

*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) Program Initiative

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

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December 2019

This publication was made possible by award number [4 H97HA28893-04-02](#) from the U. S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau's Special Projects of National Significance Program. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. government.

## Intervention Summary

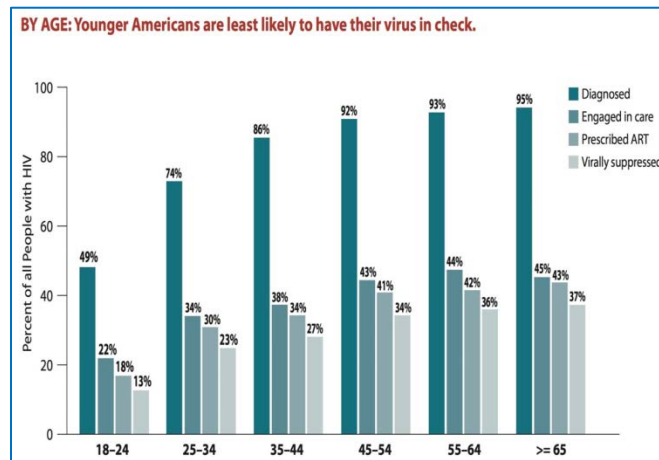
- What is “OPT-In For Life”?
  - A multi-clinic, social media-based intervention designed for young adults living with HIV (YALH) to engage them in HIV care and to provide resources about HIV and healthy living support. The intervention utilizes multiple social media platforms and a unique HIPAA-compliant mobile application (app).



- Why did we develop this intervention?
  - Nationwide YALH have lower rates of retention in care and viral suppression than other age groups. Multiple barriers exist to engage YALH in care, especially in rural or underserved areas. Youth and young adults that are active amongst social media sites often seek health-related social and emotional support online. Therefore, social media-based interventions may help reduce barriers for YALH to remain in care, improve their health outcomes, and facilitate HIV prevention.
- Who are eligible for this intervention?
  - This is a multi-site collaboration among all Ryan White-funded providers in the greater Harrisburg, Pennsylvania area (Alder Health Services, Hamilton Health Center, Hershey Medical Center, and Pinnacle Health REACCH Program) that serve nearly 2,000 people living with HIV in a large, ten-county catchment area. Individuals are eligible for this intervention if they:
    - Are between the ages of 18-34;
    - Are newly diagnosed with HIV infection in the past 12 months;
    - Had a history of falling out of HIV care in the past 24 months;
    - Have not achieved HIV viral suppression (<200 copies/ml).
- What unique features does the intervention include?
  - The “OPT-In For Life” **mobile app** includes a secure, two-way text message communication between patients and care team members, HIV-related laboratory results, journaling of health status, medication and appointment reminders, and telehealth capabilities/functioning.
  - The “OPT-In For Life” **social media platforms** are accessible to the general public and provide culturally and regionally appropriate education about HIV, sexually transmitted infections, other relevant disease topics, and healthy living.

## Rationale and Needs

- **YALH are the high risk population:**
  - In the US, YALH aged 13-34 years have a lower rate of retention in HIV care compared to other age groups and a much smaller percentage of YALH have achieved HIV viral suppression. Designing an intervention that specifically targets YALH to enhance HIV care continuum outcomes is crucial in preventing HIV-related adverse health outcomes and HIV transmission.



- **Local disease profiles:**
  - About 600 YALH living in southcentral Pennsylvania were not retained in care in YEAR?. 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 for HIV transmission.
  - Our service area comprises counties that are primarily rural along with small to medium sized urban centers. HIV primary care is lacking in most rural areas. Underserved and marginalized communities also face numerous socioeconomic factors that not only increase the vulnerability for HIV infection but also increase the likelihood of falling out of HIV care.



