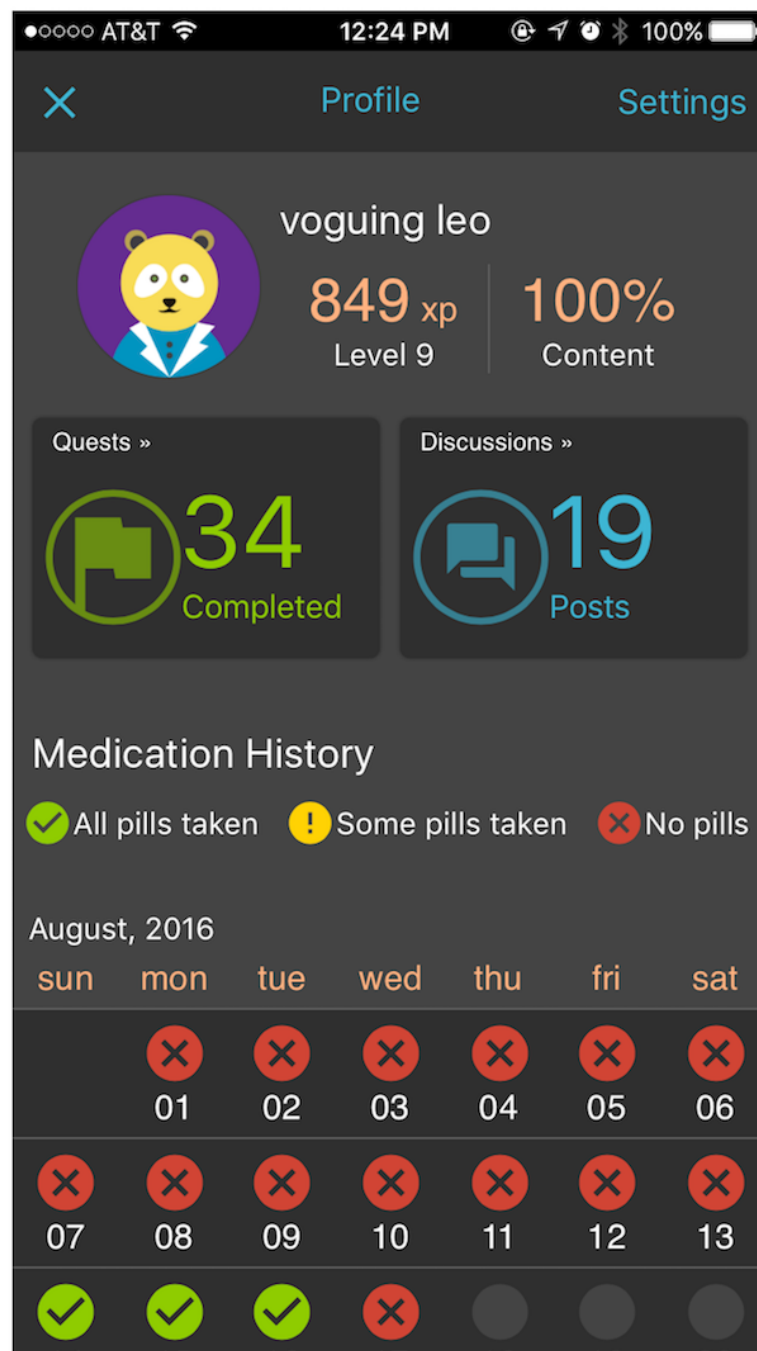


Figure 2. Daily discussion.

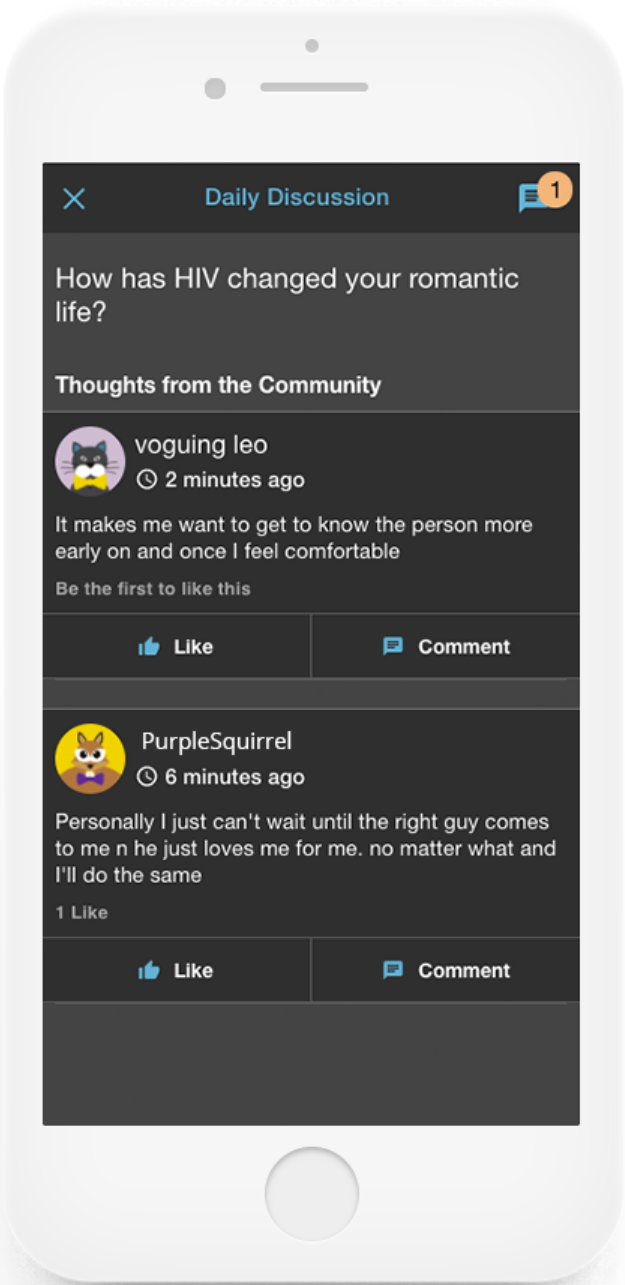


Figure 3. Medication tracker.

