

Demonstration Site Summary

OPT-In For Life: A Social Media-Based Intervention to Improve HIV Care Continuum for Young Adults Living with HIV/AIDS

The Pennsylvania State University

Hershey, PA

In the Ryan White HIV/AIDS Program (RWHAP), Part F: Special Projects of National Significance (SPNS) Initiative

Use of Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum

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Executive Summary

This overall goal of this project was to develop and sustainably implement social media-based interventions to improve HIV care continuum outcomes in young adults. Our interventions include two approaches: (1) our existing social media platforms to promote HIV testing and linkage to care and (2) a new mobile health application to help young adults living with HIV (YALH) engage in care and eventually achieve viral suppression. We have expanded our current “OPT-IN For Life” social media platforms that target local populations to deliver HIV prevention messages and to link HIV+ patients to care. We have also developed and implemented a HIPAA-compliant mobile health application, “OPT-In For Life”, for HIV+ patients to communicate with their providers, self-manage their HIV care and medication adherence, and track their general health and well-being. For the demonstration project evaluation of this project, all Ryan White-funded providers in the greater Harrisburg area (Alder Health Services, Hamilton Health Center, Hershey Medical Center, and Pinnacle Health REACCH Program) collaborated to deliver the proposed social media interventions.

For the first approach we intended to engage YALH and at-risk individuals in the region by expanding and branding the current Hershey Medical Center social media presence, OPT-In For Life, via multiple social media platforms (website, Facebook, twitter, or

YouTube). We have been working on creating a compelling brand that is targeted to youth and young adults throughout the region. We have also conducted social media campaigns (community events, radio and TV programs) to promote HIV testing and encourage newly tested positive people to seek HIV care in the greater Harrisburg area.

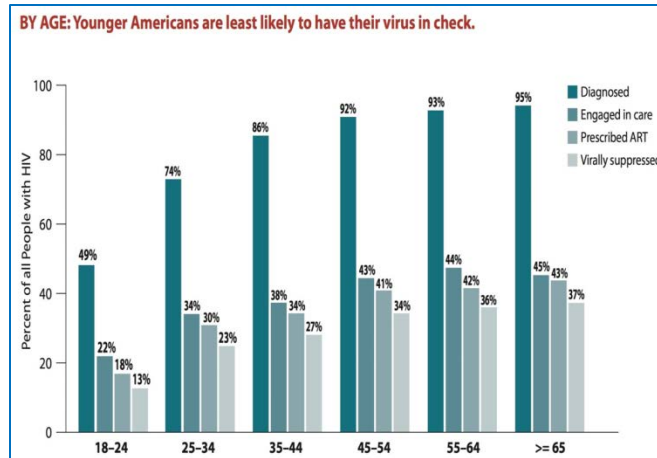
For the second approach, the “OPT-IN For Life” mobile app is specifically designed to target YALH living within our service catchment area. The unique features of this app include medical history of HIV viral load and CD4 counts, medication and appointment reminder, a text message function to allow confidential communications with members of their site-specific HIV care team, health goals, and a cutting-edge telehealth function. The app also links to all of our social media sites, all of which provide culturally and regionally appropriate education about HIV and healthy living. Using information gathered from a detailed psychosocial and social media intake, designated team members use messaging through the app to encourage retention in care, leading healthy lifestyles, adherence to treatment, and sustained viral suppression.

At the end of the demonstration project evaluation, we observed: 1) an improvement in HIV care continuum indicators (retention in HIV care and HIV viral suppression) between the pre-intervention period and the post-intervention period among our study participants; and (2) timely patient-provider communications covering a wide range of HIV-related and non-HIV-related medical needs and supportive services. We also received very positive feedback from the app users regarding their experience of using the app as a tool to improve their HIV care.

Introduction

Rationale and Description of Need/Scope of Problem

Identifying YALH and linking them to HIV care are important public health approaches to control and prevent HIV in the US. The HIV care continuum includes multiple aspects, such as the diagnosis of HIV, linkage to HIV medical care, retention in HIV medical care, appropriate prescription of ART, and HIV viral load suppression. Results from the Ryan White HIV/AIDS Program Services Report (RSR) indicate that in Ryan White funded agencies HIV+ patients with viral suppression tend to have better health outcomes. However, according to the Centers for Disease Control and Prevention (CDC), only 30% of HIV-infected individuals in the US have achieved HIV viral suppression, and the rate is even lower (15%) among YALH. Data from the 2012 HRSA RSR also show much lower retention and viral suppression rates among YALH aged 13-34 years than other age groups. Thus, there is an urgent need to develop effective interventions for improving HIV care continuum among YALH.



Currently most interventions to enhance HIV care continuum are not particularly designed for target YALH. With the rapid growth of digital technologies, it offers a great opportunity for reaching and engaging high-risk HIV- youth and young adults and YALH in HIV prevention and intervention.

Youth and young adults are keen users of new technologies. According to previous research, 73% of online American teens and young adults age 12 to 29 used a social network websites; using social media to seek health-related social and emotional support also improves health efficacy, increases communication and relationship building, and ultimately results in better clinical outcomes. Therefore social media-based interventions can be an effective approach to improve the HIV care continuum by facilitating and engaging connections and interactions between YALH and HIV care providers.

