

RWHAP SPNS Initiative: Using Social and Digital Media to Improve HIV Care in Young People Living with HIV

Presenters:

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MetroHealth System**

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of Public Health**

**John Zurlo, M.D., Co-PI of Opt-in for Life, Pennsylvania State University Medical
Center, Hershey, PA and Jefferson University, Philadelphia, PA**

**Ronald Brooks, PhD, Department of Family Medicine, David Geffen School of
Medicine, University of California, Los Angeles**

Disclosures

- No presenters listed in this session have any financial or non-financial conflicts of interest to disclose.

Learning Objectives

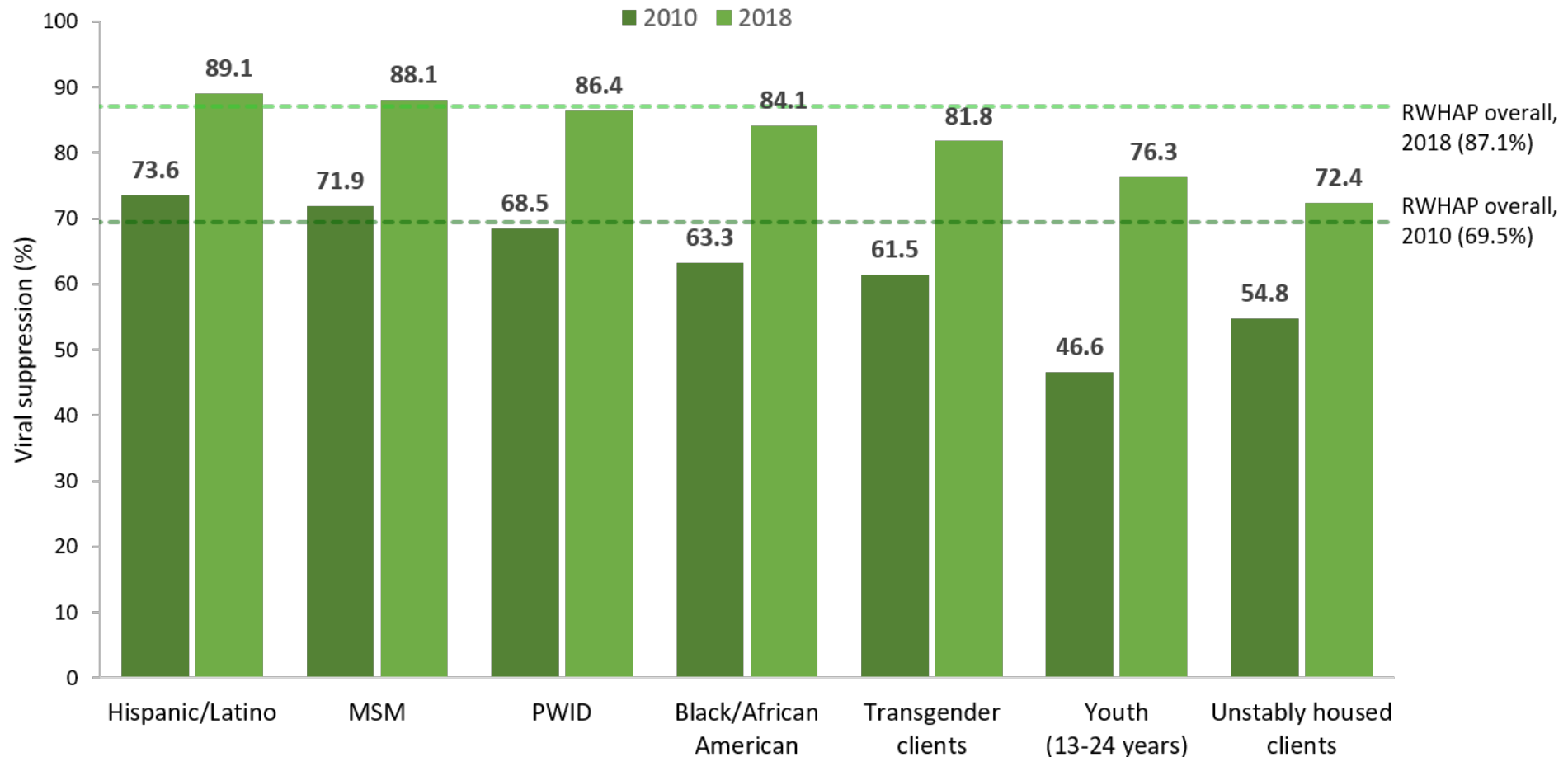
1. Attendees will gain knowledge regarding digital technology and social media based interventions to improve HIV health outcomes for young people with HIV.
2. Attendees will gain knowledge of the HIV health outcome measures used and results of the SPNS Social Media Initiative interventions targeting youth and young adults with HIV.
3. Attendees will learn of lessons learned from demonstration sites involved in developing, implementing and evaluating their own unique, innovative interventions models as part of the SPNS Social Media Initiative.
4. Attendees will be able to locate materials with details on intervention models, summary monographs, and replication manuals located on Target HIV.

