2018 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Positively Connected For Health (PC4H) - A Youth-Driven, mHealth Intervention for HIV Treatment

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Disclosures

Presenter has no financial interest to disclose.

Learning Objectives

At the conclusion of this activity, participants will:

1. Understand the process of developing HIPAA-compliant mobile applications to improve HIV care continuum for youth and young adult HIV populations.
2. Understand the (unique) challenges of implementing interventions using mobile applications (in a young population).
3. Describe lessons learned from this SPNS initiative of utilizing mobile applications as an intervention tool to engage and retain youth and young adult HIV populations in care.

1. Developing mobile applications to improve HIV care continuum for youth

Intersectionality of Technology and the Youth HIV Care Continuum

- Approximately 38,000-40,000 new HIV infections in US each year
  - Adolescents and young adults make up close to one-half of those new infections despite accounting for only one-third of the total population
  - **In 2015, 42% of new HIV infections in Philadelphia were among youth (13-29 years)**
  - Young MSM, TGW, and youth of color are disproportionately impacted

Intersectionality of Technology and the Youth HIV Care Continuum

- According to the CDC Youth Risk Behavior Survey fewer than 1 in 4 sexually active adolescents report ever being tested for HIV.
  - No change in testing rates since 2006
  - **Youth in Philadelphia are more likely to be diagnosed with HIV/STI than youth nationwide**
    - **15-24 year old made up 65% of Chlamydia, 53% of Gonorrhea, and 30% of Syphilis infections in 2015**
    - **Higher than national average**

Intersectionality of Technology and the Youth HIV Care Continuum

- Majority of youth now own and/or use smartphones as common mode of communication (texting, social media), entertainment (gaming), and relationships
  - Nearly ¾ of all youth have smartphones
  - Over 90% of teens text and send on average 30 messages per day
  - 72% of youth play games online/on phone
  - Young adults 18-30 on “hook-up apps*”
- mHealth interventions are necessary for engaging youth

*Holloway, I.W., Rice, E., Gibbs, J. et al. AIDS Behav (2014) 18: 285. https://doi.org/10.1007/s10461-013-0671-1

Philadelphia Local Initiative

PC4H Overview

- **Positively Connected for Health (PC4H)** is a HRSA-funded Special Programs of National Significance (SPNS) demonstration project to engage and retain HIV+ youth in care. This collaboration between CHOP and Philadelphia FIGHT aims to improve health outcomes HIV+ youth in Philadelphia through two distinct social media interventions:

APPlify Your Health!

A digital health literacy workshop that uses pop-up iPad and smartphone labs to support youth who will be engaged in our two social media interventions

TreatYourSelf (TYS)

A mobile app designed for and with input from HIV+ youth to improve adherence to antiretroviral therapy and engagement in care

PC4H – APPlify Your Health Workshops

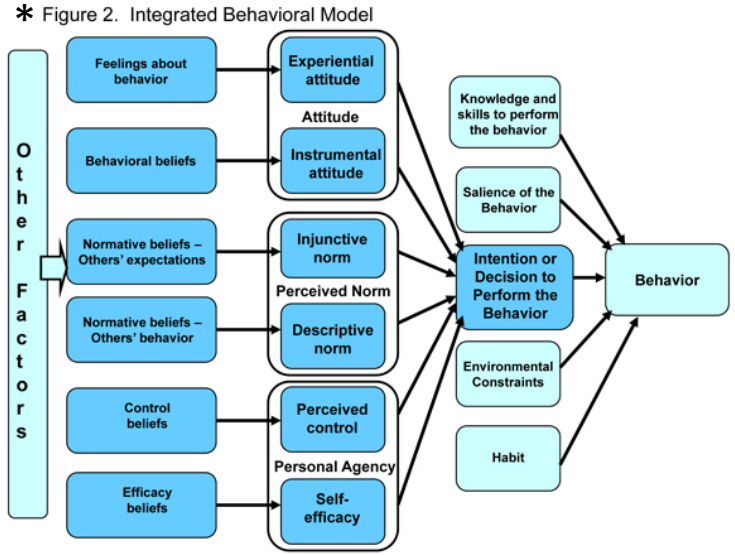
- Created by Philadelphia FIGHT within Critical Path Learning Center; modified for PC4H
  - Engages HIV+ youth through real-time, youth-centric, small group workshops using mobile devices
  - Allows youth space/time to become familiar with the functions of the TreatYourSelf app and other eHealth/mHealth tools to increase health literacy
    - Terminology, common health management issues, managing stigma and crises, triage of information
  - Individual sessions offered for youth who do not want to disclose status