Regional Epidemiology and Needs Assessment

Our service area for the demonstration project evaluation comprised 10 counties that are primarily rural along with small to medium sized urban centers. Male sexual contact is thought to represent the largest source of HIV transmission in the region. Racial/ethnic disparities also exist as African Americans accounted for 26% of prevalent HIV disease cases compared with their 11% proportion of the general population; Latinos accounted for 19% of prevalent HIV disease cases compared with their 6% of the population. The majority of our African American patients live in Harrisburg and there is a substantial portion of Latinos in Lebanon city. Both are underserved communities with low socioeconomic status and inadequate access to health services. A large portion of our population are scattered throughout the six primarily rural counties in our service area and in rural parts of the remaining counties. In all of these rural areas, Hershey Medical Center is the only HIV care provider through our satellite sites of care. Of 3,541 HIV+ people (as of 12/31/13) in the 14 counties that include our service area, nearly two thirds are in the youth and young adult age groups as shown in Table 1.

We estimated that about 600 YALH were living in our service area and were not retained in care. Our HIV comprehensive care program serves about 250 YALH and the overall retention in care rate was low (58%). While most (77%) of them were prescribed ART, only 44% had achieved HIV suppression (HIV viral load < 200/mL). More importantly, 34% had HIV viral loads above 1,000/mL, placing them at high risk of HIV transmission.

Table 1. HIV+ People Living in South Central Pennsylvania by Age Group, 2013

Age Group	Number	Percentage
13 – 19	140	4%
20 – 29	853	24%
30 – 39	1,301	37%



To address these unmet needs in HIV prevention and HIV care, all Ryan White-funded providers in the greater Harrisburg area (Alder Health Services, Hamilton Health Center, Hershey Medical Center, and Pinnacle Health REACCH Program) collaborated to develop and implement social media-based interventions using our “OPT-In For Life” brand to influence virtually all points of the HIV Care Continuum by targeting young adults population to encourage testing, linkage to care, retention in care and medication

adherence. We have been continuously monitoring the usage patterns of our social media platforms and the app to guide our intervention efforts.

Target Audience

The two unmet needs that we identified represent gaps for youth and young adults along all points of the HIV care continuum: testing, linkage to care, retention in care and medication adherence.

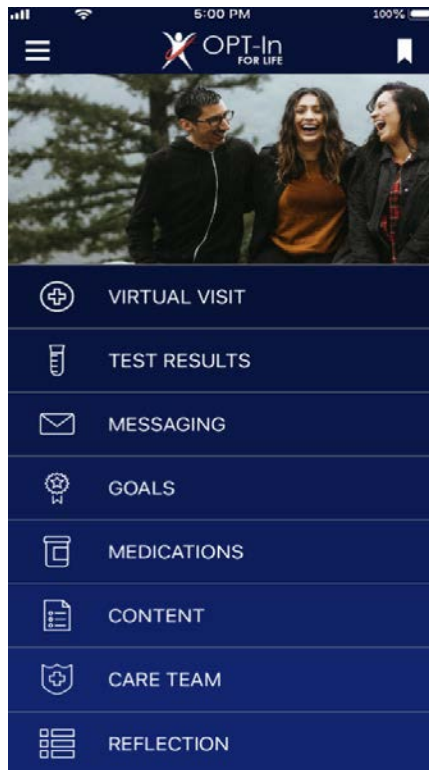
For the unmet need #1, our intervention is designed to target HIV- youth and young adults and YALH who have either not linked to care or have fallen out of care while still living in the vicinity of our service catchment areas. Our “OPT-In For Life” social media platforms (website, Facebook, Twitter, YouTube, Instagram, etc.) are accessible to the general public and provide culturally and regionally appropriate education about HIV, sexually transmitted infections (STIs), and healthy living. We have successfully conducted multiple social media campaigns promote the awareness of HIV testing and linkage to care in our region.

For the unmet need #2, we target our YALH in the 18-34 age group, either existing or newly diagnosed, who we have demonstrated are at high risk for falling out of care resulting in discontinuation of antiretroviral therapy and transmitting HIV in the community. All eligible patients (who were between the ages of 18-34 years, newly diagnosed with HIV, had a history of falling out of care in the past 24 months, or had detectable HIV viral load (>200 copies/ml) were approached either during their clinical visits or by phone contact to encourage joining our social media intervention.