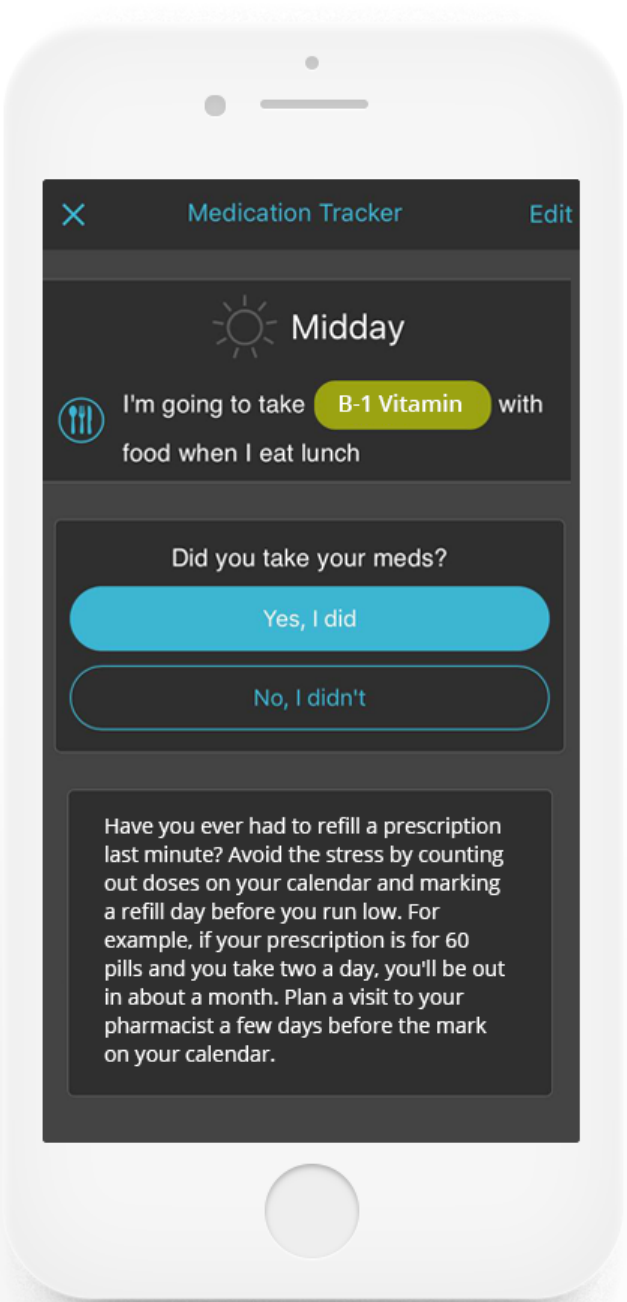


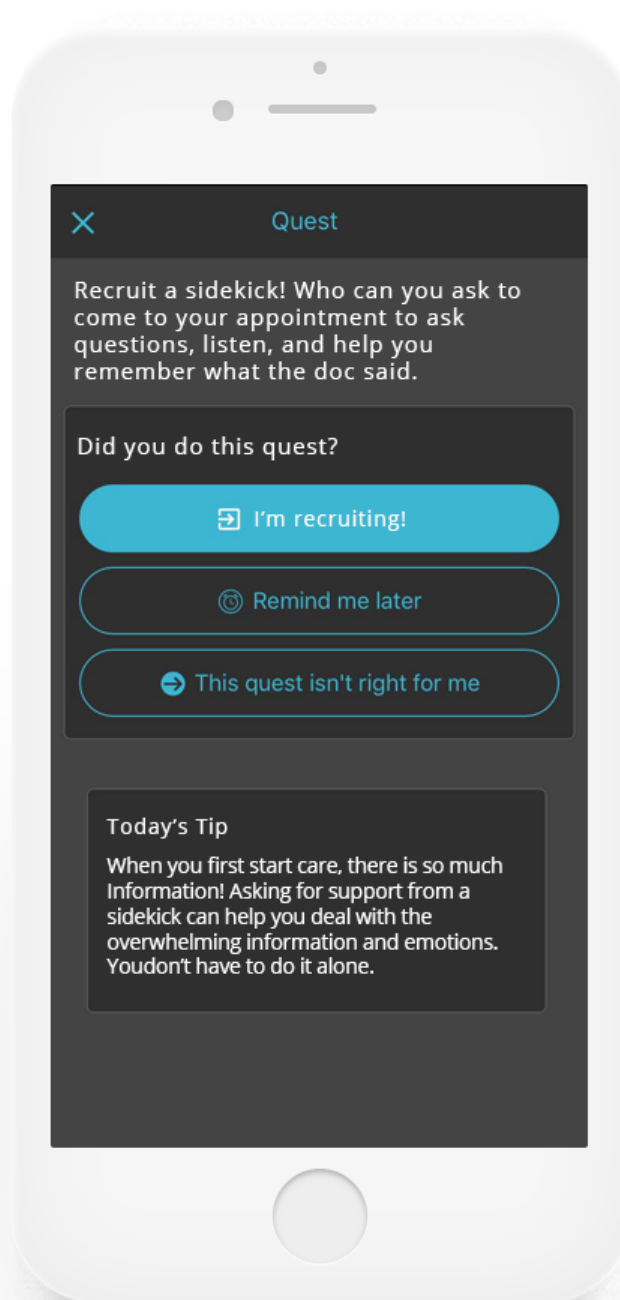
Figure 4. Daily quest.

Figure 5. Knowledge center article.