Critical Path Learning Center
A Program of Philadelphia FIGHT Community Health Centers

PHILADELPHIA FIGHT
COMMUNITY HEALTH CENTERS

TreatYourSelf (TYS) Development

- Theory guided development
  - Integrated model of behavioral prediction
  - Ecological momentary intervention
  - Supportive accountability/gaming
- Multidisciplinary Team
  - Game/app developers; research staff, adolescent medicine physician, and a "patient expert"
- Iterative process using a youth-centered, incubator approach
  - **Focus groups**
  - Usability testing

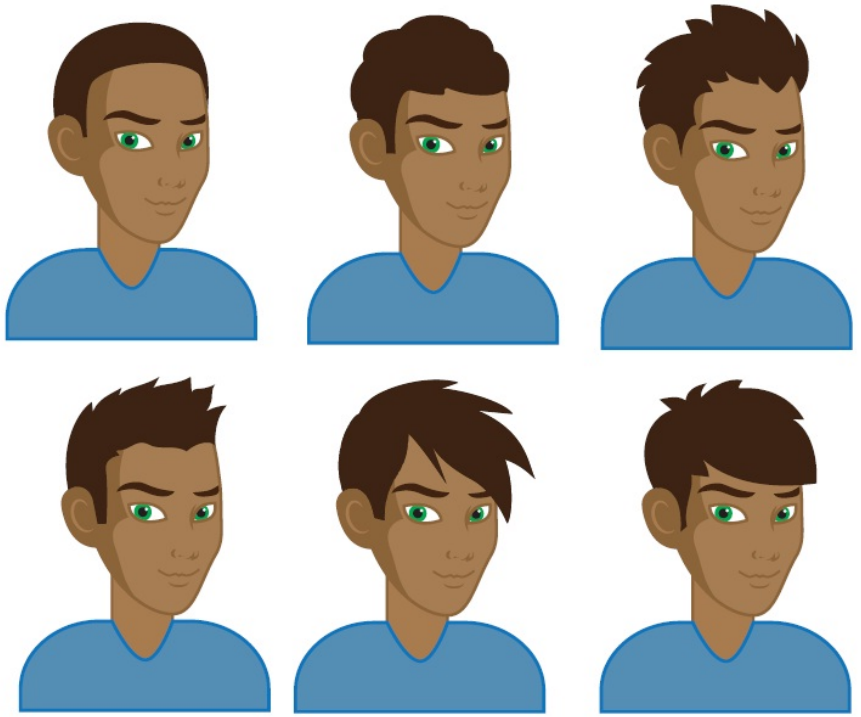


*https://www.med.upenn.edu/hbhe4/part2-ch4-integrated-behavior-model.shtml

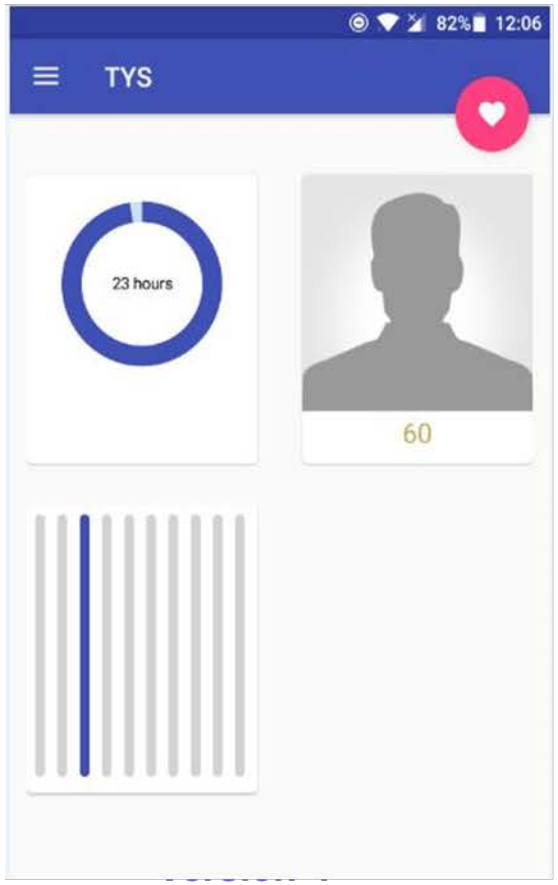
PC4H – TreatYourSelf (TYS)