Development and Implementation

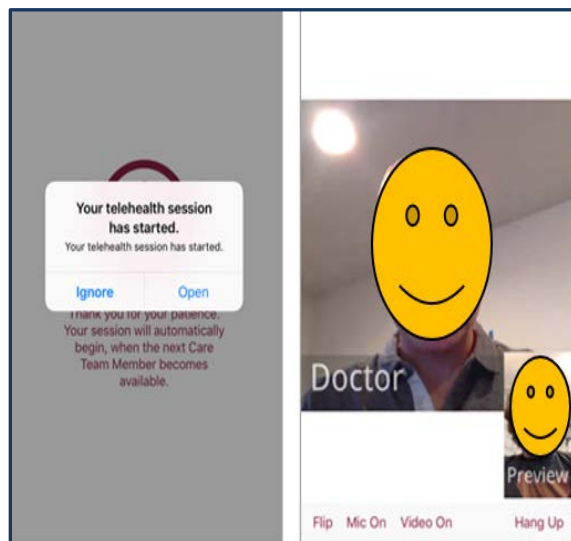
1. Our intervention primarily focuses on addressing the unmet need #2 with implementation of a health mobile application (app), “OPT-In For Life”. We collaborated with a mobile app developer with expertise in designing health apps that meet HIPAA confidentiality and privacy requirements and data security. The application is the main platform that is used only for YALH at all collaborating sites. There is less of a marketing approach when it comes to unmet need #2 since that is our population directly being considered for enrollment in the project. The app is able to be viewed on laptops, desktops, and of course on both android and iPhone smart phones (our main source of this intervention). The app is designed to engage YALH in their care through 7 main features listed below. The main feature of the app is that users are able to communicate across the app to their designated healthcare team similar to text messaging. The care team members can be case managers, nurses, physicians, and social workers who are involved in their care. The app is also dual site capable. If a patient receives medical care at one site, but case management at another site they can be registered to two separate sites and have the messaging go

to both sites. Those two sites then use internal work flows to determine who addresses a patient’s question.

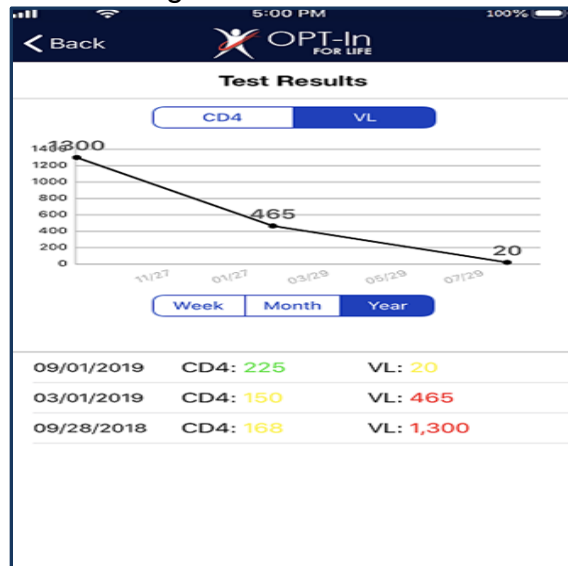


2. The main features of the “OPT-In For Life” app include:

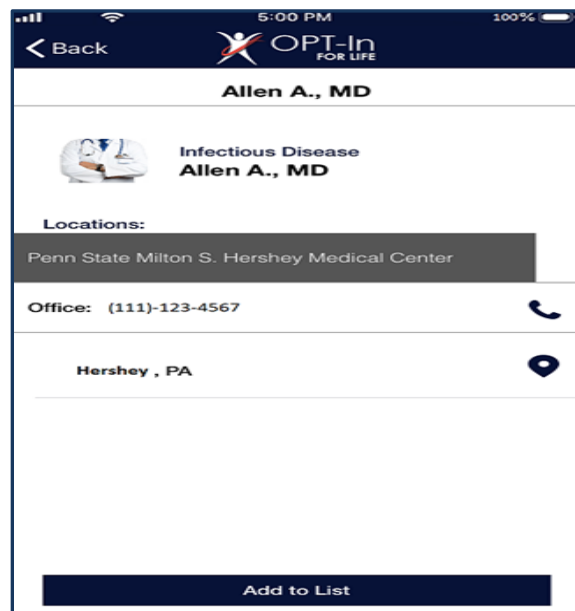
- 1) **Virtual Visit Capability:** This telehealth capability allows for HIV care team members to schedule a secure video conference with patients at a convenient time or place delivering certain aspects of HIV primary care.



- 2) **HIV-related Test Results:** Patients can view their 3-year health records of HIV viral load and CD4 counts. This feature not only provides access for the user to know and track their results over time but also support transitions in care in the event of relocating or establishing care at a different site.

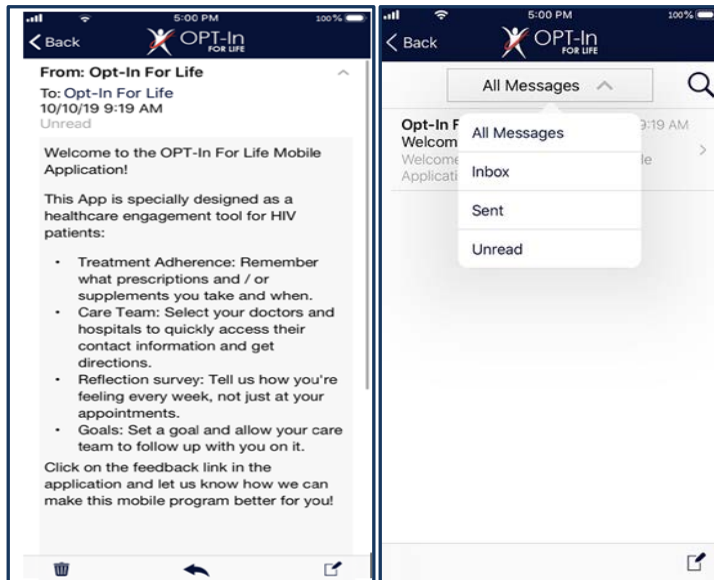


- 3) **Care team:** Under the Care Team tab, patients can find contact information from their healthcare site such as phone numbers, pictures, and bios of HIV treatment team members.