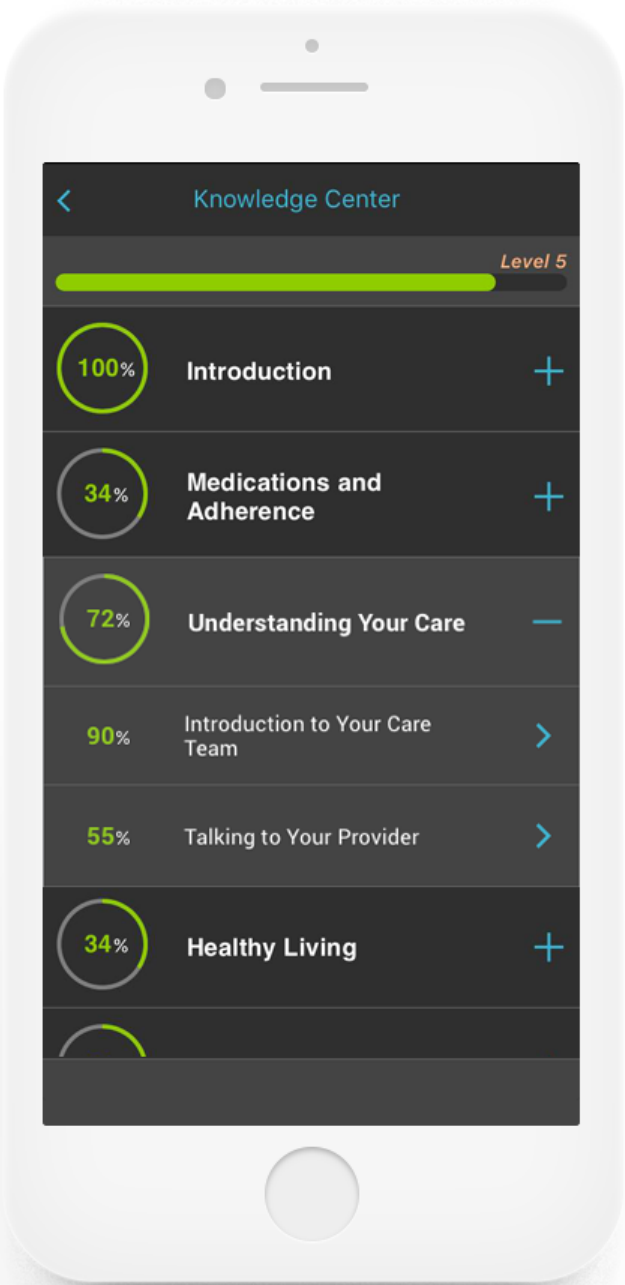


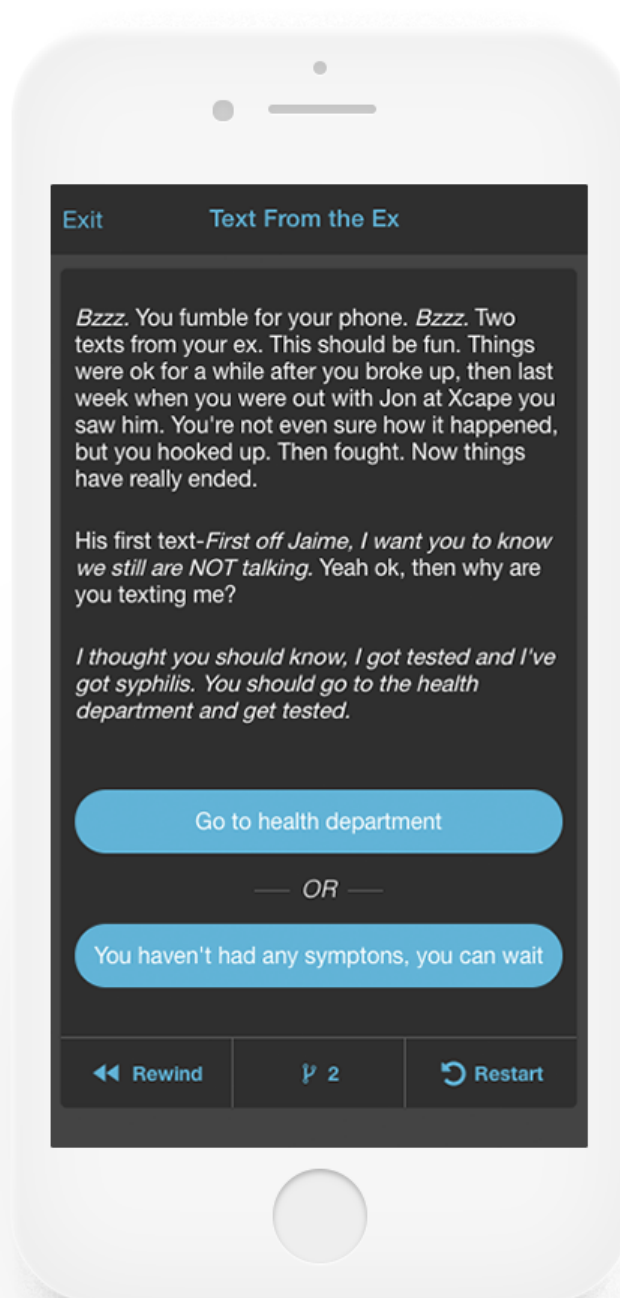
Figure 6. Narrative story.

Table 2. Demographics *AllyQuest* pilot study participants, N=20.

Variable	Statistics
Age (years), mean (SD)	21.8 (1.55)
Race or ethnicity, n (%)	
Black	17 (85)
White	1 (5)
Hispanic or Latino	1 (5)
American Indian or Alaskan native	1 (5)
Education, n (%)	
Completed high school	12 (60)
Some college	3 (15)
Did not complete high school	5 (25)
Sexual identity, n (%)	
Gay	19 (95)
Bisexual	1 (5)
Employment, n (%)	
Currently employed	13 (65)
Homeless last 6 months, n (%)	
Yes	5 (25)
In HIV care, n (%)	
Yes	20 (100)
On HIV medication, n (%)	
Yes	19 (95)