Background to the SPNS Initiative

- HIV-positive youth and young adults (ages 13-34) are the least likely out of any age group to be linked to and retained in HIV care, or to achieve viral suppression.
- Youth and young adults have high rates of social media and digital technology use that include, for example, Facebook, text messaging, and GPS-based mobile apps designed for social and sexual networking making them ideal platforms to deliver HIV care interventions to these populations.

Background to SPNS Social Media Initiative: Disparities in Viral Suppression

Youth, Transgender People, and Black/African Americans of Concern



Background (cont'd): Increasing Digital Media Use by Young People

Young People, aged 18-29,
owning a smart phone and using
regularly

2013: 78%

2014: 82%

2015: 86%



RWHAP's SPNS Response: A Demonstration Initiative

- Implement, evaluate and disseminate findings from innovative methods using digital and social media
- Underserved, under-insured, hard-to-reach youth and young adults with HIV new to care, out-of-care, or irregularly engaged in care
- Improve engagement and retention in care and viral load suppression
- Proposed innovative models to be evaluated as part of the initiative

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Health Resources and Services Administration

HIV/AIDS Bureau
Division of Training and Capacity Development

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

Announcement Type: Initial: New
Funding Opportunity Number: HRSA-15-029

Catalog of Federal Domestic Assistance (CFDA) No. 93.928

Four Years: Sept. 2015 – August 2019

Social Media Initiative Demonstration Sites

- **NY City** – New York AIDS Institute, with Northwell Health System, Mt. Sinai App lab, Long Island Crisis Center, and Hunter College
- **Philadelphia** – Philadelphia FIGHT, with Children’s Hospital of Philadelphia and Drexel University School of Informatics
- **Hershey, PA** – Pennsylvania State University School of Medicine, Hershey Medical Center, Pinnacle Health System, Hamilton Health Center, Alder Health Services, Duet Health Inc.
- **Winston Salem, NC** – Wake Forest University
- **Cleveland** – Metro Health System, with Blue Star Design
- **Chicago** – Howard Brown Health Services, with Healthvana Software Co.
- **Corpus Christi** – Coastal Bend Wellness Foundation, with San Antonio HD
- **St. Louis** – Project ARK at Washington University, with ePharmix, Inc.
- **San Francisco** – Public Health Foundation, with the SF Department of Health
- **Los Angeles** – Friends Research Institute

Demonstration Site Models

Technology Platforms used by the SPNS Social Media and Digital Technology Interventions