## Theoretical Basis/Conceptual Model

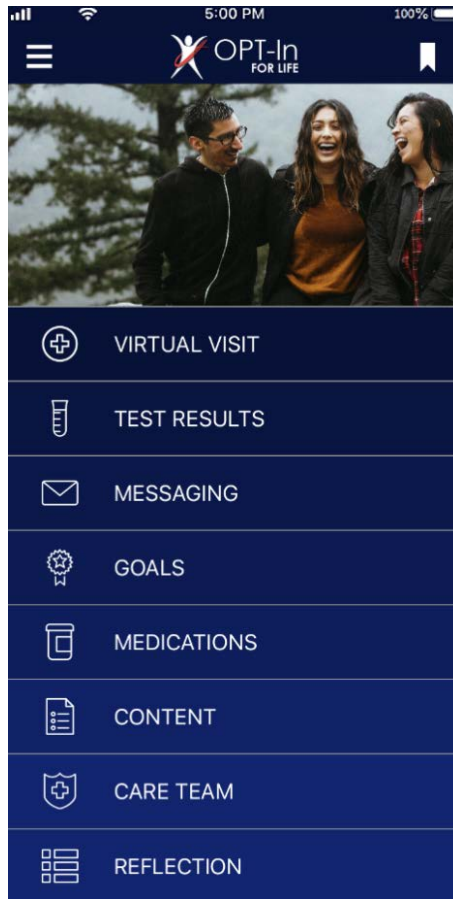
- This social media-based intervention is developed with input from our YALH community advisory boards and guided by theoretical frameworks for behavioral change, social norms, and supportive accountability.

## Intervention Description

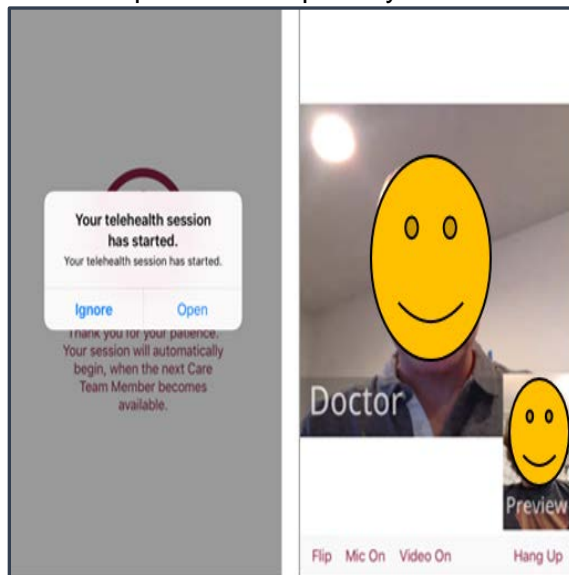
- The intervention includes both a HIPAA-compliant health mobile application (app) that is designed for YALH and social media platforms (Facebook, Twitter, Instagram, Snapchat, and YouTube) that provide HIV-related health information and are accessible for the general public.



- **The “OPT-In For Life” mobile app** was developed in collaboration with a mobile app developer (Duet Health) with expertise in designing health apps that meet HIPAA and data security requirements. The app offers flexibilities that can be easily adapted by other programs in terms of functions and branding elements. The app is “platform agnostic” and accessible across iOS and Android mobile operating systems and through laptop or desktop devices for easy access.
- The app is currently designed for YALH who are between the ages of 18-34 years, newly diagnosed with HIV, have a history of falling out of care in the past 24 months, or have detectable HIV viral load (>200 copies/ml). It provides convenient ways of accessing medical information and communicating with the HIV care team. The app focuses on supporting clinical services while delivering a personal level of care that builds a trusted relationship with OPT-In For Life users (providers and patients), including tailoring to the patient’s needs as a priority in ensuring compliance with their HIV care.

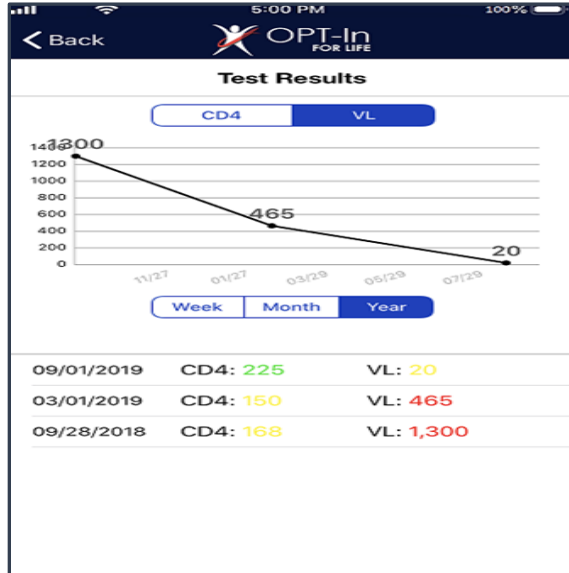


- The main features of the “OPT-In For Life” app include:
  - **Virtual Visit Capability**
    - This telehealth capability allows for HIV care team members to schedule a secure video conference with patients at a convenient time or place delivering certain aspects of HIV primary care.



- **HIV-related test Results**

- Patients can view their 3-year health record 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 at a different care site users can carry a record of their history of the infection.



- **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.

The screenshot shows the profile of a healthcare provider, Allen A., MD. The profile includes a photo of the provider, their name, title, and location. Contact information is also provided.