Key Features:

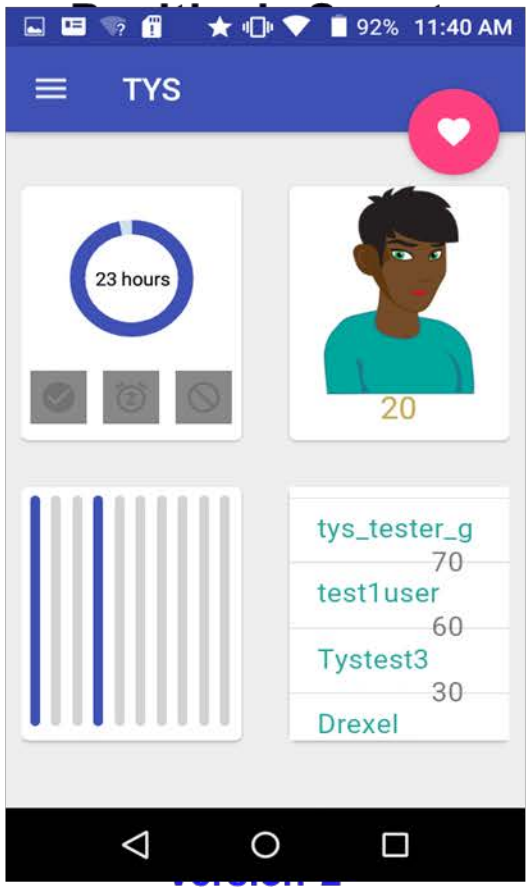
- Medication Reminder
- Appointment Reminder
- Refill Reminder
- Group Forums
- Avatar
- Points
- Resources
- Calendar tracking
- Care provider contacts



App Development Progression



Version 4.1



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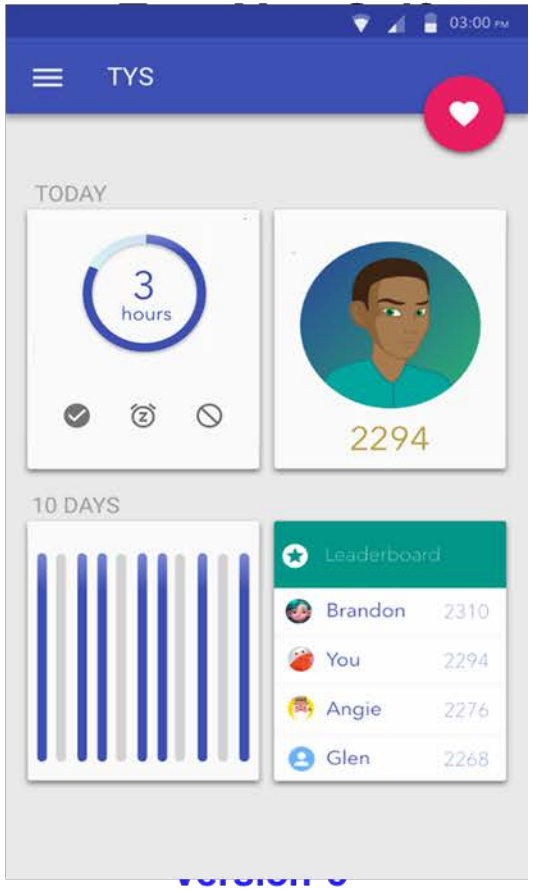
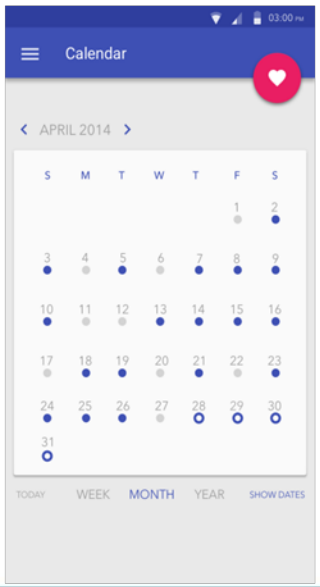


