

Demonstration Site Summary

Positively Connected for Health (PC4H)

Children's Hospital of Philadelphia, Philadelphia FIGHT

Philadelphia, 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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Intervention Summary

Intervention Description

The Positively Connected for Health (PC4H) project focuses on improving digital health literacy, medication adherence, and engagement in care for youth living with HIV (YLH). PC4H consists of a digital health literacy workshop called *APPlify Your Health* and a mobile application (app) called *TreatYourSelf* (TYS). *APPlify Your Health* is a youth-centric curriculum designed to ensure that young people living with HIV understand the many functions of the *TreatYourSelf* app as well as offer thoughtful conversations around digital literacy topics such as privacy and confidentiality in an online environment. YYS is a native Android mobile app designed for, and with input from, young people living with HIV that supports medication adherence and creates an anonymous support network of other young people living with HIV. Together, these two components have the goal of improving health outcomes of young people ages 14-34 who are living with HIV, linked to care at one of five Philadelphia-based health clinics, has an unsuppressed viral load (≥ 200 copies/ml), and/or has been out of care for ≥ 6 months in the last 24 months, and/or are newly diagnosed with HIV in the past 12 months.

Brief Rationale

As social media and mobile technology are frequently used by youth, digital interventions can be uniquely designed to provide real-time support and feedback for YLH as they go about their daily lives in order to improve health literacy and antiretroviral (ART) adherence. Furthermore, there are few digital health interventions grounded in theory that have been specifically developed and tested to improve medication adherence and engagement in care for YLH.

Rationale and Need

In Philadelphia, adolescents and young adults aged 13-24 accounted for 24% of all newly diagnosed HIV infections in 2016.¹ Fewer than half of youth who are prescribed ART achieve viral suppression.² YLH experience physical, cognitive, and social/emotional developmental changes that may impact ART prescription and adherence.³ Factors associated with non-adherence include housing instability, not understanding the need for medication, mental health and substance use issues, forgetting or not having their medication with them, and complications in daily routines.^{4,5} Factors associated with longitudinal failure to adhere to ART include younger age, disease progression, depression, and fear of disclosure among family and peers.⁶ Protective factors associated with adherence include high levels of self-efficacy, motivational readiness, and increased social support.⁷ The consequences of sub-optimal adherence to medications can be severe and may result in the development of resistance and lack of viral suppression. Additionally, people with unsuppressed viral load are more likely to transmit the virus through unprotected sex and/or intravenous drug use.⁷

With over 400 million cell phones and tablets in use in the United States,⁸ cell phones have become a common mode of communication among youth, including those who are economically disadvantaged.⁹ The use of smartphones, which are owned by 65% of the U.S. consumers¹⁰ (higher proportion among youth) creates a new opportunity for mHealth

interventions using mobile websites, social networking, gaming, and apps. Currently, over 50 mobile apps are available related to HIV prevention and treatment with limited evidence-base to support their effectiveness.¹¹ Furthermore, only several of these mobile apps exist specifically for individuals living with HIV to address adherence (iStayHealthy and PozTracker) and build support or find community (HIV Connect) with other individuals living with HIV.

PC4H was developed to address the unique needs of adolescents and young adults living with HIV in Philadelphia by utilizing mobile technology to improve their progress along the HIV continuum of care, specifically to achieve viral suppression and improve engagement in care.

Theoretical Basis / Conceptual Model

TYS is guided by three theoretical frameworks: **(1) Fishbein’s integrated model of behavioral prediction (2) ecologic momentary intervention / assessment (EMI/A) and (3) supportive accountability model.** Fishbein’s integrated model of behavioral prediction suggests that individuals act on their intentions when possessing the necessary skills and unrestricted by environmental factors.¹² This theoretical model has been successfully applied to the development of HIV primary prevention interventions and may be significantly useful in identifying targets and approaches for linkage, retention, and adherence interventions. EMI/A emphasizes that interventions should provide support and feedback in real time as individuals go about their daily lives.¹³ The supportive Accountability Model argues that human support increases adherence through accountability from individuals who are seen as trustworthy, resilient, and having prior knowledge.¹⁴

Intervention Description

The target population for PC4H consists of YLH (ages 14-34) across all gender and racial/ethnic identities, all sexual orientations, who know their status and need additional support for retention in care and medication adherence. PC4H consists of two core components: the *APPlify Your Health* workshop and the *TreatYourSelf* app.