Demonstration site	Text messaging	Mobile apps	Social networking sites or app	Social media	Website
Corpus Christi	All types*		Yes	Yes	Yes
Los Angeles	Automated, unidirectional		Yes	Yes	
Chicago	Automated, bidirectional	adapted			Yes
Cleveland	Automated, bidirectional	new		Yes	Yes
New York	All types	new	Yes	Yes	Yes
Hershey	All types	adapted	Yes	Yes	Yes
Philadelphia	All types	new	Yes	Yes	Yes
San Francisco	Live, bidirectional	new	Yes	Yes	Yes
Winston-Salem	Live, bidirectional		Yes	Yes	
St Louis, MO	All types	adapted		Yes	

Using Social Media and Digital Technologies to Engage and Retain in Care, and Achieve Viral Suppression among Youth and Young Adults Living with HIV

Quantitative Results Presented By W. Scott Comulada, Dr.P.H.

University of California, Los Angeles, Evaluation and Technical Assistance Center (ETAC) Team Members:

Ronald A. Brooks, Ph.D., Melissa Medich, Ph.D., W. Scott Comulada, Dr.P.H., Dallas Swendeman, Ph.D., Uyen Kao, MPH, Janet Myers, Ph.D., Adam Northrup, MS and Thomas Donohoe, MBA