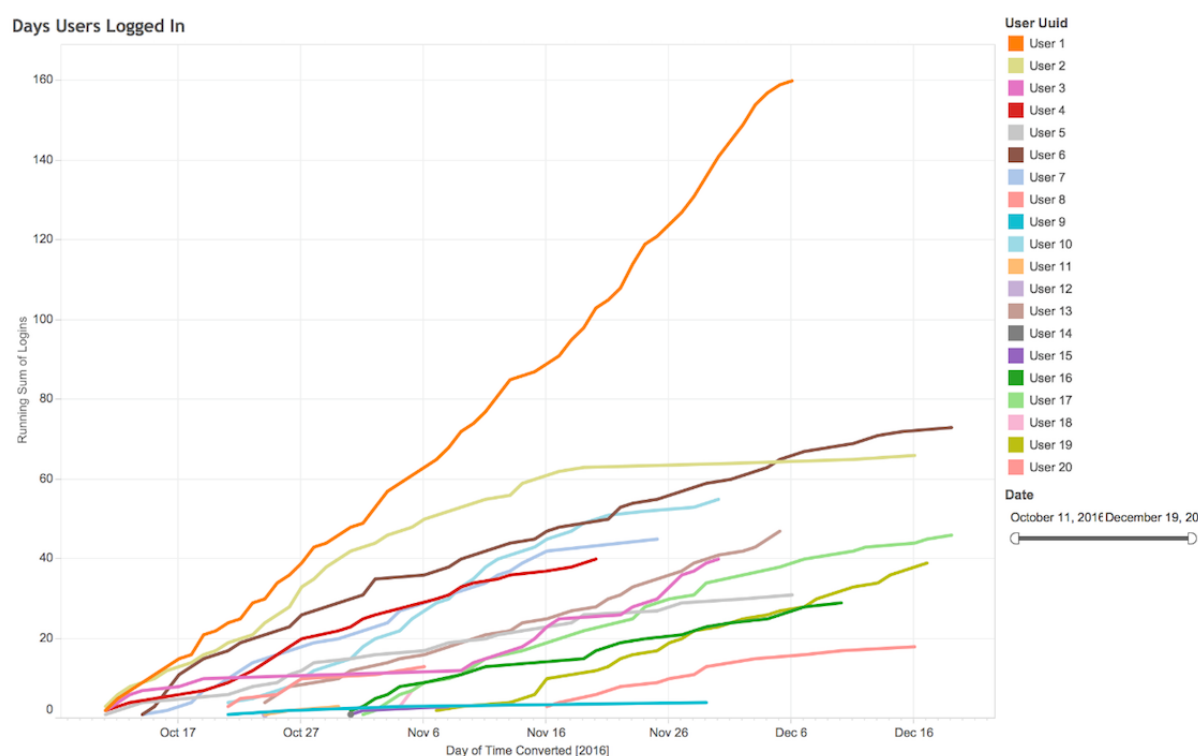
Pilot

The mean age was 21.8 years (range: 19-24), 95% (19/20) were nonwhite, 95% (19/20) identified as gay, 25% (5/20) had not completed high school, 65% (13/20) were currently employed, and 25% (5/20) reported homelessness in the past 6 months (Table 2). Most (16/20, 80%) participants had been diagnosed in the past year, all reported being engaged in care, and 95% (19/20) were currently prescribed ART. One-month retention was 85%, (17/20) though all pilot participants engaged in app use during the trial.

App Feasibility

The mean total time of app use was 158.4 min (SD 114.1), and range was 13 to 441 min. There was a mean of 21.2 days of use with a mean of 19.4 days of logging medication (Figure 7). App usage declined over the course of the trial, with a mean of 4.3, 3.4, 3.0, and 2.8 days of usage during weeks 1, 2, 3 and 4, respectively. Although participants were told that they only needed to use the app for 4 weeks, their access to *AllyQuest* was not discontinued until the final participant completed the trial. A total of 14 participants continued to use the app after their

4-week pilot trial period ended. There was a total of 17 knowledge center articles available during the pilot. Participants read a mean of 8.3 articles (range: 0-17). A total of 45 daily discussion questions were developed by the study team that appeared to participants on consecutive days during the pilot trial (eg, a participant enrolled on October 1 would see daily discussion topic #1, whereas a participant enrolling on October 7 would see would see daily discussion topic #7). If a participant did not log on, then they would not see the daily discussion topic that day but could navigate back to those conversations to comment. There were 222 posts to the daily discussion social wall, with a median of 5 posts (range: 1-11) for each daily discussion question. Most users (16/20) posted at least once during the 4-week pilot (median: 5.5 posts/person, range: 0-41 posts). The questions that received the most posts included “What is one goal you have for your health?” (11 posts), “How do you start the safe sex conversation?” (8 posts); “How do you deal with people who react badly to your status?” (7 posts), “How did you incorporate taking meds into your routine?” (7 posts), “What qualities do you appreciate in a healthcare provider?” (7 posts,) and “How has HIV changed your romantic life?” (7 posts).

Figure 7. Days and log-ins among participants in *AllyQuest* pilot trial.

App Acceptability

Acceptability ratings were high. Overall, participants found the app easy to use and navigate, not intrusive, and few reported technical issues (Table 3). The mean score on the CSQ-8 was 27.8 (SD 5.9). Most rated the quality of the app as excellent (n=10) or good (n=7), and overall, 15/17 were satisfied with the app. Overall, 16/17 participants felt they were getting the

kind of service they wanted from the app, 14/17 felt that the app met most or almost all of their needs, 15/17 reported being mostly or very satisfied with the amount of help they received from the app, and 15/17 felt the app helped them deal more effectively with their HIV. Most (16/17) would recommend the app to a friend if they were in need of similar help, and 16/17 would use the app again.

Table 3. *AllyQuest* pilot study outcomes (n=17); 5-point Likert scale (1=strongly disagree-5=strongly agree).

Survey item	Mean (SD)	Median (Q1, Q3)	Minimum, maximum
Would use this app frequently	4.41 (1.18)	5.00 (4.00, 5.00)	1.00, 5.00
App was easy to use	4.76 (0.56)	5.00 (5.00, 5.00)	3.00, 5.00
Felt very confident using the app	4.47 (1.01)	5.00 (4.00, 5.00)	2.00, 5.00
App is accurate	4.53 (1.01)	5.00 (4.00, 5.00)	1.00, 5.00
App is dependable	4.53 (0.62)	5.00 (4.00, 5.00)	3.00, 5.00
Interaction with app is consistent	4.18 (0.95)	4.00 (4.00, 5.00)	2.00, 5.00
Found app unnecessarily complex	1.65 (0.86)	1.00 (1.00, 2.00)	1.00, 3.00
Would need technical assistance to use app	1.71 (1.16)	1.00 (1.00, 2.00)	1.00, 5.00
App features are well integrated	4.53 (0.80)	5.00 (4.00, 5.00)	2.00, 5.00
Most people could learn to use app quickly	4.65 (0.61)	5.00 (4.00, 5.00)	3.00, 5.00
Found app cumbersome to use	2.76 (1.64)	3.00 (1.00, 4.00)	1.00, 5.00
After versus before: connected to others with HIV	4.12 (0.70)	4.00 (4.00, 5.00)	3.00, 5.00
After versus before: ability to manage HIV	4.47 (0.72)	5.00 (4.00, 5.00)	3.00, 5.00
After versus before: ability to reliably take ART ^a	4.59 (0.71)	5.00 (4.00, 5.00)	3.00, 5.00
After versus before: knowledgeable about HIV	4.29 (0.77)	4.00 (4.00, 5.00)	3.00, 5.00

^aART: antiretroviral therapy.