APPlify Your Health Workshop

This 20-60 minute workshop engages young people in small groups or individually and allows them to become familiar with the various functions of the *TreatYourSelf* app. *APPlify Your Health* is designed to prepare youth to be community members when it comes to the “social” parts of *TreatYourSelf* and encourage them to embrace the app as a tool that they will want to engage with in managing their care. To achieve this, this *APPlify* curriculum was designed carefully with a guiding pedagogical philosophy that 1) believes that young people are the experts of their own experience and 2) integrates a harm-reduction approach that allows young people to decide for themselves how they will use the app without judgement from the facilitator. As a group workshop, it is estimated that 40 minutes are needed due to its focus on discussion and engagement of youth. As a 1:1 workshop, it may be completed in 20 minutes or less.

The workshop has four specific learning goals. Participants will:

- Be proficient with all features of the *TreatYourSelf* app
- Identify strategies for navigating the social and emotional challenges that the app may address
- Identify and apply best practices for behavior in online spaces in order to support health goals
- Learn about additional mobile-technology resources (apps & mobile sites) to support health goals and manage HIV care

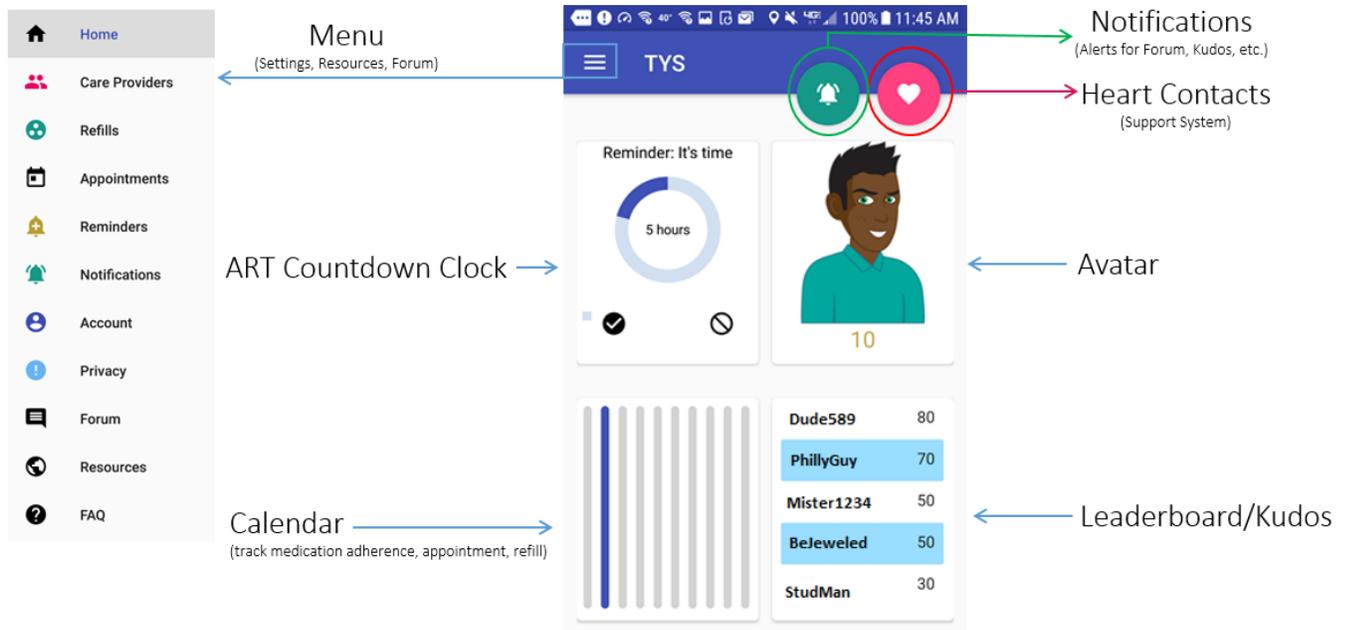
This workshop is designed to strengthen digital literacy skills through a series of activities while also improving health literacy. Some of these skills include:

- Practice using core features of the operating system
 - Through actions that the *TreatYourSelf* app offers such as setting dates and times or typing with the keyboard, participants who may not have as much experience using their phone may gain knowledge in how to use additional features on their phone outside of the *TreatYourSelf* app. As one example, the user interface that is presented for participants to set the time of their medication reminders is a similar interface used to set times for other “stock” Android apps, such as an alarm clock. By practicing this skill in the workshop, users may feel more confident interacting with other parts of their device that they had not previously explored. This is especially true for users who receive a project-provided phone.
- Using apps as tools to help manage health and wellness
 - The workshop asks the participant to discuss how they currently use digital tools to manage their care which gets the participant accustomed to the idea that a smartphone can help manage their care if they haven’t been using it already.
 - The workshop also identifies that some people use multiple apps to manage their care (one app to set reminders, another to chat with folks, etc.) which may be a bit cumbersome and difficult to track. The workshop instructor is able to show participants that it is possible to utilize many desired features all within the convenience of a single app, if so desired.

APPlify Your Health Evaluation Results: These workshops are acceptable and feasible to YLH based on preliminary findings of 48 participants enrolled into the PC4H demonstration project. There was high satisfaction with the *APPlify Your Health* workshop and the workshop instructors: 98% of youth found what they learned in the workshop was important and relevant and 92% of youth said they would use the *TreatYourSelf* app more because they participated in the workshop. Additionally, after 3 months in PC4H, digital health literacy among participants increased ($p=0.02$) on the eHEALS Scale,¹⁵ an 8-item measure of knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems.

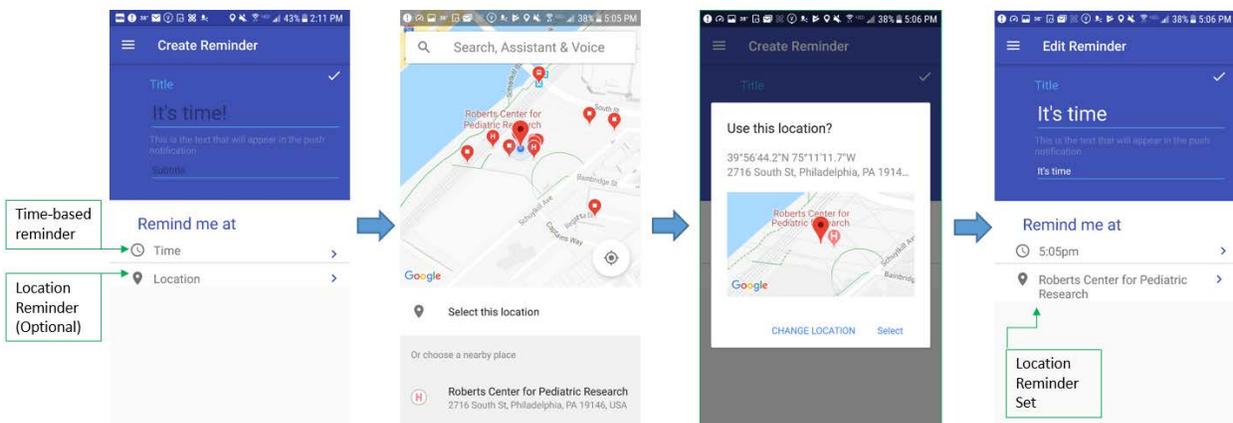
TreatYourSelf (TYS) Mobile App

TreatYourSelf is designed to be used on any device that runs on an Android operating system and is available to participants through an invitation-only download link. Designed with input from YLH and a larger youth community advisory board, and grounded in health behavior theories, key features of the app include medication reminders and adherence tracking, refill and appointment reminders, leaderboard and adherence points, internal community supports through discussion forums, peer-to-peer kudos, and community-based resources list.