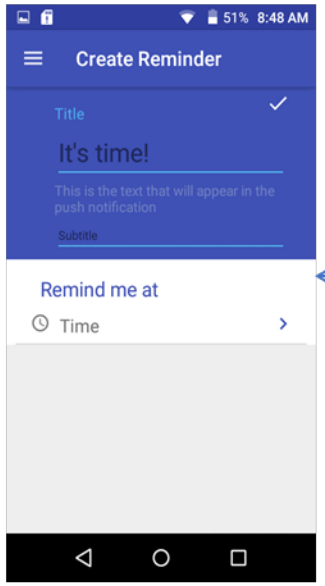
Version 4.3

Android TYS Layout

App icon

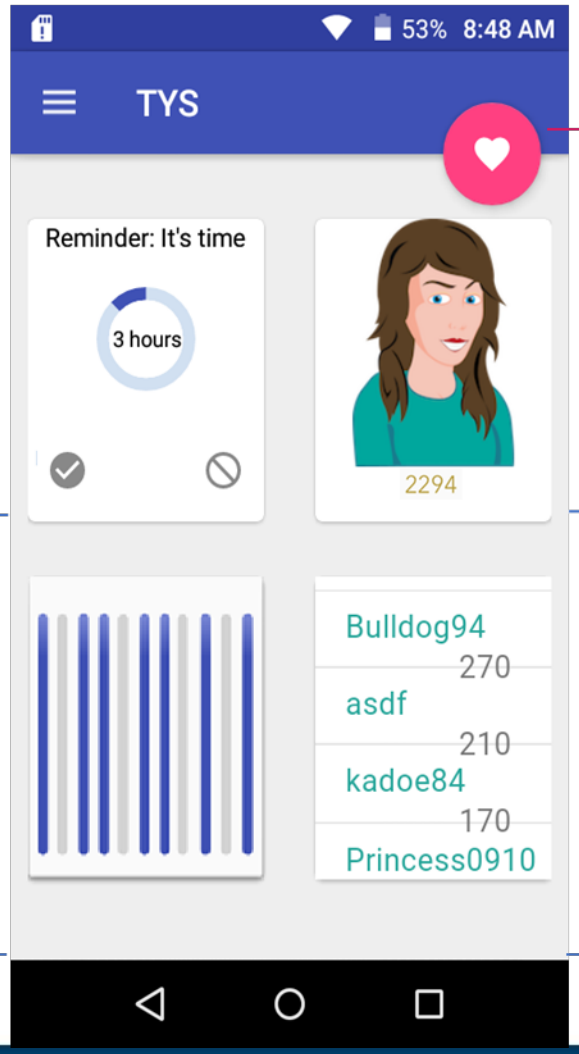
Menu
(Settings, Resources, Forum)





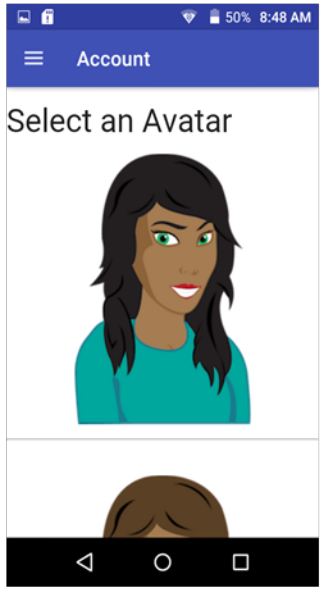
ART Reminder

Calendar
(track medication adherence, appointment, refill)