Table 4. Correlations between app usage and HIV self-management outcomes, n=17. Outcome compared with before participating in the study.

App analytics	Connected to others with HIV, rho (<i>P</i> value)	Knowledgeable about condition, rho (<i>P</i> value)	Ability to manage condition, rho (<i>P</i> value)	Ability to reliably take medication, rho (<i>P</i> value)
Days logged in	.31 (.22)	.53 (.03)	.33 (.19)	.49 (.05)
Days logged medication	.34 (.20)	.42 (.10)	.19 (.48)	.41 (.11)
Total time on app	.13 (.61)	.42 (.09)	.04 (.86)	.15 (.58)
Articles read	.01 (.98)	.29 (.28)	-.10 (.72)	-.07 (.78)
Social wall posts	.34 (.18)	.48 (.52)	.40 (.12)	.35 (.17)
Daily quests	.32 (.22)	.43 (.88)	.12 (.63)	.36 (.16)

Qualitative exit interviews (n=17) identified areas for app improvement, including the need for additional tailoring and personalization. Overall, *AllyQuest* met the needs and expectations of its users, as expressed by some users:

But, you know, it did help me to overall accept that I have to take this prescription because it's only going to help me in the long run. So it was good as far as helping me remember to take the medicine. [Participant 1004]

Being that I'm not much of a public speaker, in a sense, or an extroverted personality, the app kinda allowed me to, you know, bolster my genuine personal personality in a discrete manner, it was enjoyable. [Participant 1008]

Next I know I was just on this thing all day. My friends are like, "You're always on your phone." I'm like, "Oh yeah, it's this app. I really can't talk about it's my personal life." They're like, "Oh, okay." So I'm just always on my phone. [Participant 1007]

The daily discussion and medication tracker were users' favorite features. The discussions gave users a safe space to give and receive advice and made them feel less alone:

When I would read other people's comments on the little discussion panel thing—I would feel like I wasn't so alone...it made me feel like I was a part of a community that understood how hard it is dealing with something like that, because HIV is, like—it's something that's serious, and I always thought it was a death sentence because when I first found out I had it, I literally thought I was gonna die. [Participant 1020]

You're talking to profiles and it's really, really cool cause I get a lot of feedback that I would need in my life because I don't talk about it with a lot of people. So this is a way that I get to keep it private and to myself and also get help. So it's really been amazing. [Participant 1007]

The medication tracker helped users establish a medication strategy and normalize taking medications daily, as described by one user:

I've downloaded other apps where like a medicine tracker...it was just a very basic thing. And also I've had discussion forums on my phone where it just dove clean into something that was, like, I'm not gonna

talk about that just yet. So I think the app was, like, right there in the middle. It offered the avenue to go deeper into the conversation and it offered just a safe space at the same time. [Participant 1008]

Overall, users liked and trusted the health information on the app. Overall, they felt that the tone and content in the narratives was important and relevant. One participant described how these stories influenced his relationship with his partner:

Interviewer: How did the stories motivate you in the app?

Participant: It kinda motivated me to be more open with my partner...I would keep a lotta things from them. Like, I would go through stressful times and I wouldn't tell them...but after seeing how a lotta that stuff played out, like in the [app] stories, I try to start opening up more, and I think we're gonna stay together for a long time. [Participant 1002]

Participants did comment that they wanted more information regarding sexual health, relationships, mental health, and nutrition.

HIV Self-Management

Higher levels of app usage were positively correlated with HIV self-management outcomes, and there was a statistically significant ($P<.05$) positive association between the number of days logged into the app and knowledge and confidence in the ability to reliably take HIV medication (Table 4). Although statistical power was limited because of the small sample size, results are promising for a full intervention trial.

Discussion

Principal Findings

In this paper, we describe the development of a novel, theory-based ART adherence app for YMSM that showed strong acceptability, feasibility, and preliminary impact on HIV self-management outcomes. Prior work has established that technology-based interventions—particularly mHealth platforms—can provide tailored adherence interventions and allow YMSM to engage and connect with others [25-27]. Furthermore, daily mobile phone-based contact is acceptable to youth living with HIV and is associated with improved adherence [29]. Although several mHealth adherence studies for MSM are underway or under development [65,66], to our knowledge, there are no currently available interventions for

YMSM that include the range of features incorporated in *AllyQuest* or are poised to utilize technology in a similar highly innovative and engaging way.

HIV-positive YMSM were instrumental in informing all stages of *AllyQuest* development. Prior research with HIV-positive YMSM informed the inclusion of essential elements in the initial *AllyQuest* prototype, including information on both HIV-related issues and general health and wellness [64], anonymity and privacy features [58,59,64], medication reminders and tailored adherence strategies [59,63,67-69], and provision of social support and a connection with others [61,70]. Youth advisory board and usability participants provided further feedback that was incorporated in an agile way to allow for ongoing modifications and enhancements. The result of this process is a user-centered, highly engaging, multicomponent care support app.

AllyQuest accommodates different learning styles, motivations, and needs among YMSM through features including app-guided tailoring of content, personalized messages, and inclusion of game-based elements. Gamification uses game design components in nontraditional gaming contexts, thus providing opportunities for a greater level of engagement of participants in online behavioral interventions [60,71]. Interventions can utilize gamification to deliver highly engaging content and promote participant interactions both within and outside the intervention, thus increasing the potential for health behavior change. To optimize intervention engagement and impact, *AllyQuest* integrates health-related challenges, rewards, social connectivity, and “unlocking” character-driven narratives [60,71].