TYS Functions

REMINDERS:

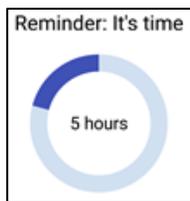


Push notifications. Participants receive pop-up reminders at times they programmed in the app to help them remember to take their ART medication, prescription refills, and appointment reminders. Participants are able to customize the messaging content of the pop-up reminder themselves or use the default option for both the main title and subtitles. Additional support in the real times and places where needed may provide distinct advantage over traditional

methods where adherence may not be addressed by patient and provider for months between clinical visits.

- 📌 **Medication reminder** push notifications prompt the user to answer if they did or did not take their medications or “Snooze” (to get reminded later with another push notification) with the option of using “smart reminders” (location-based reminders that go off within a 100m radius geofence of a specified location once the user enters the area).
- 🔄 **Refill reminders** are programmed to remind the user 30 days from the last day they picked up their medication. For example, if a user enters in the date they picked up their medication from a pharmacy in the application, the app will remind the user 30 days from that date to pick up their next prescription refill.
- 📅 **Appointment reminders** can be programmed in the app’s calendar section or side menu button as soon as they set a date/time for their next visit.

Medication Reminder Countdown. Additionally, there is a countdown clock on the home screen that shows the time left until the next medication reminder. This clock gives participants a visual cue in advance of their next reminder.

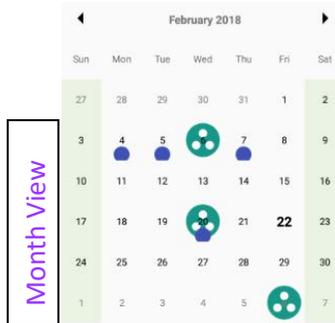


MEDICATION ADHERENCE SELF-MONITORING & TRACKING

Self-monitoring. The push notification reminders also prompt the user to answer if they did or did not take their medications. Responses are recorded in the app’s calendar and used for calculating points in the leaderboard screen.

Calendars. The home screen of the application depicts a calendar that shows the recorded medication adherence information. Participants can choose to see their adherence in different views: week or month.

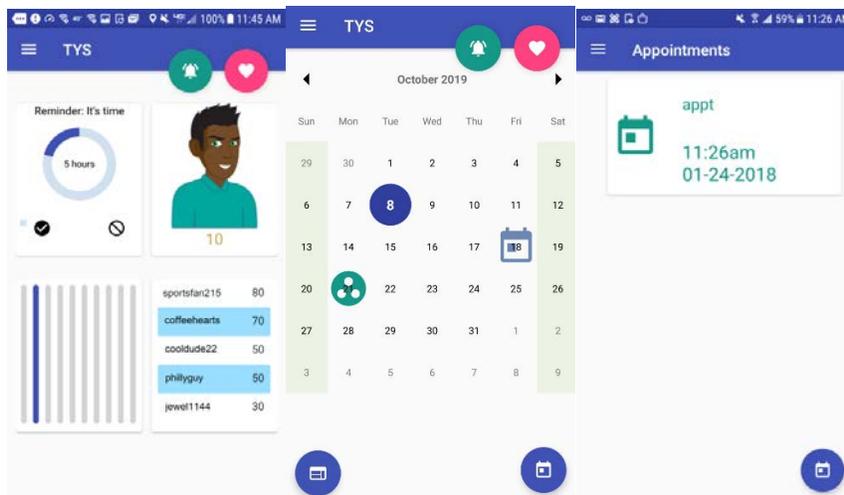




When the calendar is open, there are 2 different colored dots underneath each day to indicate medication adherence:

- Bluish purple = recorded meds taken
- Grey = recorded meds not taken

Additionally, users are able to save and view their medical appointments in the calendar (square calendar icon) as well as their refills (green circle icon with three white dots). Dark blue circle on top of the date indicates today's date for the user.



GAMING:

TreatYourSelf uses a system of immediate feedback and incentives based on gamification, which operates on theoretical principles of aligning with users' intrinsic motivation and providing carefully selected extrinsic rewards to achieve behavior change.