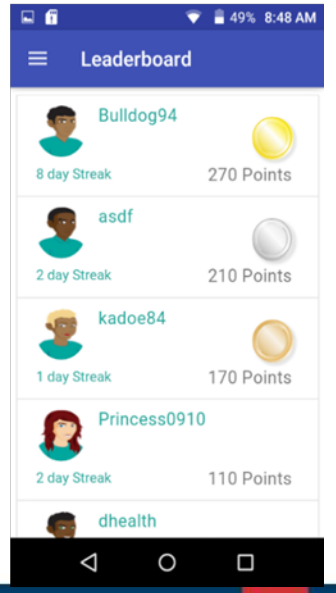


Heart Contacts
(Support System)

Avatar



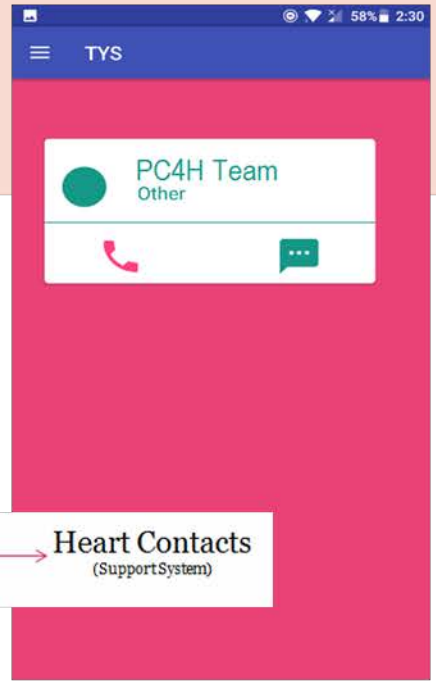
Leaderboard



TYS Delivery Methods and Resources

SMS/Text

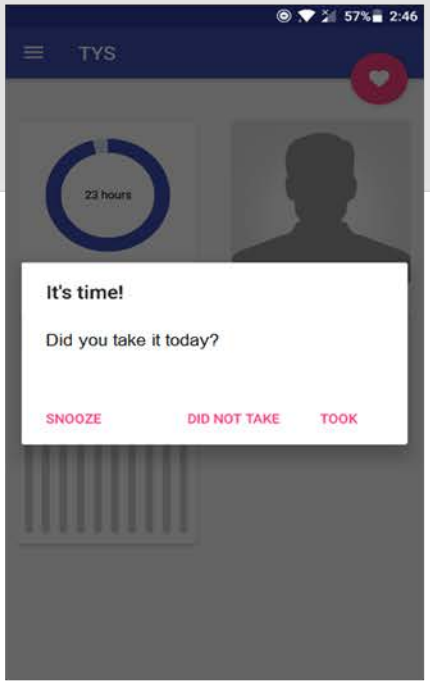
- Bi-directional
- Sent as needed
- In real-time



Heart Contacts
(Support System)