Ryan White Conference, 2020

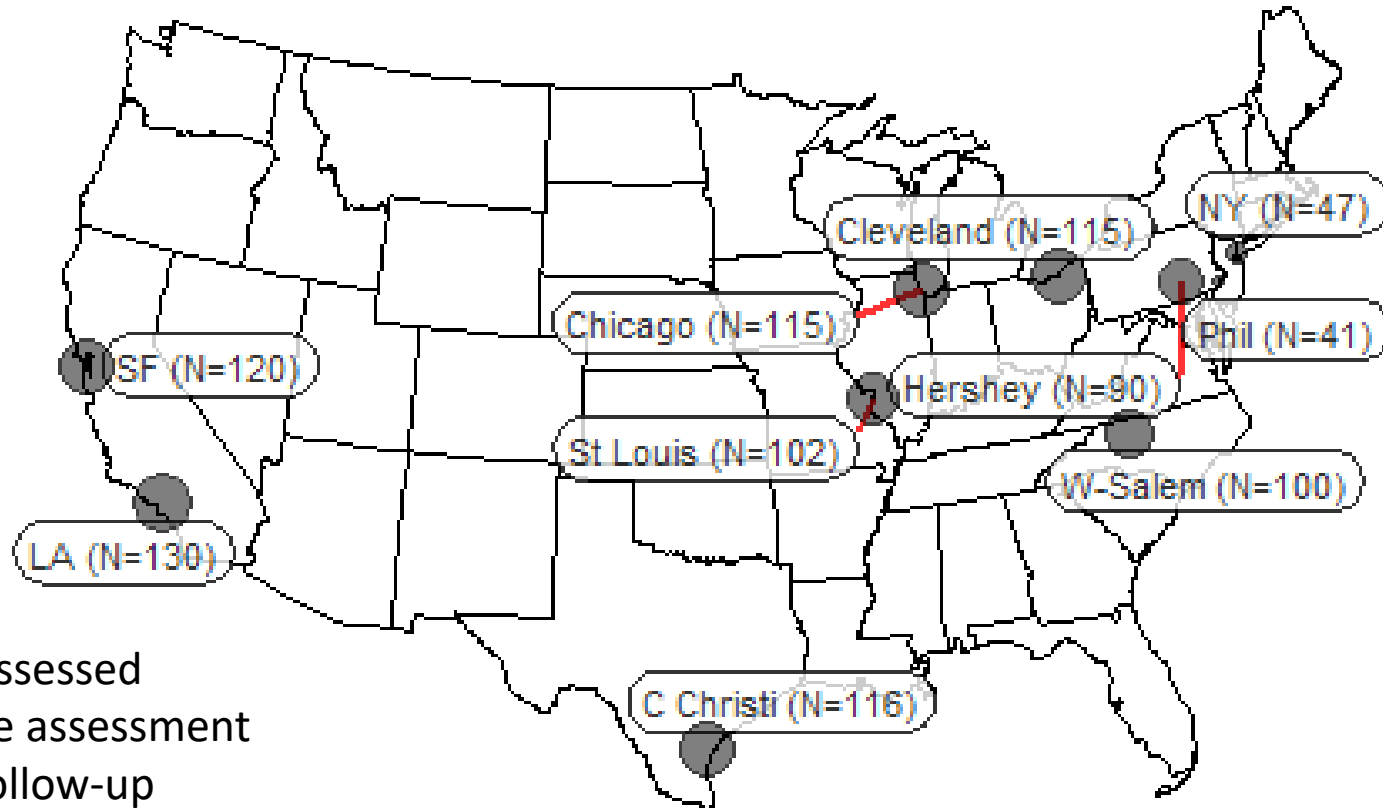
Background

Ten demonstration sites across the U.S. funded by HRSA/SPNS to develop and implement innovative social media and digital technology interventions to improve HIV care engagement and viral suppression among youth and young adults living with HIV. The sites included:

1. Coastal Bend Wellness Foundation Inc., Corpus Christi, TX
2. Friends Research Institute, Inc., Los Angeles, CA
3. New York State Department of Health, NY
4. Howard Brown Health Center, Chicago, IL
5. The Metro Health System, Cleveland, OH
6. Pennsylvania State University, Hershey, PA
7. Philadelphia FIGHT/ CHOP, Philadelphia, PA
8. San Francisco Department of Public Health, CA
9. Wake Forest University, Winston-Salem, NC
10. The Washington University, Saint Louis, MO

HRSA also funded the University of California, Los Angeles, to serve as Evaluation and Technical Assistance Center (ETAC) to implement a multi-site evaluation of the interventions.

Map showing sites across the U.S.