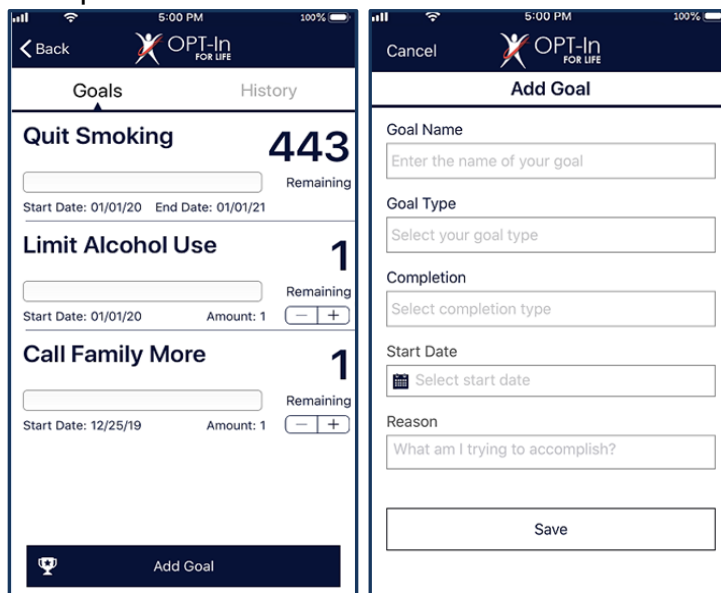


- 4) **A two-way, secure messaging function:** The care team members can send out general messages or tailored messages to patients. Patients are able to communicate through the app to their designated health team members. One of the HIV care team members receives a secure notification regarding the message

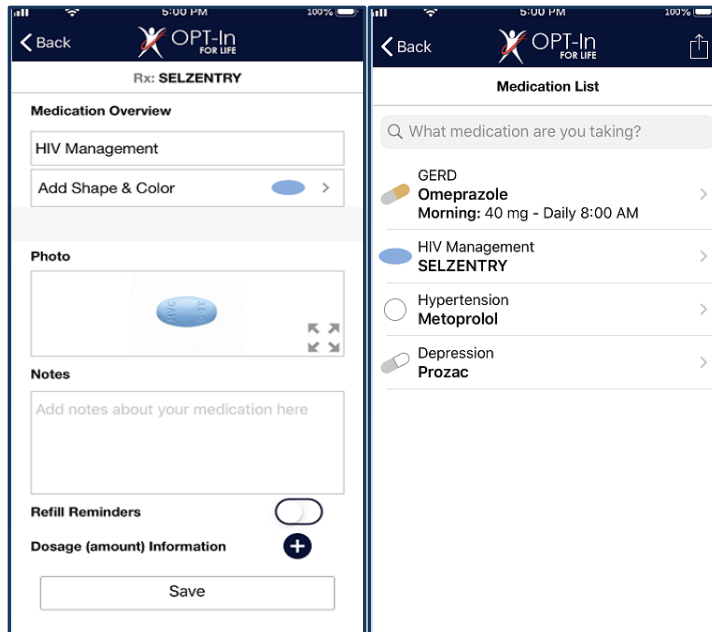
that the patient sent. The team member can directly respond to the patient through the app.



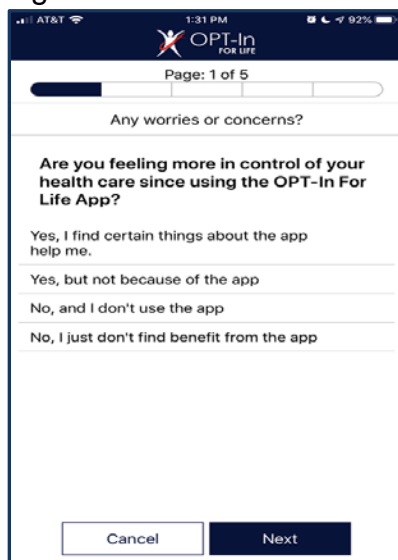
- 5) **Goal setting:** Patients can set up their own health goals. HIV care team members can review the goals through the app and help patients to meet their health needs beyond the scope of the HIV care.



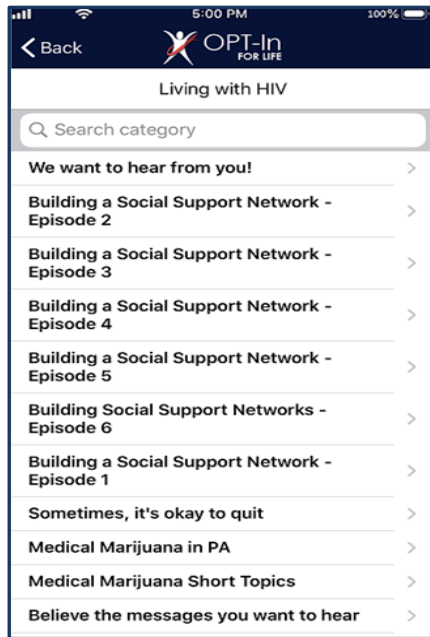
- 6) **Medication reminders:** A medication database containing all FDA-approved drugs and over-the-counter drugs is included in the app. Patients are capable of setting reminders for different medications that display as private messages within the app automatically.



