RESEARCH PROTOCOL

Promising Approaches for Engaging HIV-positive Youth and Young Adults in HIV Primary Care
Using Social Media and Digital Technology Interventions

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Introduction

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 to older HIV-positive populations. Zanoni & Mayer [1] estimate that only 25% of HIV-positive youth and young adults are linked to care, 11% retained in care, and 6% virally suppressed. While limited information is available on clinical outcomes in youth, their retention in care rates suggest that they are less likely to be meaningfully engaged in care and to achieve viral suppression [2–4]. Current ART regimes are less toxic and simpler, nonetheless 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 (e.g. homophobia, race/ethnicity, 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 infections, with African Americans (54%) and Latinos (22%) being the largest racial/ethnic groups affected [7]. 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 healthcare 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 healthcare insurance and lack of transportation, especially among those who are low income and/or racial/ethnic minorities [14–16].

Most interventions that address barriers to care have been developed for adults [1] and have not been geared to youth struggling with identity formation, economic hardship and unstable housing among other daily survival issues [1,7]. One promising new strategy is the use of digital technology. Such technology use among youth constantly increases and new forms of communication technology and online social networking offer opportunities to reach and engage young people for health promotion [17–19].
Social Media and Digital Technology

Significant gains can be made to improve the health outcomes of HIV-infected youth and young adults using social media and digital technology for engagement and retention in HIV medical care. Media and technology that facilitate social interaction (i.e., social media) are preferred among young adults, who spend more time with media and digital technology than any other activity [20,21]. The science and practice of using social media and mobile application (apps) interventions hold great promise. A growing body of evidence suggests that social media and app-based interventions can help in achieving HIV care program priorities, including: linkage to care, retention in care, and adherence to HIV medications [22–25]. Significant advantages to using social media and 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 anonymity. 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 [26–29]. Over 95% of all Americans own a cell phone [30] and over half (77%) own a smartphone; the highest percentage (92%) of smartphone owners are between the ages of 18-29 [30].

Overview of the SPNS Social Media Initiative

On September 1, 2015, the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB), 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). The initiative includes ten demonstration projects in HIV care sites or community-based organizations located throughout the U.S. An Evaluation and Technical Assistance Center (ETAC) was awarded to the Department of Family Medicine at the University of California, Los Angeles to provide technical assistance to demonstration projects, and develop and implement a rigorous multi-site evaluation. Demonstration projects use social media and digital technology for identifying, linking, and retaining HIV-positive, underserved, underinsured, hard-to-reach youth (ages 13-24) and young adults (ages 25-34) in HIV primary care and supportive services. The overarching goal of this initiative is to create a system change – improvements in policies and procedures – that results in improved HIV health outcomes for youth and young adults. Demonstration sites and the ETAC are funded for four years.

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

Demonstration Sites

Via a competitive proposal process, HRSA selected demonstration sites that reflected innovative approaches using a variety of social media and digital technology strategies deployed via internet, or mobile applications that have been designed to improve engagement and retention in care and achieve viral load suppression among youth and young adults living with HIV. The ten demonstration sites are located in: Los Angeles, CA; San Francisco, CA; Chicago, IL; St. Louis, MO; Winston-Salem, NC; New York, NY; Cleveland, OH; Hershey, PA; Philadelphia, PA and Corpus Christi, TX. Each demonstration site proposed and is using its own outreach, linkage, and retention strategies tailored for their local target populations. All sites used youth advisory boards, either to modify and tailor existing or to develop new intervention approaches for the populations they are serving.

Target Population

The initiative focuses on youth and young adults. As such, HRSA defined youth as persons between the ages of 13 and 24 and young adults as persons between the ages of 25 and 34. Sites focused on age ranges of their target population based on groups most affected by HIV in their local communities. The SMI includes all genders, races/ethnicities, and sexual orientations. Nonetheless, some interventions focus on specific populations, such as transgender women, men who have sex with men (MSM), or MSM within specific racial/ethnic groups such as African American or Latino. Interventions classified and described the respective target populations by setting, age, gender, race/ethnicity and sexual orientation for each demonstration site.