AllyQuest was built on an established platform developed by our technology partner, Ayogo. In a world of ever-shrinking resources, developing apps for ART adherence *de novo* may not take advantage of prior work done to improve treatment adherence in other disease states, thus failing to capitalize on lessons learned and software assets developed. Furthermore, collaborating with technology partners with established products allows for some degree of cost-sharing, ensuring that the app will be updated as needed and can be scaled up if proven effective. However, this process still requires active engagement with the target population to ensure adaptations are both developmentally and culturally congruent with their needs. Allowing sufficient time for iterative adjustments to the intervention is critical.

Understanding the full spectrum of app feasibility and acceptability before large-scale efficacy testing is essential. This entails measuring and subsequently aligning multiple streams of both in app (metrics of use and participant postings) and out of app (pre- and posttest surveys and qualitative exit interviews)

data. Ensuring the app has a robust back-end data system to capture all app analytics is a crucial piece that should be prioritized early in development. In this study, feasibility and acceptability metrics aligned with our primary HIV self-management outcomes, increasing the likelihood that *AllyQuest* could in fact impact long-term HIV ART adherence among HIV-positive YMSM. However, identifying additional strategies to ensure consistent and sustained app engagement should be considered. Integration of features that provide users who may not respond to technology-only solutions (eg, two-way text messaging or video counseling sessions with an adherence counselor) or stepped transition to in-person interventions should be considered in future studies.

Limitations

This study is not without limitations. Data on HIV self-management outcomes were self-reported and were only measured among participants who received the intervention. Due to the limited scope and length of this pilot study, enrolling a control group would not have been feasible, and measuring changes in biologic outcomes would not have been clinically meaningful. Statistical tests should be interpreted with caution, given the sample size. Findings may not be generalizable to YMSM from other sociodemographic backgrounds or geographic locations. Although we attempted to enroll diverse youth, the majority of participants were YMSM of color. Given the disproportionate impact of HIV among YMSM of color in the United States, these youth represent the population in highest need of interventions. Finally, we had 3 participants who did not complete their follow-up survey or interview, though all 3 participants logged on to the app and used it during the pilot study. Additional engagement and retention strategies will be important particularly when evaluating the impact of the app on out-of-care youth.

Conclusions

This small pilot trial confirmed that an interactive app is feasible and acceptable to YMSM as a tool to address ART adherence. Future work should build on the promising data from this trial to test *AllyQuest* in a larger, diverse sample to assess intervention efficacy for improving ART adherence and increasing sustained viral suppression. If a highly scalable technology such as *AllyQuest* could ultimately demonstrate effectiveness in implementation studies, it would be a powerful tool for realizing the individual and public health benefits of biomedical advances in prevention and care therapies. Furthermore, placing these tailored technologies in the hands of YMSM offers an approach to HIV self-management that may empower youth as they establish optimal HIV care engagement habits for the future.

Conflicts of Interest

Authors MS and EL were employees of Ayogo, Inc at the time of the study. There are no other conflicts to declare.

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Abbreviations

ART: antiretroviral therapy
CSQ-8: Client Satisfaction Questionnaire-8
FBM: Fogg Behavior Model
mHealth: mobile health
MSM: men who have sex with men
SCT: social cognitive theory
SUS: System Usability Scale
YMSM: young men who have sex with men

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Greg Millett On What Black People Can Learn About HIV Outreach

By David Artavia

Despite that HIV diagnoses have fallen slowly in recent years among black people — 25 percent in women from 2010 to 2016, 26 percent among straight men, and 5 percent among gay/bisexual men — the virus continues to impact the population in disproportionate numbers. While black people comprise only 13 percent of the U.S. population, they account for 43 percent of all HIV diagnoses, according to the [Centers for Disease Control and Prevention](#).

This year on National Black HIV/AIDS Awareness Day, it's time to broaden HIV education to not only reach black queer populations, but their families, friends, and health professionals as well. After all, everyone plays a part in helping to eradicate the virus — and we *can* do it if we come together.

If there's one person who can attest to the power of community, it's Greg Millett.

As vice president and director of public policy at amfAR, Millett has had significant experience working at the highest levels of HIV policy development at both the White House and the CDC. Growing up in New York City in the 1980s, his dad worked in St. Vincent's Hospital, which at the time was ground zero for HIV.

By the time he graduated Dartmouth, he had at least 20 friends who had died of AIDS complications. That's when he and his community of black and Latino gay men decided to do something about it by getting involved in work around safe sex and education about HIV. Together, they attended ACT UP meetings and started learning about local and federal policies. These years lead him to get a degree in public health where he eventually fell in love with research, and thus began his career as a scientist with the CDC.

A black man living with HIV himself, Millett was also one of *Plus's* [Most Amazing Poz People](#) last year. Recently, the scientist spoke with *Plus* about the past, present, and future HIV outreach:

How important is it to have people of color in the research team and in the health industry? Do you think it changes perspectives in strategy?

It does and it doesn't. It does in the sense that it provides some sort of cultural framing and background for certain things. I remember when I was in school of public health in North Carolina, and we were speaking with a team of researchers who were trying to more black women to be involved in exercise classes. They said that they were having trouble getting black women involved, and we asked, "Well, have you spoken to any black women about issues in terms of hair care and everything else? Because if you have perm and you have sweat, it ruins a very expensive hairdo that you have." These researchers had no idea about that. In that sense, it was extremely helpful.

Also, for me, by the time that I came on the scene and we kept seeing these exploding rates of HIV among black gay men while at CDC, the main narrative was that these men are engaging in very high rates of risk behavior. I did not see that from the accumulated data from studies beforehand — nor any of the studies that I had at CDC. That's where I built my career in trying to change the narrative among scientists to say: "This isn't about risk behavior. It's about greater rates of HIV within this community." So you have a greater community prevalence that's placing these men at risk, but they're actually engaging in lower rates of risk behavior compared to white gay men.

That tilt in perspective can change a lot.