N = 976 participants assessed

- 16 without baseline assessment
- 154 (16%) lost to follow-up

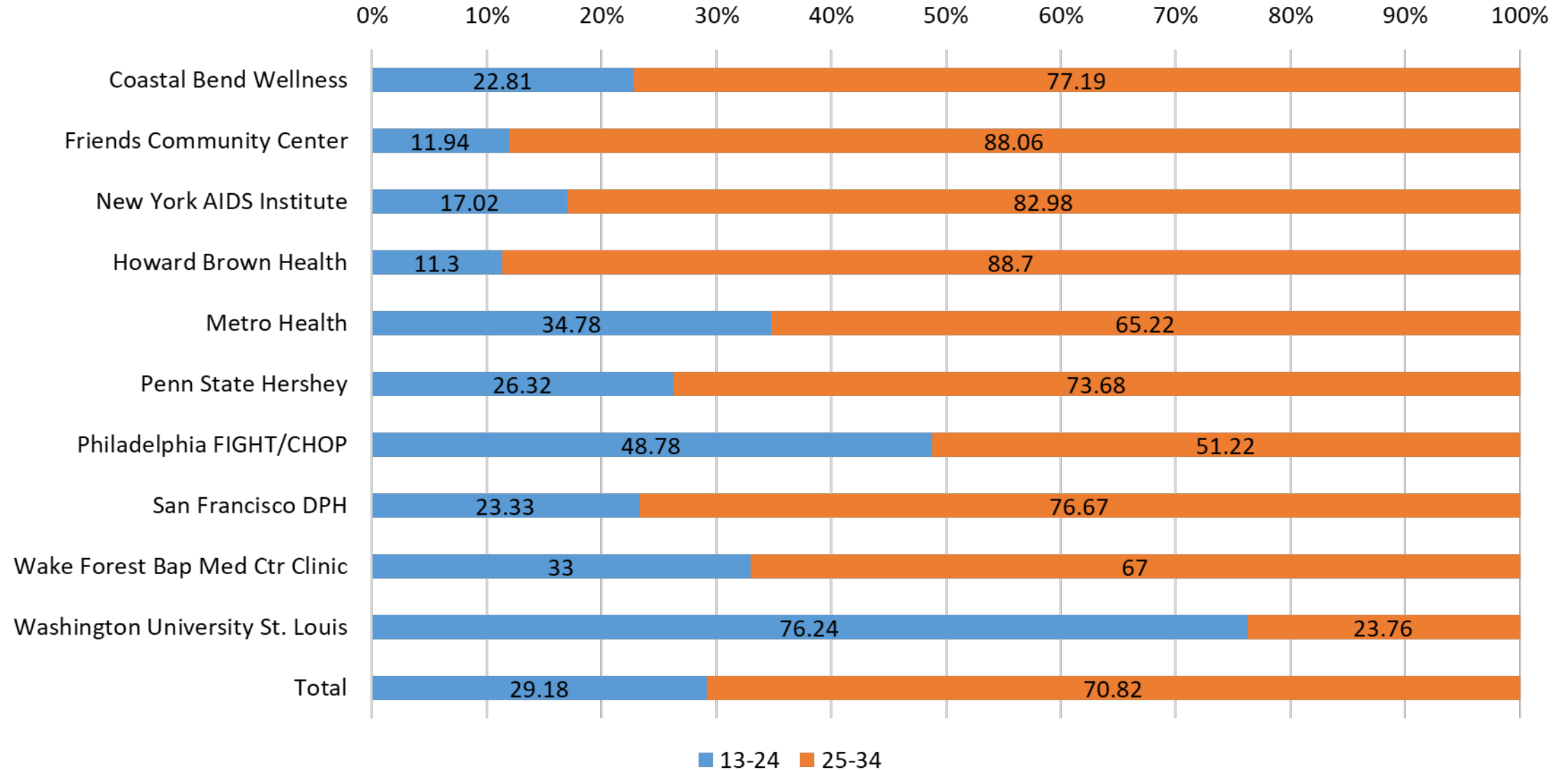
Analyses make use of all available data.