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. Engaging the target population 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 [31]. 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. Demonstration site staff typically recruited youth to attend regular meetings to ensure young people had consistent opportunities to provide input in developing strategies and to gather feedback about the effectiveness of implemented strategies. As an initiative, 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 [31]. Thus, 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 established a classification system that systematically summarized the main components of the interventions into a typology of the interventions. 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 [32]. 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 [33] The typology developed by the UCLA ETAC 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 ETAC used this typology in developing components of its multi-site evaluation of these interventions. Table 1 includes information on the respective target populations by setting, age, gender, race/ethnicity and sexual orientation for each demonstration site.

<table>
<thead>
<tr>
<th>Demonstration Site</th>
<th>Setting</th>
<th>Age</th>
<th>Gender</th>
<th>Race/Ethnicity</th>
<th>Sexual Orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coastal Bend Wellness Clinic</td>
<td>Community Clinic</td>
<td>&lt; 18 (13-34)</td>
<td>Male &amp; Female</td>
<td>All (focus on African American &amp; Latino)</td>
<td>All</td>
</tr>
<tr>
<td>Friends Research Institute Community Research Site</td>
<td>18+ (18-34)</td>
<td>Transwomen</td>
<td>All (tailoring to HIV+, young, transwomen)</td>
<td>Transwomen</td>
<td></td>
</tr>
<tr>
<td>Howard Brown Health Center Clinic</td>
<td>&lt; 18 (13-34)</td>
<td>Male &amp; Transwomen</td>
<td>All</td>
<td>MSM and heterosexual</td>
<td></td>
</tr>
<tr>
<td>MetroHealth System Clinic</td>
<td>&lt; 18 (13-34)</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td></td>
</tr>
<tr>
<td>Clinic</td>
<td>Inclusion Criteria</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>---------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New York State Department of AIDS Clinic</td>
<td>18+ (18-34), All, All, All (primarily MSM)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pennsylvania State Hershey Community and University Clinic</td>
<td>&lt; 18 (13-34), All, All, All (primarily MSM)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Philadelphia FIGHT/CHOP Community Clinic</td>
<td>&lt; 18 (14-29), All, All, All</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>San Francisco Department of Public Health Clinic and Hospital</td>
<td>18+ (18-34), All, All, All (primarily MSM &amp; transwomen)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wake Forest University University Clinic</td>
<td>&lt; 18 (13-34), Male, All, MSM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washington University St. Louis University Clinic</td>
<td>18+ (18-29), Male &amp; Female, All (primarily African American), MSM &amp; heterosexual (primarily young MSM)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Inclusion Criteria for Enrollment in the Multi-Site Evaluation

HIV medical eligibility criteria for enrollment in the multi-site evaluation is based on the U.S. Health and Human Services (HHS) common core indicators of for monitoring HHS-funded care services (https://www.hiv.gov/blog/secretary-sebelius-approves-indicators-for-monitoring-hhs-funded-hiv-services) 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, but had a gap in their HIV care that was greater than 6 months, within the last 24 months, and 4) Not being virally suppressed, defined as having a viral load of ≥ 200 copies/mL at their last lab test. Additional eligibility criteria included: 1) being between the ages of 13 and 34, 2) being HIV-positive, 3) meeting at least one of the above medical criteria determined from tests or medical records 4) providing informed consent (if 18 or older), or providing informed assent (if 13-17), and if required by state laws and regulations, obtaining consent from a parent/legal guardian, and 5) meeting any demonstration site-specific criteria (e.g., own a smartphone, be a patient at the site’s clinic) as necessary.

Technology Platforms
While each Demonstration Site’s intervention is unique, there are common components and functions. For example, all ten Demonstration Sites included a text messaging service component in their intervention, with three sites using text messaging services exclusively. The text messaging is done through short message services (SMS) or private messaging (PM) applications such as WhatsApp (https://www.whatsapp.com/) or Kik (https://www.kik.com/), while PM functions in mobile-web Apps or social media Apps/Sites. Almost all (n=9) of the Sites are using social media platforms such as Facebook, Snapchat, Instagram, and Twitter for outreach and recruitment. The different technology platforms used in each intervention are provided in Table 2.