In those regards, I do think it's helpful to have communities of color represented among scientists just to help frame what's [actually] going on. Or they might see certain things that are happening. I definitely don't believe this type of work, particularly research in communities of color, is solely the domain of scientists of color. I know incredible scientists not a part of this community who are doing such incredible work, who are really chipping away at why we see greater rates of HIV in the black community that I think is incredibly novel and innovative. Quite frankly, we're dealing with an emergency here, and we need as many minds as possible to really help solve this problem.

Which HIV education strategies have you seen work, and which have you seen that failed?

Strategies that haven't worked have been some of the behavioral interventions that CDC traditionally had in the '80s and the '90s. Interventions where they would try and reduce what they would call risk behavior — unprotected sex, the number of sex partners, drug use, etc. The problem with a lot of those strategies is that black gay men were already engaging in less unprotected sex and had fewer sex partners than white gay men, but the rates of HIV were still higher. So you had this paradox that was taking place: They were also less likely to use drugs at the time, particularly any club drugs or methamphetamine.

[Still,] that wasn't explaining the high rates of risk behavior, and those strategies were not helpful. It was great when CDC started to finally pivot away from those strategies for this population because they realized through my research and research of others that that's not the reason why we're seeing these high rates of [contraction].

The strategies that do work are really dealing with social determinants of health, dealing with some of the structural inequalities, not having access to healthcare. If you don't have access to healthcare, you're less likely to be on antiretroviral medication if you're HIV-positive, which means you're less likely to get virally suppressed, which means that you're more likely to transmit HIV to your partners. Also, access to healthcare means you also are more likely to get tested for HIV. And if you're not tested for HIV, you don't realize that you're HIV-positive, [then] you unwittingly transmit HIV to your partners. You see that often in black communities and particularly among black gay men where there are high rates of unrecognized HIV [contractions].

Also, a lack of access to PrEP right?

Pre-exposure prophylaxis [PrEP] is an incredible innovation, and would be helpful if scaled up, but you find that communities of color are less likely to [practice PrEP]

compared to white communities in the United States. That's another part of the reason why we see these exploding rates particularly among black gay men. We really need to deal with some of these social determinants, which we started doing with the passage of the Affordable Care Act where you see more black gay men getting health insurance, more black gay men who are getting PrEP, more black gay men who are actually receiving antiretroviral therapy.

A lot of those types of interventions, particularly health insurance, is under threat right now. We have a new administration that doesn't necessarily believe in the Affordable Care Act, that wants to roll back pre-existing conditions as a determinant of getting healthcare, which can have dire consequences.

Living in New York City, I see advertisements for PrEP almost daily on subways and radio spots. Do you think that's helping target the communities it needs to reach?

Honestly, I think there's so much need in making sure that people understand that [PrEP] is a medication that's out there that can actually reduce or actually prevent HIV infection at astonishing rates, 99 percent or so. The funny thing is that most of the American public doesn't know this.

There was a study the Kaiser Family Foundation found that a plurality of youth, young people are at high risk of HIV, particularly in people of color, never heard of pre-exposure prophylaxis. I think that Gilead is doing the right thing by really trying to increase the awareness about it. And where I think it's helpful is two ways: One, for those people who have friends or others in their community who they know may be at high risk, might be gay or bisexual or transgender, having your mother, your sister, your brother, somebody say, "Hey, I heard about this pill called PrEP, I saw it on the T.V. or heard about it on the radio. Is this something you're considering taking? I want to make sure that you're okay and that you're healthy and that we prevent HIV." Something to that degree is going to be helpful by widening the message.

I also think that widening the message is helpful for those groups who don't necessarily identify as gay or lesbian. If you're only advertising in lesbian and gay magazines, you're going to miss men who have sex with men who don't identify as gay. Even though their risk for HIV is less compared to men who do identify as gay, there's certainly men who don't identify as gay who are at a high risk of HIV and do get HIV — and unknowingly transmit to their male or their female partners. Broadening the message also reaches that group of men as well, who you may not necessarily get through the gay media. That's extremely helpful.

How important is it for celebrities to get involved in the fight against HIV?

It helps amplify the message to many different groups. You need to have different types of messengers to carry the same message. And sometimes a particular messenger is more likely to get that message through than another messenger. For instance, dealing with our current Congress, instead of me as a black gay man going to a Nebraska seat in the House of Representatives, a grandmother from Nebraska might be a better representative in conveying an HIV message. You find the same thing with celebrities. Celebrities are going to reach people and break through to certain groups more so than perhaps other communities. I think it's really a value-add to have them involved.

What other barriers do you think interfere with educating the community about HIV, and how can we overcome those? Does homophobia play a factor?

I think one of the biggest barriers is the fact that HIV isn't as visible in the media any longer. It's an issue that has been relegated to something that takes place over there, usually in sub-Saharan Africa. It's not necessarily an issue here. You don't see people who are walking around the streets with [Kaposi's sarcoma] or any other visible signs of HIV that you used to see. People with HIV are living normal and healthy lives, which is something that we should all be very thankful for with the advent of the new medications. But I think the side effect of that is that it's not as visible to the American public any longer.

There's a belief that this is something we have addressed and it's not necessarily an issue, and that's a problem, particularly when we're not even close to getting to zero rates of new [contractions] anywhere really in the United States at this moment, particularly in communities of color. If we still have this belief that HIV is no longer an issue here, it certainly affects what takes place in Congress in terms of funding for HIV both domestically as well as globally, which is part of the reason we have to keep putting pressure on congressional officials, through the media. It's really shown a light how the HIV epidemic persists in the United States, but despite the fact that it's not as visible as it used to be.

Can you give us a reason to be optimistic in the future for people who might look at what's happening around them in this political climate and feel a bit lost or scared for their future healthcare?

I think the optimism we do have is that for the most part, at least recently, HIV is becoming more of a bipartisan issue. It certainly has been that way for global HIV. It's increasingly becoming that way for domestic HIV as well, particularly with the opioid crisis and you're seeing large numbers of people who inject drugs or numbers of people who inject drugs who unfortunately are being diagnosed with HIV — particularly in red states in the United States where congressional officials who previously didn't think that this was necessarily an issue for them are now having to confront this.