Project

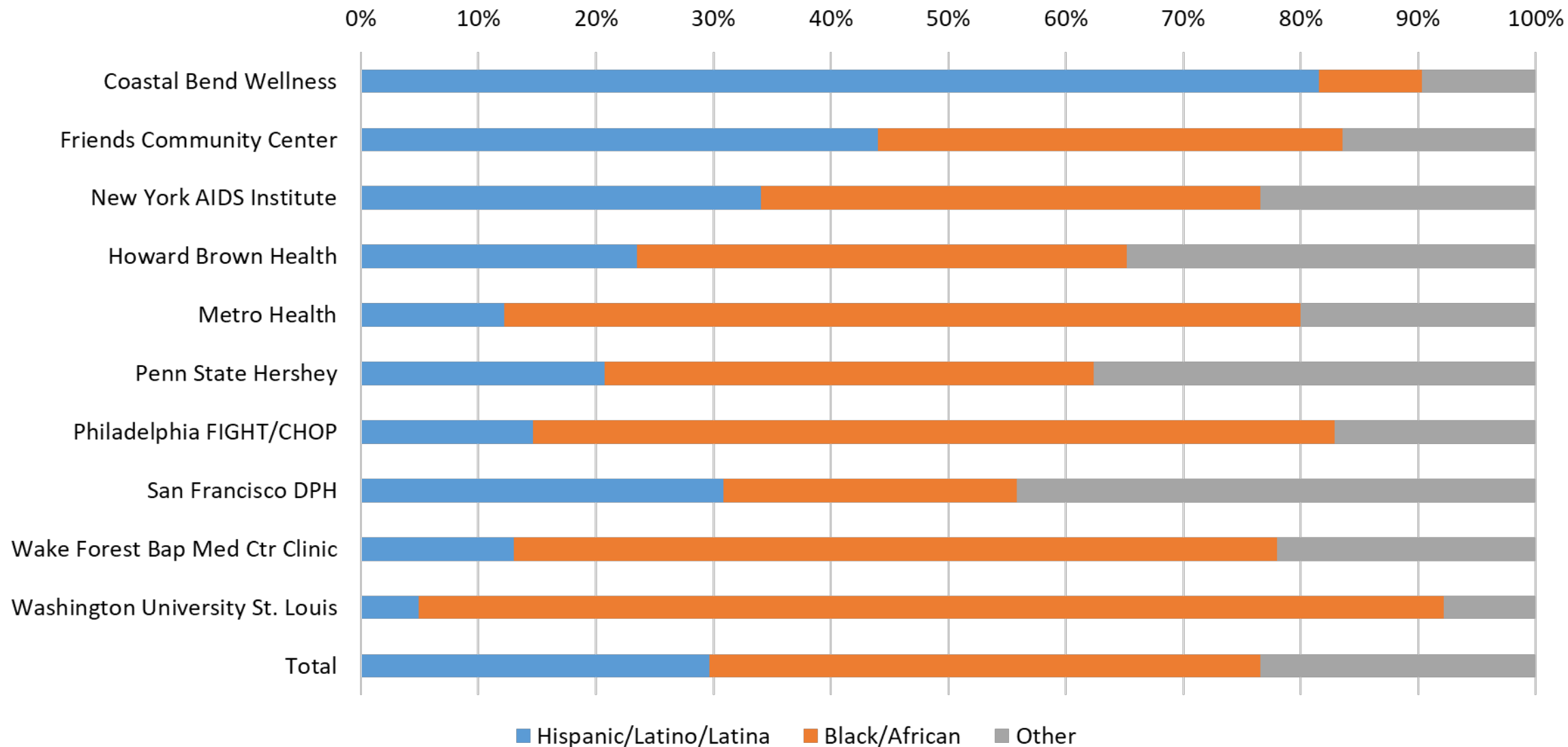
- This presentation will provide findings on changes in HIV health outcomes across the ten demonstration sites.
- The ETAC conducted a longitudinal assessment of changes in HIV health outcomes over an 18-month period.
- The multi-site evaluation includes surveys conducted with intervention participants at baseline and 6, 12, and 18-month follow-ups.
- Medical chart data was also extracted for intervention participants.

Baseline characteristics of participants in the Social Media Initiative

Percentage of youth (13-24 yrs old) and young adult participants (25-34 yrs old) by site (N=965)