Table 2: SMI Technology Platforms

<table>
<thead>
<tr>
<th>Demonstration Site</th>
<th>Facebook</th>
<th>Mobile Applications</th>
<th>Social Media: Instagram, Twitter, Snapchat, YouTube</th>
<th>Social Networking Sites / Apps</th>
<th>Text Messaging: automated, live, both</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coastal Bend Wellness, Corpus Christi, TX</td>
<td>√</td>
<td></td>
<td>√: Twitter, Instagram, YouTube</td>
<td>√</td>
<td>√, both</td>
<td>√, mobile optimized</td>
</tr>
<tr>
<td>Friends Research Institute, Los Angeles, CA</td>
<td>√</td>
<td></td>
<td>√</td>
<td>√</td>
<td>√, automated</td>
<td>√</td>
</tr>
<tr>
<td>Howard Brown Health Center, Chicago, IL</td>
<td>√ (adapted)*</td>
<td></td>
<td>√</td>
<td>√, automated</td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>MetroHealth System, Cleveland, OH</td>
<td>√</td>
<td>√ (new)</td>
<td>√</td>
<td>√, automated</td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>New York State Department of AIDS, New York, NY</td>
<td>√</td>
<td>√ (new)</td>
<td>√</td>
<td>√, both</td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>Pennsylvania State Hershey, Hershey, PA</td>
<td>√</td>
<td>√ (new)</td>
<td>√</td>
<td>√ – social networking,</td>
<td>√, both</td>
<td>√, mobile optimized</td>
</tr>
<tr>
<td>Philadelphia FIGHT/CHOP, Philadelphia, PA</td>
<td>√</td>
<td>√ (new)</td>
<td>√</td>
<td>√, both</td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>San Francisco Department of Public Health, San Francisco, CA</td>
<td>√</td>
<td>√ (new)</td>
<td>√</td>
<td>√, live</td>
<td>√</td>
<td></td>
</tr>
<tr>
<td>Wake Forest University, Winston-Salem, NC</td>
<td>√</td>
<td></td>
<td>√</td>
<td>√, live</td>
<td>√</td>
<td></td>
</tr>
</tbody>
</table>
Functions of the Interventions

The interventions perform ten functionalities represented in Table 3. Most Sites’ interventions had 7-9 functions (an average of 7) while one Site had only one, automated information function via SMS, and one other contained all ten. The most common components of the interventions are communication, information, social support / networking, and reminders for HIV medical care appointments, HIV medication, and non-HIV care related reminders. The least common components are the skills building and gaming components. In general, advisory groups communicated that medical appointment reminders and support for medication adherence were important. As a result, most interventions focused on helping participants to develop good habits in this regard. Developing skills and gaming were functions of interventions that targeted youth (13-24 years of age). The idea of “gamification” includes interactive games, quizzes, puzzles, and a points system for use of the mobile phone application. One Site’s mobile application and gaming components offers immediate feedback and incentives while using avatars to be more attractive to their target population.

Table 3: SMI Intervention Functions

<table>
<thead>
<tr>
<th>Function</th>
<th>Definition</th>
<th># of Interventions (out of 10 total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Two-way, active communication between participants and service providers.</td>
<td>9</td>
</tr>
<tr>
<td>Education</td>
<td>Two-way or interactive teaching of information or content.</td>
<td>6</td>
</tr>
<tr>
<td>Gaming</td>
<td>“Gamification” functions embedded in the social media tools (e.g. points systems, rewards, incentives, or games). May have reference to other participants (competition) or not.</td>
<td>4</td>
</tr>
<tr>
<td>Information</td>
<td>One-way or “push” of content to inform participants (e.g. tips, referral resources)</td>
<td>9</td>
</tr>
<tr>
<td>Skills Building</td>
<td>Social media tools specifically designed to build skills through demonstration and practice.</td>
<td>3</td>
</tr>
<tr>
<td>Social support / social networking</td>
<td>Provides participants with opportunities to receive social support from peers, family, service providers, or others.</td>
<td>9</td>
</tr>
<tr>
<td>Reminder - general</td>
<td>Reminders other than for HIV care appointments or HIV adherence.</td>
<td>9</td>
</tr>
</tbody>
</table>
Reminder – medical appointment
Appointment reminders for HIV medical care, delivered via the social media intervention tool (can be automated) 9

Reminder – medication adherence
Antiretroviral medication reminder that can by automated, live, or both. 8

Reminder – monitoring / tracking
Participants record or report information via the social media tools (i.e. self-monitoring, logging, self-tracking) 7