- 7) **Reflection journal:** The reflection journal functions as a self-monitoring tool to support self-management. It also offers a directionally guided path of questions that allows HIV care team members to understand patients' needs more reliably and in finer grain detail that recall during clinical visits. The care team can also use the reflection journal to design a survey and collect feedback from patients about the app usage.



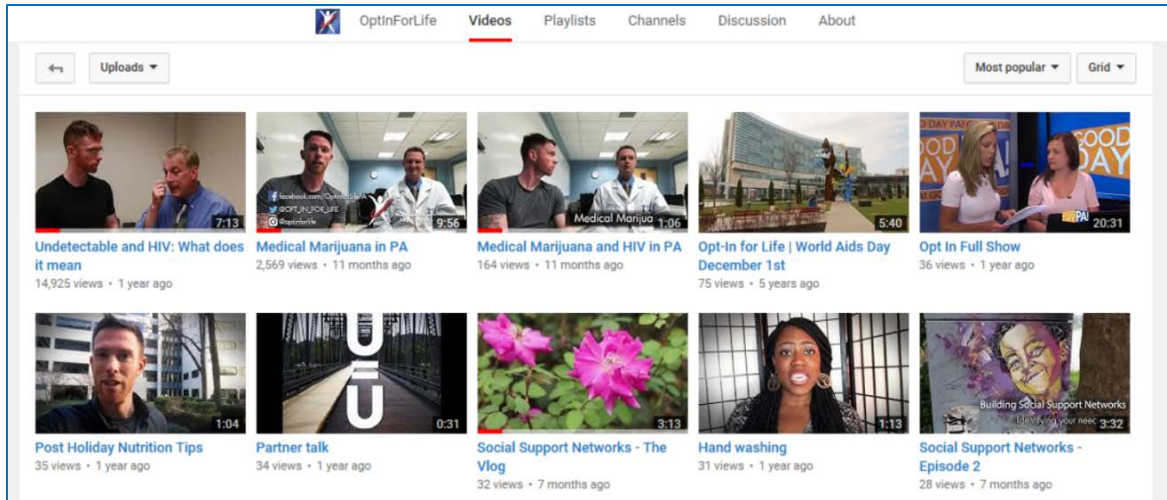
- 8) **HIV-related health content:** Content that is posted on social media outlets are linked to a news-feed on the app. This way, patients may stay connected to all of the OPT-In For Life social media directly through the app while maintaining greater privacy than afforded on web-browsers and social media platforms.



3. The “OPT-In For Life” brand: For unmet need #1 that targets HIV+ and HIV- at risk population to promote HIV prevention and linkage to care, the platforms most commonly used for social interaction among 18-34 year olds are website, Facebook, Twitter, YouTube, Instagram, etc. under the brand name of “OPT-In For Life”, and clearly designate the health and wellness with an HIV focus. They depict various contents including, but not limited to videos, blogs, pictures, serial-stories, etc. The platforms also reach out to the general public in Central Pennsylvania to engage and inform the public about health and wellness, and HIV care.

OPT-In For Life social media platforms (website, Twitter, and YouTube)





The over-arching goal of this portion of the social media usage is two-fold. One is to make at risk or HIV+ youth aware of the “OPT-In For Life” brand, and what HIV prevention services or HIV care we offer. The second is to make the Harrisburg community at large more comfortable with talking about HIV.

The usage of social media in this aspect is structured around taking information that already exists regarding HIV and crafting it to be more localized for Harrisburg, and in ways that YALH absorb. The media is carefully structured and evaluated by our research team so as not to be contrived or forced, but natural as if in a normal conversation. We have also engaged community members periodically to seek their feedback about our social media contents.

Marketing

Marketing strategies have varied depending on the targeted audience or demographic. For Unmet Need #1 we pursued a campaign based on “health and wellness with a unique HIV focus”. Keeping in line with that our posts and information we share can take on a wide variety of topics as we seek to grow our local audience. We did this effort through Social Media platforms as well as through other traditional outlets like local news stations, bus and bus stop posters, and fliers. Marketing strategies were developed in keeping abreast and in line with the current best practices for social media. It is difficult to ever deliver a timeless step by step guide to this process since these platforms are ever changing and evolving. Staffing or outsourcing to someone knowledgeable in Marketing, with a focus on Social Media, is essential.

Example of “OPT-In For Life” campaign to promote HIV prevention intervention education to the general public



ABC 27 News - Good Day PA

Why was the “Opt in for Life” program for HIV patients started? 30 second answer from, John Zurlo, M.D., Infectious Diseases at Penn State College of Medicine. Learn more at optinforlife.