**Allen A., MD**  
Infectious Disease  
Allen A., MD

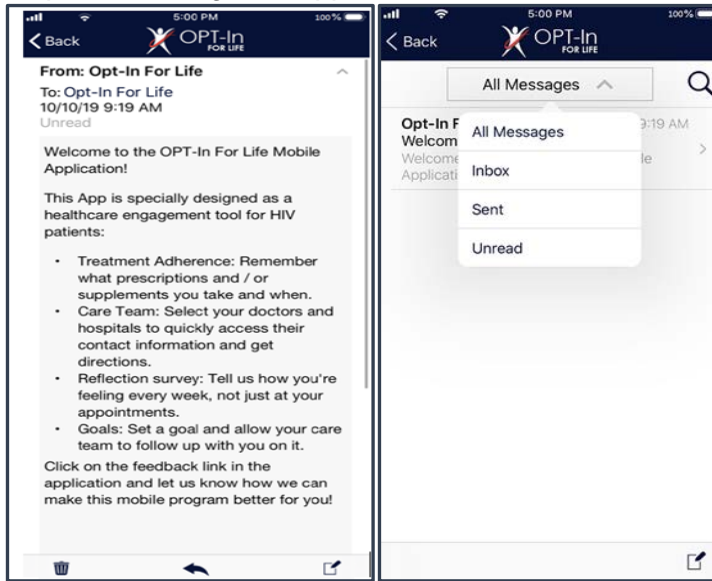
**Locations:**  
Penn State Milton S. Hershey Medical Center

**Office:** (111)-123-4567

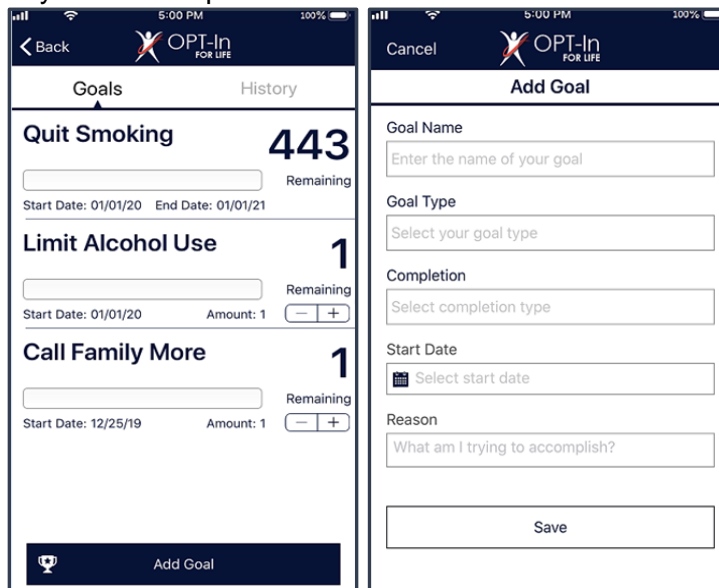
**Hershey, PA**

**Add to List**

- **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.

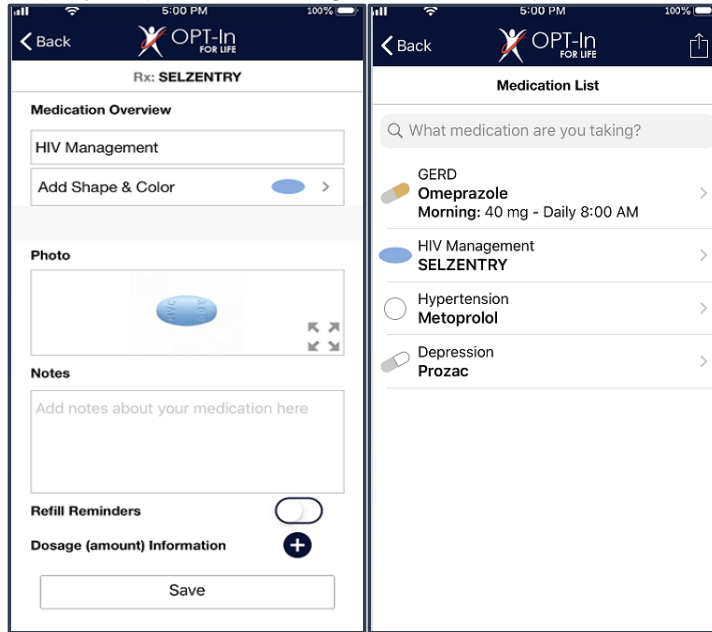


- **Goal setting**
  - Patients can set up their own health goals. HIV care team members can review the goals through the app and help patients to meet their health needs beyond the scope of the HIV care.