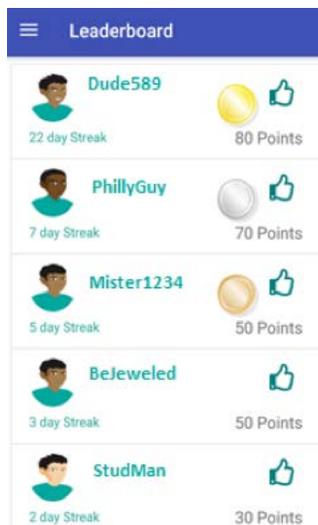
Points System. Every time participants record that they took their medication in response to push notification prompts, they receive points in the app. Points are recorded daily and based on adherence streaks (taking medications for multiple days in a row). Each user gets 10 points per day with an additional 5 points per day for every 5-day streak (see below for accrual system). The accrued points for all users reset to zero at the end of each month so that new

users can join and participate in a level playing field and current users who may have struggled previously have an opportunity to improve which keeps all users engaged and competitive.

Number of Days (streak) User Recorded They Took Their ART:

- Day 01-05: 10 points per day
- Day 06-10: 15 points per day
- Day 11-15: 20 points per day
- Day 16-20: 25 points per day
- Day 20-25: 30 points per day
- Day 26-30: 35 points per day

Leaderboard. As each user earns points for daily adherence, these points are displayed under the user’s avatar on the leaderboard, with the person with the most points for that month listed first. Additionally, first, second, and third place users are given a gold, silver, and bronze medal, respectively, on the leaderboard. Users have a visual of how they are doing compared with their peers and able to support those peers who are doing well by giving them a kudos (thumbs up) or to those who may be struggling.



Avatar. TYS also has an Avatar feature that allows users to select one of 60 avatar character images to use as their personal avatar that is displayed on the **home screen**, in the **Discussion Forum**, and on the **Leaderboard**. Using an avatar instead of a picture helps protect users’ privacy and maintain anonymity in the Discussion Forum and Leaderboard as well as allow users to be creative in choosing an avatar they feel best represents them in the app.



SOCIAL SUPPORT/NETWORKING:

Creating a network of social support through group-based gaming and interaction is also an integral part of TYS app. Creation of social networks of individuals with similar health problems has been shown to be effective in improving adoption of new health behaviors. The app provides opportunities for social support, including, the **Discussion Forum**, the **Heart Contacts**, and the **Leaderboard**, that may overcome some of the isolation and multiple layers of stigma often experienced by YLH.

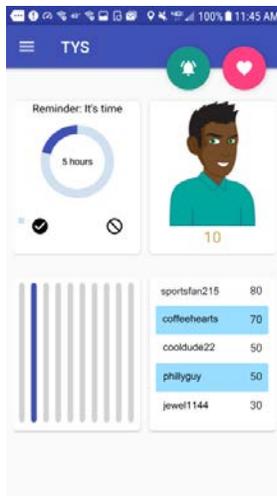
COMMUNICATION:

Leveraging the supportive accountability model of mHealth interventions, the TYS app has two main communication features: Heart Contacts and Discussion Forums.

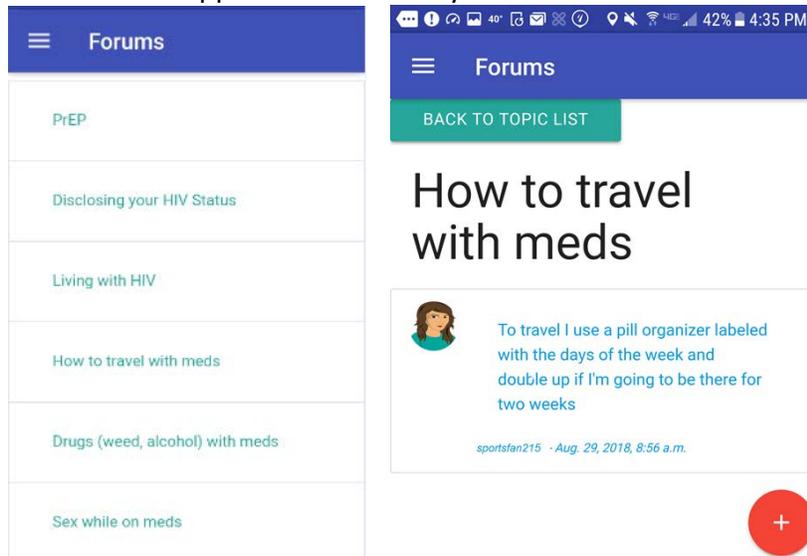


Heart Contacts.