In the current marketing climate, please to be aware of:

- Be honest. Don't ever try to lie or mislead people. They will figure you out, call you out, and do it all over your own social media channels.
- Have an answer for negative feedback. Don't censure or erase comments or complaints that are negative because you fear the impact. Answer the person as best and as fast as possible.
- Be genuine. It might seem like a quick and easy way to get some engagement by latching onto what is a currently trending topic, but your audience may feel like you are forcing yourself into a conversation where you don't belong. If you wouldn't barge into a conversation with irrelevant discussion at a dinner party, don't do it with your audience.
- Promotion of the OPT-In For Life brand has been focused around being local, accurate, and honest. We do not participate in click bait, paid followers, or trending topics that are irrelevant to the matters of Health, Wellness, and HIV.
- This can be done through organic posting growth and the best practices associated with that.
- Or it can be achieved through paid (sponsored) posts by patients.

Staff Roles

The “OPT-In For Life” team members have general knowledge on social media use as well as long-term experience in working with PLWHA and understanding their health/wellness needs. All staff members are honest, genuine, open for feedback, and advocate for the “OPT-In For Life” image. The interdisciplinary team includes the following members:

1. HIV Clinical Care Team

- The clinical team members include HIV providers and nurses who have been providing HIV primary care. They are familiar with the patient population and have direct impact on patient care.
- They serve as crucial personnel throughout the intervention period. They are responsible for answering questions from the patients and facilitating other team members to engage with patients and provide supportive care. Other responsibilities include:
 - Recruiting patients for the intervention and reviewing patients' app usage
 - Seeking feedback from patients to improve the app designs.
 - Obtaining relevant clinical data for program evaluation.
 - Allowing flexibility by traveling to sites in our region where patients are most comfortable in order to best ensure retention in care.
 - Maintaining self-guidance and team collaboration with the assigned tasks that arise throughout the course of the intervention.
- Estimated efforts for the intervention: for 100 patients enrolled in the intervention: 5%-10% per staff during the recruitment stage; 5% per staff during the implementation stage; and <5% for monitoring all other activities (minimal number of staff needed: 2 members).

2. Social Media Content Development Team

- The social media content writers are essential personnel who are responsible for developing appropriate HIV-related health/wellness content, overseeing social media communications with patients, and promoting HIV prevention education with the general public.
- The main responsibilities include:
 - Developing marketing strategies toward brand embellishment and content management given current functions of the mobile application itself.
 - Engaging patients in the app use and responding patients' questions in a timely manner within the app and involved social media sites.
 - Providing recurrent social media/patient education sessions to ensure patient involvement with their care and with their health care team members.
 - Identifying areas of improvement with open and honest engagement with feedback from users.
 - Obtaining relevant app usage data
- Estimated efforts for the intervention: 50%-75% per staff throughout the intervention (minimal number of staff needed: 1 member).

3. Administrative support team

- Administrative support members have a vital role in allowing for communication and directing patient needs to the appropriate services offered. Administrative support is responsible for performing clerical and administrative work necessary for management of other team members to work with one another.
- The team is responsible for:
 - Assisting with the intervention team for all intervention-related activities.
 - Communicating with patients to learn their needs.
 - Identifying and overcoming patients' obstacles to care (e.g. transportation, changing network providers, language barriers, etc.).
 - Explaining medical information with consultation from the care team to improve medication adherence and support with increased knowledge of personal medical care.
 - Providing patients with appointment reminder phone calls or rescheduling if necessary to maintain retention in care.
- Estimated efforts for the intervention: for 100 patients enrolled in the intervention: 5%-10% per staff throughout the intervention (minimal number of staff needed: 1 member).

Lessons Learned

- In developing mobile app technology, it is wise to choose a vendor that has health-care related experience and a proven track record.
- Keep the look and feel of the app fresh and continue to be creative and responsive in content development.
- Consider the stigma of HIV, particularly for clients living in rural settings, when creating public HIV/AIDS-themed social media sites. Individuals are not likely to engage in such sites if they can be personally identified.
- Maintain caution about cybersecurity in any social media project that involves protected health information (PHI). Be prepared for ongoing institutional barriers with regards to contracting, cybersecurity demands and IRB updates.
- Allow for the ability to target specific populations in group messaging (e.g. young MSM).

Monitoring and Evaluation

Aims for Local Evaluation

We have enrolled 92 patients for this evaluation project and demographic characteristics of study participants are presented in Table 2. The overall objectives of our evaluations are:

- To monitor intervention activities and to provide feedback to the investigative team;
- To assess both the population-level and the patient-level social media usage statistics;
- To learn users' experiences regarding to the use of social media platforms and the mobile app for managing HIV care;
- To assess the effect of OPT-In for Life intervention on improving HIV care continuum outcomes;
- To identify best practices for improving retention in HIV care and medication adherence.

As evaluation of social media-based interventions is still in its infancy, we have utilized established epidemiologic methods to (1) describe social media engagement statistics at the population level and the patient level; (2) compare changes in the usage of social media platforms before and after the intervention is implemented; (3) correlate social media engagement with patients' characteristics and HIV care utilization; and (4) perform multivariable analysis to examine the association between social media engagement statistics and HIV care continuum outcomes.