Results

Comprehensive Evaluation Strategy

In order to determine the relative effectiveness of the interventions taking part in this initiative, the ETAC is conducting a rigorous, multi-site evaluation of the demonstration sites’ interventions. The evaluation plan assesses outcomes, processes, and cost of using social media and technology based interventions to ensure that they have maximum impact on engagement, retention, and health outcomes of HIV-infected youth and young adults. The parts of the quantitative multi-site evaluation are informed by the components of each site’s intervention and the type of data the components capture (e.g., intervention exposure such as backend data or person-to-person contact by intervention staff), and engagement and outcomes of care measures approved by the Department of Health and Human Services to monitor HHS funded services [34]. Demonstration sites plan to recruit a total of 1,066 participants across the Initiative during 20 months of recruitment ending in April 2018. 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 multi-site evaluation. All data are submitted to the ETAC through an online secure portal for analysis.

<table>
<thead>
<tr>
<th>Methods</th>
<th>Time frame</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACASI Surveys</td>
<td>Baseline, 6-, 12-, 18-months</td>
</tr>
<tr>
<td>Cost Assessments</td>
<td>Annually</td>
</tr>
<tr>
<td>Intervention Exposure</td>
<td>Monthly/every encounter</td>
</tr>
<tr>
<td>Backend Data</td>
<td>Weekly</td>
</tr>
<tr>
<td>Medical Chart Data</td>
<td>Every 6 months</td>
</tr>
</tbody>
</table>

ACASI Surveys
Self-administered 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) socio-demographic characteristics (e.g., 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. 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 to engagement and retention in medical care.

Cost Assessments

Cost assessments are conducted annually to determine the cost of implementing each intervention. Sites use standard micro-costing techniques (incremental time required for each intervention) combined with direct costs to obtain an estimate of total incremental recurring costs. Program start-up and capital costs are also considered by converting them by site on an annual cost. Cost assessments also indicate successful strategies for labor and programmatic costs for each social media intervention to inform future replication.

Intervention Exposure: Backend data and Person-to-Person

Intervention exposure collected weekly helps identify which components of the interventions contribute to desired outcomes. Two forms of exposure data are being captured in the SMI, person-to-person and backend data. Person-to-person exposure is defined as any type of contact between participants and intervention staff. Backend data include participants’ activities on mobile applications, private Facebook pages, or other social media platforms used in this intervention.

Medical Data

Medical data are collected every 6 months and facilitate the evaluation of HIV health outcomes over time. Sites use either the standardized Ryan White HIV/AIDS Program Services Report (RSR), or abstract data from medical records by hand. Participants’ identification numbers are 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 counts, viral load testing, the first date of antiretroviral prescription, and any breaks in highly active antiretroviral therapy.
Qualitative Analysis

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 health-related interventions, thus providing context and informing quantitative HIV health outcome data. In addition, qualitative methods afford better understanding of participants’ experiences with social media and digital technology to link, engage, and remain 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 multi-site evaluation will assess engagement and retention in care, and health outcomes associated with participation in the social media and digital technology-based interventions, and individual-level factors that impact the feasibility, usability, acceptability, and effectiveness of these interventions.

The quantitative evaluation primarily looks at differences in intervention type and exposure in terms of changes in HIV care continuum outcomes and related health outcomes over time. Statistically significant changes in mean outcome levels 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 standard errors that will be estimated by the regression models. The majority of the analyses will be conducted on non-normally distributed outcomes and will use random effects generalized linear models with appropriate outcome link functions.

The qualitative evaluation will document and analyze the barriers and facilitators to the effective implementation of interventions. Qualitative data sources include individual, semi-structured interviews with participants/clients and key informants (site staff implementing the social media interventions), review of secondary sources of information (e.g., demonstration site grant proposals, notes from ETAC site liaisons, ETAC site visit reports, site presentations at grantee meetings, and de-identified qualitative data collected by the sites for the purposes of local evaluation, including any formative work), and
observations of project operations and clinical settings. Interview transcripts will be iteratively coded, sorted and analyzed using a thematic analysis process [35]. Themes will be selected based on prevalence across the data set 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 future use of social media and digital technology to improve HIV health outcomes for 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 digital technology.

DISCUSSION

This HRSA/SPNS initiative, Using Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum emphasizes the primary goals for HIV prevention and care outlined in the US National HIV/AIDS Strategy: to reduce new infections, to increase access to care, to improve health outcomes for people living with HIV, and to reduce HIV-related health disparities and health inequities that HIV-positive youth and young adults face.

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

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References