TYS has a heart icon that functions as a contact button that participants can update with contact information for anyone in their support network. This button allows participants to directly text (via SMS) or call their providers or other support when they need.



Discussion Forums. The TYS discussion forum allows for private communication between app users in a group format with moderation by the project team. Pre-populated topics, such as disclosing HIV status and PrEP for partners, are available as well as an option for users to generate their own topics. In this capacity, users are able to anonymously discuss topics of interest in a supportive community.



INFORMATION RESOURCES:

Resources. The TYS app has a Resource section that provides a curated list of other mobile-friendly sites that provide additional information. The current list includes:

- [iknowUshould2](#)
- [Take Control Philly](#)
- [The Body](#)
- [AIDS InfoNet](#)
- [AIDSinfo](#)
- [The AIDS Library](#)
- [InSpot](#)
- [National HIV Infoline](#)
- [HIV hotlines – PA, NC, & DE](#)
- [Project Safe](#)
- [Project Inform](#)
- [POZ Magazine](#)
- [PWN \(Positive Women’s Network\)](#)
- [AIDs Library Resource Guide](#)
- [211 SEPA](#)
- [PrEP Facts – San Francisco AIDS Foundation](#)
- [AVERT](#)
- [ASK the HIV Doc YouTube Playlist](#)
- [Greater Than AIDS](#)

- [PrEP Philadelphia FIGHT](#)
- [Project TEACH – Adherence](#)

Frequently Asked Questions (FAQs). The FAQs page in the TYS app provides help regarding different features of the app (points system, changing their avatar, creating reminders, etc.), resetting their password, and how to get in touch with the project team.

FAQ
How do I create my username/password?
How do I change my username/password?
What do I do if I forgot my password?
How do I add contacts to My Support heart?
How do I change my Avatar?
How do I buy things for my Avatar?
How many points do I get each day?
How do I create a medication reminder?
What is the Smart Reminder?
How do I create a refill reminder?

In addition to the app’s key features, there several features that can be adapted to meet specific needs of participants. These adaptable features include (1) avatars with semi-customizable character images that can be modified specific to the participant (2) discussion forums with different pre-populated topics that participants can build conversations with and (3) resources consisting of links to other community-based organizations, community-based partners, and other local support services.

TYS App Evaluation Results: TYS is feasible and acceptable among YLH. In preliminary findings, participants who used the app and returned for a 3-month study visit (35/48=73% retention), the majority of participants (32/35 = 91%) reported that they would prefer to use the app in addition to their regular medical care rather than standard of care alone and 94% reported that they would want to continue to use the app after the study was over. Additionally, youth self-reported medication adherence on the visual analogue scale (VAS, 1-100) improved significantly from baseline to 3-months [VAS mean (SD): 76.2 (27.9) to 88.3 (21.4), p=0.03].

Development of the App and Workshop

Pre-Implementation app and workshop development occurred from January 2015 through June 2017 and consisted of the following:

1. **Mobile App Development:** Partnership and collaboration with Drexel University’s College of Computing and Informatics to develop and design the TYS app was solidified. Ongoing meetings to discuss app development features, create a prototype, develop the

final agreed-upon version of the app, continuously test the app, and fix bugs prior to initial roll out.