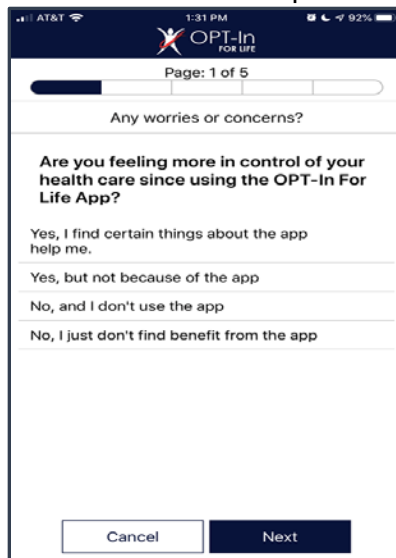
- **Medication reminders**

- 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.



- **Reflection journal**

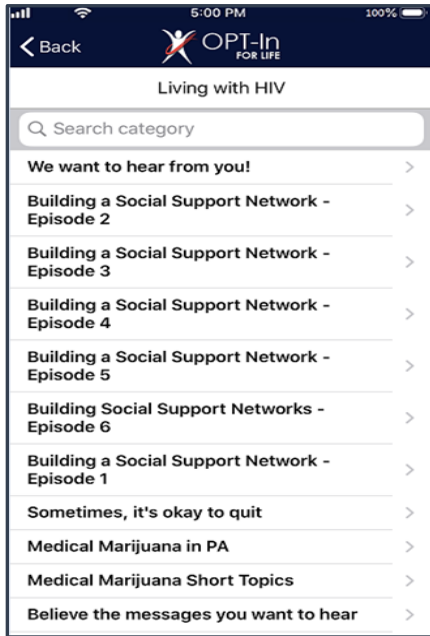
- The reflection journal functions as a self-monitoring tool to support self-management. It also offers a directionally guided path of questions that allows HIV care team members to understand patients' needs more reliably and in finer grain detail that recall during clinical visits.
- The care team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





○ **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.



● **The “OPT-In For Life” brand:**

Not only does our intervention primarily focus on the YALH care continuum but also it allows for the general public to access information on understanding HIV prevention or living with HIV. Marketing the OPT-In for Life brand was achieved through the use of popular social media platforms such as Facebook, Twitter, YouTube, Instagram, etc. while providing content with an HIV focus in health and wellness.



Increasing Impact through  
**TRANSPARENCY**  
**ACCOUNTABILITY**  
 & **PARTNERSHIPS**

World AIDS Day **WORLD AIDS DAY 2017 DECEMBER 1**

Tweets 2,144 Following 657 Followers 1,081 Likes 40

Opt-In For Life  
 @OPT\_IN\_FOR\_LIFE

Tweets Tweets & replies Media

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Undetectable and HIV: What does it mean  
 14,925 views · 1 year ago

Medical Marijuana in PA  
 2,569 views · 11 months ago

Medical Marijuana and HIV in PA  
 164 views · 11 months ago

Opt-In for Life | World Aids Day December 1st  
 75 views · 5 years ago

Opt In Full Show  
 36 views · 1 year ago

Post Holiday Nutrition Tips  
 35 views · 1 year ago

Partner talk  
 34 views · 1 year ago

Social Support Networks - The Vlog  
 32 views · 7 months ago

Hand washing  
 31 views · 1 year ago

Social Support Networks - Episode 2  
 28 views · 7 months ago

## Implementation

- **Programmatic requirements:**
  - The “OPT-In For Life” app has been development and the app meets HIPAA requirements, data security, and cybersecurity. It is ready to be used or adopted by other HIV programs.
  - A strong interdisciplinary team is needed for planning, implementing, monitoring, and evaluating the intervention activities (see the details in the staff roles below).
  - Identifying social media sources that are focused on communication with certain members or groups allows for more individualized and intimate interactions for YALH with their health care providers.
- **During the implementation stage:**
  - Social marketing campaigns and advertisement of the “OPT-In For Life” brand has been conducted through the traditional media platforms (such as local news stations, bus and bus stop posters, social events, and study fliers) to further promote the awareness of HIV prevention resources and reduce social stigma of HIV infection.



- Regular team meetings have been conducted to track the intervention progress, to communicate with all the stakeholders and community advisory board members, and to identify and overcome barriers for program implementation.



### 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:

➤ **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).

➤ **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).

➤ **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).

### 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](#)