Table 2. Demographic Characteristics of Study participants

Characteristics	N (%)
Age	
18-21	9 (9.8%)
22-25	26 (28.3%)
26-29	30 (32.6%)
30-34	27 (29.3%)
Sex	
Male	67 (72.8%)
Female	23 (25.0%)
Transgender	2 (2.2%)
Race	
Black or AA	40 (43.5%)
White	49 (53.3%)
Other	3 (3.3%)
Ethnicity	
Hispanic	15 (16.3%)
Non-Hispanic	77 (83.7%)
Eligibility criteria *	
Lost-to-follow up in care	54 (58.7%)
HIV RNA viral load>200	28 (30.4%)

Characteristics	N (%)
Newly diagnosed	22 (23.9%)
HIV RNA viral load at baseline	
<=200	63 (68.5%)
>200	28 (30.4%)
Site	
HMC	55 (59.8%)
Pinnacle	32 (34.8%)
Hamilton	5 (5.4%)

*One patient may meet multiple eligibility criteria.

- Participants/Sample for Local Evaluation:** The eligibility criteria and selection processes for local evaluation activities are the same as the ETAC multi-site evaluation (MSE). Additionally, we are able to obtain the medical records of eligible patients who are not enrolled in the study to form a comparison group for local evaluations.

Monitoring Progress

Table 3. Program Evaluation Plan

Data source	Internal evaluation or MSE	Data format	Data collection timeframe	Data storage and transfer
Social media engagement statistics (Google Analytics and Duet Health)	Internal	Excel (converted into SAS)	Monthly	Internal secure server
Patient survey (onsite collection)	MSE	ACASI	Baseline and 6-month follow-up	ETAC
Intervention exposure (onsite collection)	MSE	Excel (SAS)	Monthly	ETAC
HIV clinical data (EMR)	Internal and MSE	Excel (SAS)	Annually	Internal secure server and ETAC
Patient interview (onsite collection)	Internal and MSE	Audio recording	One time (at Y3)	ETAC
Patient feedback (onsite collection or social media)	Internal	Text (SAS)	Annually	Internal secure server

1. The following key metrics have been measured to reflect engagement in our **social media platforms** according to the listed categories:

Facebook: People Reached, Post likes, Post Shares, Page Likes, Page Views

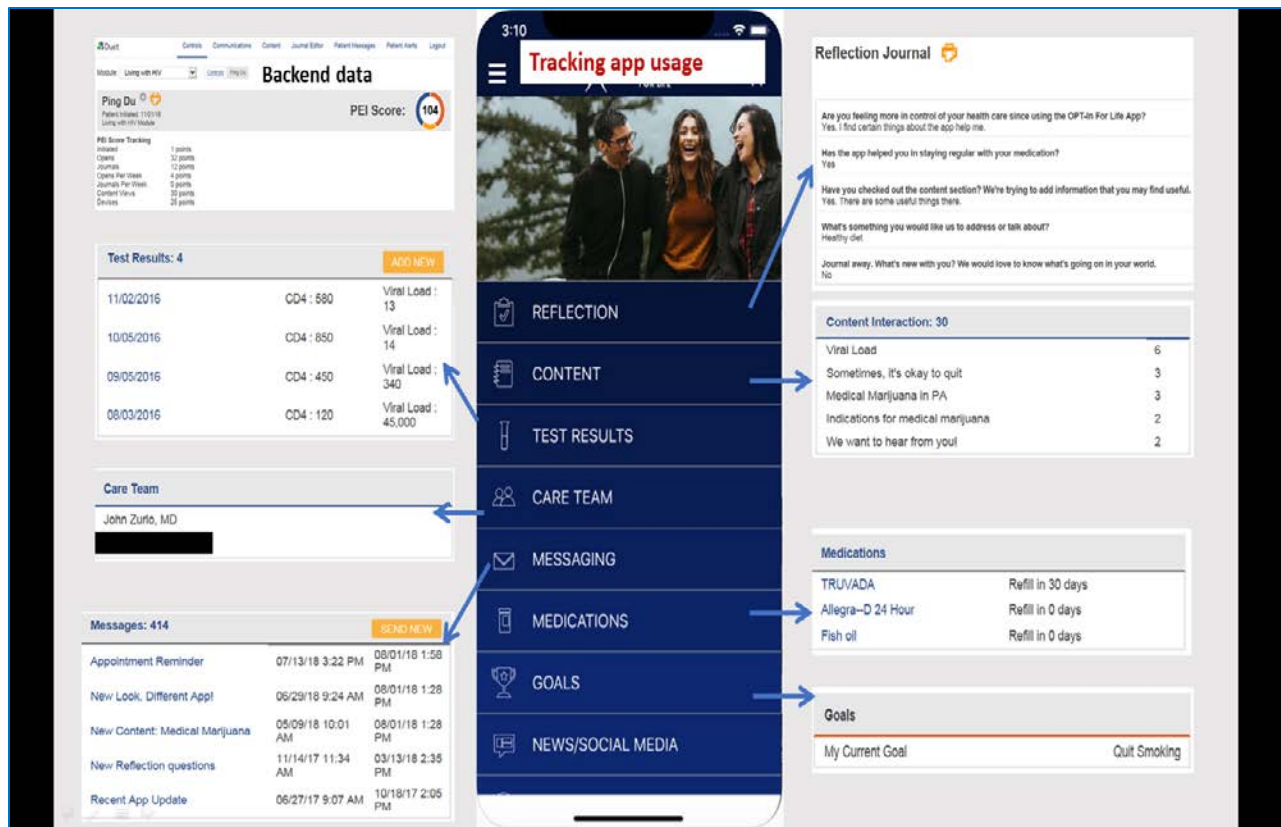
Twitter: Impressions, Likes, RTs, mentions, followers