2. **Focus Groups:** Philadelphia FIGHT conducted one focus group consisting of older local youth, ages 25-29, where youth were asked about their mobile phone use as well as to describe features of a mobile app that would be most helpful in increasing their medication adherence and reducing sexual risk behaviors. CHOP conducted two focus groups consisting of YLH, ages 18-24, where the study team presented a list of app features and asked the youth to identify what would be most helpful in increasing medication adherence and reducing sexual risk behavior.
3. **Usability Testing:** Usability testing involved a group of YLH interacting with a preliminary draft of the app and providing feedback on what they found to be most helpful and useful. All individuals who participated in the focus groups and usability testing were compensated for their time.
4. **Creation and Adaptations of *APPlify* curriculum:** Integrated into the mobile app design was an ongoing iterative process to design a brief workshop around the key features that would also bring up topics around using digital technology for health care. Curriculum was reviewed by FIGHT staff and tested through presenting to several audiences prior to roll-out.
5. **Creation of Guidelines:** Development of: 1) *TreatYourSelf's* Community Guidelines for TYS app users on appropriate behavior and use as well as respect and support for other users as well as 2) *TreatYourSelf's* Study Phone Distribution Guidelines for youth who were given temporary Android phones to use the TYS app on appropriate and legal behavior on the smartphone (activity on social networking apps, SMS, web browsers).
6. **Ongoing App Development and Refinement:** Throughout the project implementation period from June 2017-2019, app development continued with partners from Drexel University in order to refine key app features, build backend data development and maintenance, add additional features (geolocation smart reminders, Google Play Update to SDK version 27, kudos feature, and notification alerts), and address app bug issues.
7. **Enrollment and Engagement of Youth:** Ongoing activities were required to enroll and engage youth during the demonstration project. This included, constant engagement with clinic teams, ongoing communication with community partners, regular discussion around recruitment/engagement/retention strategies, purchasing and maintenance of mobile phones with phone plans for youth with iPhones or without phones, updating protocols, directly reaching out to eligible participants, and maintaining contact with participants. CHOP also created supplementary materials to support the engagement of participants including a 1-page study summary, study flyers, and checklists for each project visit.

Implementation Summary

Implementation Activities

This section provides an overview of recommended staffing roles and functions, and activities involved, in implementing PC4H. The intervention is intended to be implemented during a routine medical or case management visit although more time would be needed to ensure

fidelity to the intervention than the typical time allotted for a medical visit. Sites wishing to implement the PC4H intervention would need to 1) offer and support youth to download the *TreatYourSelf* app, 2) facilitate the *APPlify Your Health* workshop as part of the process of introducing the app in order to increase the likelihood of its usage, 3) be able to monitor and troubleshoot app issues over time.

Enrolling Participants. The typical total amount of time needed to enroll a person in PC4H is 30-40 minutes which includes: teaching the *APPlify Your Health* workshop (15-20 min), downloading the app and making sure it is set up and working for the patient (10 min), and time to answer the patient's questions (5-10 min). Example questions are below:

- How much memory does the app use on my phone?
- What do I do if I forget my password?
- Can I use this app to program my other health appointments and medication reminders?
- Am I allowed to change my avatar?

Ongoing Troubleshooting. Staff time may be needed over time to help troubleshoot any technical issues with the app that arise. It is estimated that about 5-10 minutes is needed for a typical troubleshooting problem. This can be done over the phone, during a routine medical visit, or scheduled as a separate visit. It is recommended that, at minimum, staff ask patients about their use of the app during any routine visits or phone calls as a check-in to ensure there aren't any issues that have prevented the patient from using the app effectively.

Partners and Staffing Required for Implementation of the Intervention

Organizations implementing PC4H would ideally replicate the partnering processes conducted in development and demonstration of the intervention. These include:

- Youth and Community Advisory Board (YCAB)
- Clinic and Case Management Partners
- Community Collaboratives working with youth
- Mobile application programming partner (for maintenance or adaptations, if not working directly with the original PC4H team)
- Organizational Health Informatics or Information Technology offices

Staff who could implement this intervention includes anyone who is working directly with YLH (13-34 years old) including: physicians, medical case managers, behavioral health or adherence specialists, mental health professionals/therapists, community health workers, and treatment education staff.

Staff implementing PC4H should have the following skills:

- 1) Excellent communication skills
- 2) Comfort using and manipulating technology, mobile apps in particular
- 3) Comfort discussing issues around adherence, confidentiality online, and stigma and privacy as it relates to using technology for one's health care.

To implement at sites, at least one staff member would need to be an administrator in the Google Play Store console to be able to give permissions to specific users to download the app as it is not available publicly for the protections of YLH. Those staff members should also understand TYS app functions and familiarize themselves with the *APPlify Your Health* curriculum prior to delivering the intervention.

Because the intervention itself is a short workshop and an app, replication should not require resources that are unavailable in most HIV prevention settings. The goal is to use this intervention as an additional tool to support adherence and engagement in care. The following staff should be assigned or designated to ensure fidelity to the intervention:

Project Manager (>.05 FTE)

- Oversees the replication and quality of *APPlify Your Health*
- Understands and oversees the strategy to promote usage of *TreatYourSelf* within the clinical site or community-based organization
- Ideally this person should be integrated with or part of the clinical team. They could be a social worker, clinician, or adherence specialist.