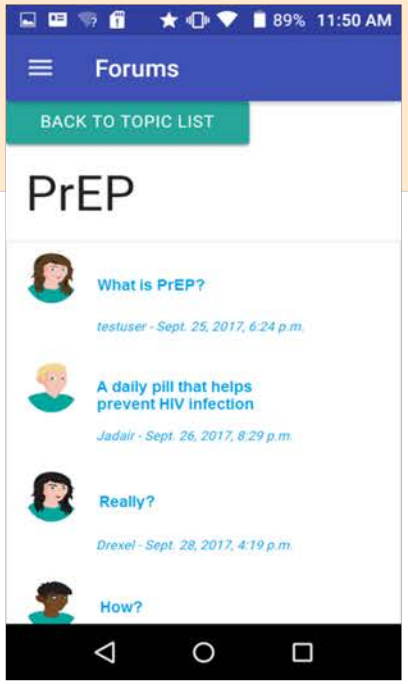
Push Notifications

- Automated
- Once or twice a day (pending ART regimen)
- Location reminder*



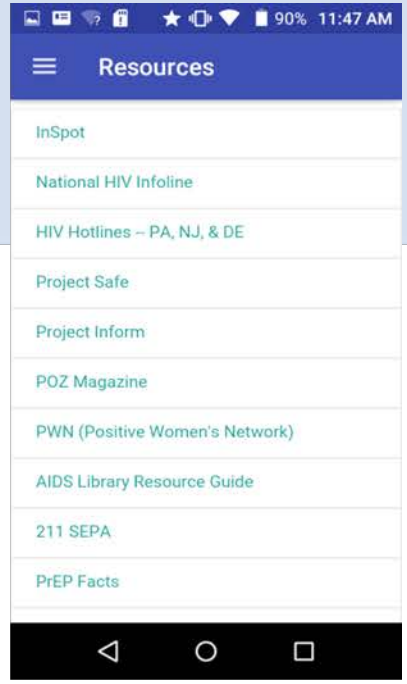
Discussion Forums

- Pre-populated topics
- Used as needed
- Usernames only



Resources

- Weblinks open up within app, not browser, for extra privacy



Menu
(Settings, Resources, Forum)

Philadelphia Cohort

Participant Characteristics, N=48 (Self Reported)	n (%)
Mean age (SD, Range)	25.52 (4.64, 17-34)
Race	
• Black or African American	33 (68.75)
• White	4 (08.33)
• Other or Multi racial	11 (22.92)
Ethnicity	
• Hispanic/Latin	9 (18.75)
• Non-Hispanic/Latin	39 (81.25)
Sex assigned at birth	
• Male	36 (75.00)
• Female	12 (25.00)
Reported Gender	
• Cisgender Male	31 (64.58)
• Cisgender Female	13 (27.08)
• Trans Male	1 (02.08)
• Trans Female	2 (04.17)
• Other	1 (02.08)

Participant Characteristics (Continued)	n (%)
Sexual Orientation	
• Straight	16 (33.33)
• Lesbian or Gay	21 (43.75)
• Bisexual	9 (18.75)
• Other/Don't know	2 (04.17)
Engagement/Retention Risk	
• Unsuppressed VL (≥200 copies/ml)	32 (66.67)
• Out of care for ≥6 months	22 (45.83)
• Newly Diagnosed	8 (16.67)
Antiretroviral Therapy Status at Baseline	
• On ART	42 (87.50)
• Not on ART, but will start soon	6 (12.50)

Philadelphia Cohort

Usage, N=48	n (%)
Phone Ownership*	
• Android	23 (47.92)
• iOS (iPhone)	22 (45.83)
• No Smartphone	3 (06.25)
Hourly phone use daily Mean (SD, Range)	11.2 (7.00, 1-24)
Hourly WiFi use daily Mean (SD, Range)	9 (7.97, 1-24)
Phone disruption in past year	
• No disruption	21 (43.75)
• 1 time	12 (25.00)
• ≥2 times	15 (31.25)

***iOS and non-smartphone users were provided a study issued Android smartphone to use in the study**

Digital Health Literacy: Before APPlify and at 3-month

eHealth Literacy Scale Item	Pre=APPlify, N=48 Agree/Strongly Agree n (%)	3-Month, N=32 Agree/Strongly Agree n (%)
I know what health resources are available on the Internet	37 (77.1)	28 (87.5)
I know where to find helpful health resources on the Internet	37 (77.1)	29 (90.6)
I know how to find helpful health resources on the Internet	43 (89.6)	31 (96.9)
I know how to use the Internet to answer my questions about health	42 (87.5)	30 (93.8)
I know how to use the health information I find on the Internet to help me	35 (72.9)	31 (96.9)
I have the skills I need to evaluate the health resources I find on the Internet	39 (81.3)	28 (87.5)
I can tell high quality health resources from low quality health resources on the Internet	29 (60.4)	21 (65.6)
I feel confident in using information from the Internet to make health decisions	25 (52.1)	22 (68.8)