YouTube: Subs, views, watch time, likes, shares

Instagram: Likes, views, followers

Website: Unique visitors, time on site, shares

2. **OPT-IN app:** weekly usage (login time, health journal, goals, content review, number of messages, etc.)



Additionally, qualitative data (e.g., text messages, posts, comments) have been collected and analyzed.

Methods for Local Evaluation

The **primary study outcomes** are two HRSA-defined HIV care continuum indicators: retention in HIV care and HIV viral load suppression. These study outcomes are compared between the pre-intervention period and the post-intervention period among our study participants and between enrolled patients and eligible but non-enrolled patients.

- (1) Retention in HIV care: defined as HIV+ patients who had at least one HIV medical care visit in each 6 month period during the 18 month study period, with a minimum of 60 days between the first medical visit in the prior 6 month period and the last medical visit in the subsequent 6 month period.
- (2) HIV viral load suppression: defined as having HIV RNA viral load <200 copies/mL in each 6 month period during the 18 month study period.

Our “OPT-In For Life” brand is designed as one-stop sources for HIV-infected and affected people to seek information and action related to HIV prevention, education and HIV comprehensive healthcare services. Therefore, the **secondary study outcomes**

include the following social media engagement statistics to reflect the usage of “OPT-In For Life” brand.

OPT-In app: weekly logins, user journals and trackers, number of messages, etc.

Facebook: People reached, post likes, post shares, page Likes, page views

Twitter: Impressions, likes, re-twit, mentions, followers

YouTube: Subs, views, watch time, likes, shares

Instagram: Likes, views, followers

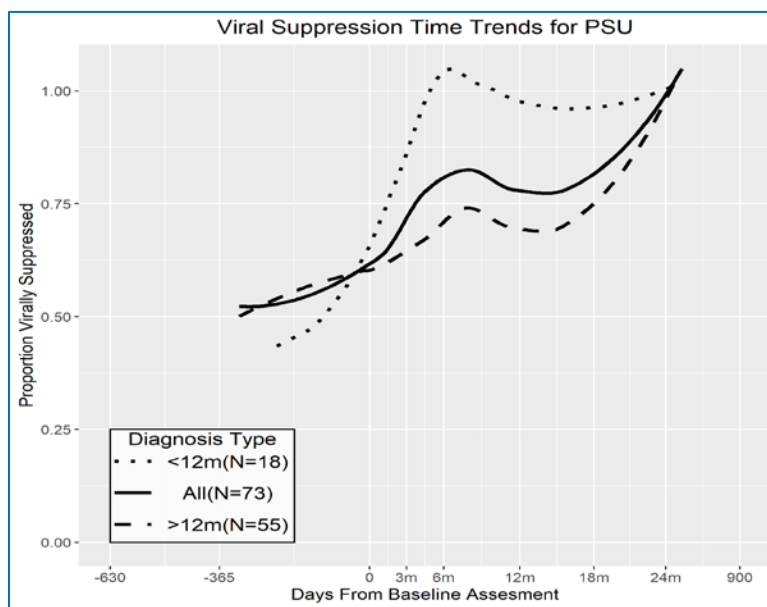
Website: Unique visitors, time on site, shares

For the exploratory purposes, we also conducted qualitative analysis using text data (messages, posts, comments) to gain better understanding of user experiences/behaviors.

Preliminary results

To evaluate if this social media-based intervention improves HIV care continuum, we hypothesized: (1) there would be significant increases in HIV care continuum outcomes between the pre-intervention period and the post-intervention period among enrolled patients and between enrolled patients and eligible, non-enrolled patients; and (2) our social media-based intervention would enhance patients’ engagement in HIV care, measured by patient-provider communications and HIV care utilization. We have conducted both internal evaluations and collaborate with UCLA ETAC for the multi-site evaluation. We have also related social media engagement statistics to clinical outcomes at the population level and at the patient level.

Preliminary result for viral suppression before and after the intervention among study participants (The result was provided by UCLA ETAC)



Available Resources

Social Media Sites



-
- Opt In Mobile Application
 - Website
 - [OptInForLife Website](#)
 - YouTube Channel
 - [OptInForLife](#)
 - Twitter Page
 - [@OPT_IN_FOR_LIFE](#)
 - Facebook
 - [@OptinforLifePA](#)
 - Instagram
 - [@optinforlife](#)
 - Local News Outlets: ABC 27 News-Good Day PA Episode
 - [Good Day PA: Opt In For Life Episode](#)