TreatYourSelf and APPlify Instructor (Approximately .10-.25 FTE depending on number of participants.)

- Runs *APPlify Your Health* workshop (group or 1:1) with participants
- Helps participants download the app and set it up
- An effective communicator who can discuss complex issues around confidentiality, adherence, and digital health literacy with young people
- This person can be a social worker, clinician, case manager, adherence specialist, sexual health educator, community health worker who is the “go-to person” for the intervention
- Ideally this person is embedded in a clinical setting or team

Technical Support (Approximately .05 FTE)

- Ensures that the app is working properly on users’ smartphones
- Troubleshoots any issues that arise
- Pushes out updates if necessary and alerts users
- This position could be the same person as the *TreatYourSelf* and *APPlify* Instructor or it could be an IT person within an organization.
- This person should have a high comfort level with technology and/or experience with help desk support.

Recommendations for Future Implementation

PC4H App and Workshop Adaptation and Usage

- Consider using a low cost or open source existing app platform, such as TYS, in lieu of a new app
- If creating or adapting TYS, work with developers that best fit the goals of your project and can support front and back-end needs as well as features that may be adapted
- Ensure availability and functionality of app on multiple operating systems and smartphone device types
- PC4H Adaptations:
 - a. TYS app's avatar, discussion forum, and resources may all be easily adapted for another HIV prevention clinic/program (i.e., PrEP clinic) or population with a different chronic disease.
 - b. The *APPlify Your Health* curriculum is also readily adaptable for different populations and individuals with other chronic illnesses that may benefit from additional support.
 - i. Develop and update digital Health literacy workshop as technology and health information online evolves with accompanying app guides

Engagement with Clinical Team or Clinic Flow

- Conduct focus groups with clinical/program staff to get feedback & buy-in on intervention
- Clinical workflow: Engage and train existing clinical team to deliver the app to participants and provide technical support quickly

Additional Resources

- Consider providing phones with data/voice plans: Although not required for implementation, for patients without smartphones or Android phones, setting aside funds to provide smartphones with 1-year unlimited data plans is a good digital health equity strategy as it would support patients particularly at-risk of being lost to care or struggling with adherence who experience phone disruptions due to lack of access and issues with affordability.

PC4H Resources

Project Webpage Descriptions

- [Positively Connected for Health \(PC4H\): Use of eHealth/mHealth tools to Improve Health of HIV+ Youth](#)
- [APPlify Your Health](#)

Conference Abstracts and Publications

- [Publications - Nadia L. Dowshen, MD, MSHP](#)

- [TreatYoSelf: Empathy-driven behavioral intervention for marginalized youth living with HIV](#)
- [2018 Society of Pediatric Psychology Annual Conference: Developing and Implementing mHealth Interventions to Improve Health Outcomes of AYA Living with Chronic Health Conditions: Lessons Learned and Practical Advice](#)
- 3rd Annual Johns Hopkins University (2018): Digital Solutions for Sexual and Gender Minority Youth Across the HIV Care Continuum,
- [2018 Ryan White Conference: Challenges to the implementation and evaluation of Social Media Interventions Designed to Engage Young People Living with HIV](#)
- [2018 Ryan White Conference: The development of mobile applications to improve the HIV care continuum for adolescents and young adults from three interventions in the SPNS Social Media Initiative](#)
- Johns Hopkins University Digital Wings Symposium (2019): Digital Solutions for Youth HIV Prevention and Treatment
- 2019 Society for Adolescent Health and Medicine (SAHM) Conference: [Positively Connected for Health \(PC4H\): Acceptability and Feasibility of a Digital Health Adherence and Engagement in Care Intervention for Adolescents and Young Adults Living with HIV](#)
- 2019 Society for Adolescent Health and Medicine (SAHM) Conference: [Developing and Implementing mHealth Interventions to Improve Health Outcomes of AYA Living with Chronic Health Conditions: Lessons Learned and Practical Advice](#)

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