2. Challenges of implementing interventions using mobile applications.

Implementation Challenges

- Recruitment/Retention
  - Population unlikely to regularly engage with healthcare[1,2]
    - Average age of 25.6 years
    - History of poor ART adherence (80.5%) and inconsistent visit attendance (41.5%)
    - Frequent cancellations/no-shows prompting many reminder calls/texts/emails/app messages
  - Incentives were not in cash – competing initiatives
    - Only FIGHT study to not offer cash incentive
  - Delays in reporting lost/broken phones cause missed and late visits and data jeopardy
  - Study team changes during active recruitment
    - Lengthy training/onboarding processes

1. Ryscavage et al. (2016) Linkage to and retention in care following healthcare transition from pediatric to adult HIV care, AIDS Care, 28:5, 561-565, DOI: 10.1080/09540121.2015.1131967
2. Brian C. Zanoni and Kenneth H. Mayer.AIDS Patient Care and STDs.Mar 2014.ahead of printhttp://doi.org/10.1089/apc.2013.0345

Implementation Challenges

- Regulatory Issues
  - Updated OHRP regulatory guidelines delayed – difficulties coordinating requirements between IRBs (3)
    - Varied review frequencies
  - Delayed Certificate of Confidentiality from parent site delayed release of stamped ICFs from some local IRBs
    - Local CoC required – created additional hurdles
  - Numerous amendments
    - Inclusion/exclusion updates not eligible for expedited review per some local IRBs
  - Number of local studies with non-compete clauses limit patient pool

Implementation Challenges

- Technology
  - Academic partner (Drexel)
    - Student vs faculty involvement
  - Single platform (Android)
    - Initial feasibility identified Android as most common platform – shift between feasibility and implementation
    - Much more iPhone use
    - Patients unwilling to carry 2 phones to participate
  - System and operational issues (Google PlayStore) slowed down release of new features

3. Lessons learned from utilizing mobile applications as to engage and retain young HIV+ populations in care

Lessons Learned

- It takes a village…
  - Numerous study staff applying countless hours
    - Community outreach (and advertising)
    - Targeted outreach in-clinic
    - Staff education
  - Buy in from medical staff
    - Acting patient liaisons
    - Understanding of life patient circumstances
  - Multidisciplinary approach
    - Utilization of existing technology (EMR) for both recruitment and retention
    - Case management, pharmacy staff, education, etc.
- Academic vs industry partnerships
  - Availability and accountability
  - Monetary cost vs speed
  - Understanding of material and personal investment

Ranking of TYS Features and TYS Proficiency

Rank	Most Useful	Least Useful
1	Medication/Refill reminders	Nothing, everything is useful
2	Calendar Tracking	Avatar
3	Heart Contacts	Heart Contacts
4	Forum	Seeing spaces for features that don't exist yet
5	Anonymity/Privacy & Resources (tied)	

TYS app proficiency, N=48	Agree/Strongly Agree, n (%)
Feel proficient with operation TYS app, including	
• Avatar	45 (93.8)
• Medication reminder	47 (97.9)
• Calendar	48 (100.0)
• Leaderboard/Forum	39 (81.3)
Feels they will use TYS app more because of workshop	44 (91.7)

More Lessons Learned

- Youth-centric is key
  - Participant Likes
    - Reminders (daily medication, appointment, and refills)
    - Calendar/medication adherence progress
    - Total accrued points/Leaderboard
    - Forum/Heart (care provider) contacts
  - Participant Dislikes
    - Nothing, liked the app as is
    - TYS app bugs (crashes, reminders not firing when scheduled)
    - Point system (wanted a tangible reward for high points and disliked having to start at the bottom tier of point accrual earning if they missed 1 day after a long streak)
  - Participant Suggestions
    - Fix app bugs more quickly
    - Introduce something interactive weekly (trivia, photos) to “keep it fun”

More Lessons Learned

- Future Considerations:
  - Supplemental content
    - CAB for ongoing content development
    - Local content vs broadly applying content
    - Improve utilization of the “Resource” folder
  - Supplementary Applify Classes
  - App interface with providers
    - Telehealth?

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