There are certain things the president is saying that we're seeing in the administration as well that's going to be helpful for people living with HIV. There are now efforts afoot to reduce drug costs in the United States across the board. And that's certainly going to be helpful for people living with HIV in terms of being able to afford certain drugs, making sure that their insurance is able to put them on drugs that could help get them to viable viral suppression. Many more people being able to get access to these drugs if it's less money for them insurance-wise, and that's certainly something that's helpful.

What about U=U? How do you think we can get that message across as well in a way that resonates as strongly as PrEP?

One thing that we keep seeing over and over again is that despite being in the midst of this epidemic for 30 years, there's been little impact in terms of HIV/AIDS stigma. A lot of the same biases we've seen for people living with HIV from the 1980s persisted up until maybe about seven, even eight years ago. Now, we're starting to see a precipitous change in that. Some of that change was really heralded by PrEP, particularly in the gay community. We used to have essentially these HIV ghettos. We

used to call it HIV apartheid where positive gay men only dated positive gay men, and negative gay men only dated negative gay men. With the advent of PrEP, that completely changed the calculus where HIV status is not necessarily as limiting factor for dating any longer.

I think that U=U also has the same possibility for reducing HIV/AIDS stigma where people living with HIV are no longer looked at as vectors of disease; where people would understand that being undetectable means that you have essentially zero risk of transmitting HIV as long as you remain undetectable and on your [meds]. I think the extension of that message is something that we're definitely going to see in the future.

The thing we need to take a look at is that being undetectable is not the goalpost now. Continued viral suppression is the main goalpost because there are data that CDC announced during the last black HIV/AIDS Awareness Day that were really concerning for a lot of us: Among all people living with HIV in the United States, about 52 percent of us were not continuously virally suppressed. That's a problem. And the CDC also found that it didn't matter which demographic group of African-Americans who we're looking at compared to whites — be it men, women, youth, gay men, transgender individuals, people who inject drugs. African Americans were less likely to be continuously virally suppressed as compared to their white counterparts in each one of those groups.

If we don't have continuous viral suppression, then we will never be able to end AIDS in the United States. We need to make sure that people who are living with HIV are not just virally suppressed, but continue to be virally suppressed for the extent of their lifetime and have that through affordable healthcare, making sure that mental health counseling, as well as drug counseling, is available for those individuals who need it, and making sure that there's access in transportation to healthcare services because we get health insurance largely through insurance through employment in the United States, making sure that PWAs are gainfully employed. So, there are many things we need to do to make sure that people living with HIV are consistently virally suppressed.

Sex Workers Are the Real Experts At HIV Outreach

By Savas Abadsidis



Sex workers, often overlooked in HIV outreach, finally get attention.

October 31 2018 5:00 AM EDT

The weekend before the 2018 International AIDS Conference, a group of media representatives toured Amsterdam's Red Light District, which has the largest concentration of sex workers in the Netherlands. Amsterdam's efforts to prevent HIV in the sex worker community takes a harm-reduction approach, which is perhaps why you are more likely to get an STI from a university student than a sex worker in the country, according to director of the Prostitution Information Center, Nadia van der Linde.

The center provides a wealth of material about the local sex work scene. Van der Linde soberly explains that the city's conservative voices are calling for further curtailing or complete elimination of both the sex and cannabis trades due to what's being seen as an "unsustainable" influx of tourists seeking both.

Van der Linde joined the PIC board in 2016 when its founder, Mariska Majoor, retired from the role. Van der Linde is also a coordinator at the Red Umbrella Fund, a global grantmaking organization run for and by sex workers.

Majoor, a former sex worker, is also cofounder of Proud, a Dutch sex workers union; and author of several books about sex work. Majoor and van der Linde reiterate that the female (both cis and transgender) "freelancers" who work in the Red Light District have lower STIs and HIV transmission rates than female students in the Netherlands.

"It's the stigma," Majoor says about what makes sex work dangerous, even in Amsterdam's permissive (but heavily regulated) environment. "The more you criminalize sex work, the more every aspect of the business becomes stigmatized and invites more danger." And stigma, she

underscores, “is what really kills.”

Lyle Muns, a student of political science at the University of Amsterdam, agrees. Sex work is Muns’s side hustle. He’s also a vocal advocate for people living with HIV. He came out as HIV-positive last year in a YouTube video.

“People with HIV usually do not say they have it,” Muns says. “While it’s fine to live with this virus, there are a lot of misunderstandings so talking about it is difficult. So, I call it a coming out because I want to emphasize that. If I did not get out of the closet, it wouldn’t fight the stigma as well.” The young student is also in favor of global decriminalization of sex work and represented the Netherlands as part of the country’s delegation at the International AIDS Conference.

Most of the effort to test and treat sex workers in Amsterdam falls on the shoulders of the Prostitution and Health Center 292, which provides general healthcare and STI testing (including HIV), as well as counseling and treatment. While primarily serving women, counselor Sjaak van der Kolk said he sees nearly 300 male sex workers a year, most who have sex with other men. Van der Kolk estimates the total population of male sex workers in the city to be nearly 700 — far less than the estimated number of women (3,000).

Muns supports laws against sex trafficking, but he suggests the enforcement of these laws making sex work a crime can cast a wide net by also putting those who practice consensual sex work in jail. “Look, sex work exists in any kind of society, it doesn’t matter what kind of laws you have,” Muns says bluntly. “Whether you completely criminalize it or completely legalize it, the question is how much you know about it and how able are you to control the issues that are going on in the sector, to provide health, to guarantee security.”

With criminalization, comes stigma, fear of retribution, and less control over sex workers’ own agency — all of which can actually invite violence, abuse, and trafficking. An advocate for PrEP, the HIV prevention strategy that when taken as prescribed makes it virtually impossible to contract HIV, Muns argues one of the reasons he acquired HIV was because PrEP is not widely available in the Netherlands and that the cost (nearly \$600 a month) is prohibitive for most people. Hopefully that will change. Muns says the LGBTQ community is “working towards getting PrEP covered by the government and educating the public.” But there is still a long way to go.

“[Doctors] only think that men that have sex with men are the only ones who should have access,” Muns says. “But I think anybody that has certain sexual health risks should have access to PrEP, right?”