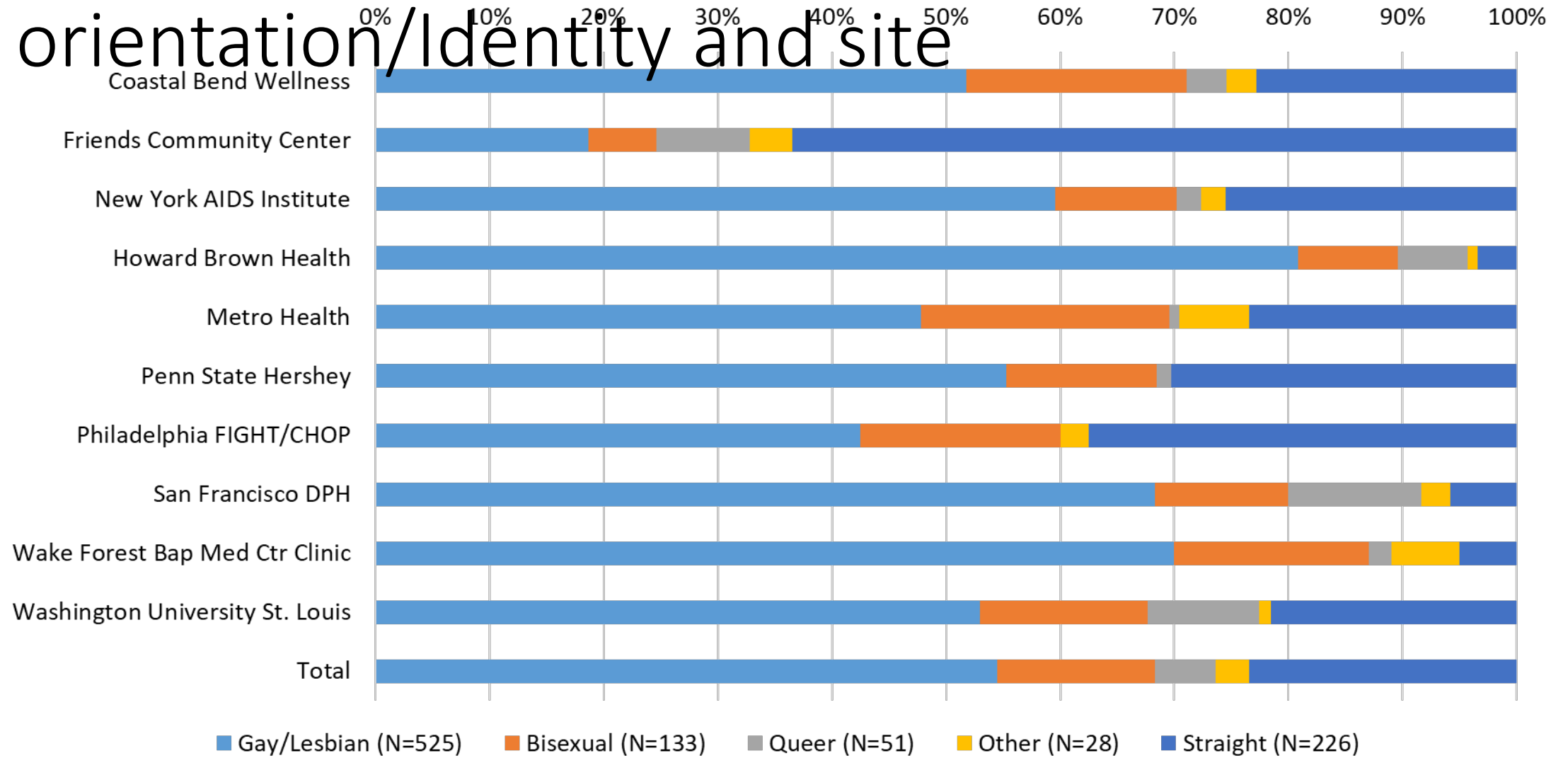


Percentage of participants by ethnicity / race and site (N=965)



Percentage of participants by sexual orientation/Identity and site

Percentage of participants by sexual orientation / identity and site (N=963; 2 non-response)



Results from Analysis of HIV Care Continuum Outcomes

Data Sources



Medical chart extraction

- Viral suppression (yes / no)



ACASI (self-reported) binary (yes / no) measures

- Medical visit for HIV care past six months
- Viral load test past six months
- Currently taking ART
- Adherence to ART based on Likert scale measure
- Undetectable viral load (VL) based on last VL test

Statistical Methods

Random effects (longitudinal) logistic models to evaluate changes in mean outcome levels between baseline and follow-up time points through 18 months

Two models for each outcome

- Main models including covariates for site and time
- Models with additional covariates for HIV diagnosis type and HIV diagnosis type by time interaction
 - Diagnosis type
 - New diagnosis: Diagnosis within the past 12 months
 - Established: Longer period since diagnosis
 - Models allow different outcome trajectories by diagnosis type

Statistical Methods (cont'd)

Time modeled to reflect data structure

- Continuously for viral loads from medical chart data
 - Linear and quadratic time covariates to capture curvilinear time trends
 - Include VL measurements up to six months before ACASI baseline assessment
- Categorical time variable for ACASI data assessed at baseline, 6-, 12- and 18-months

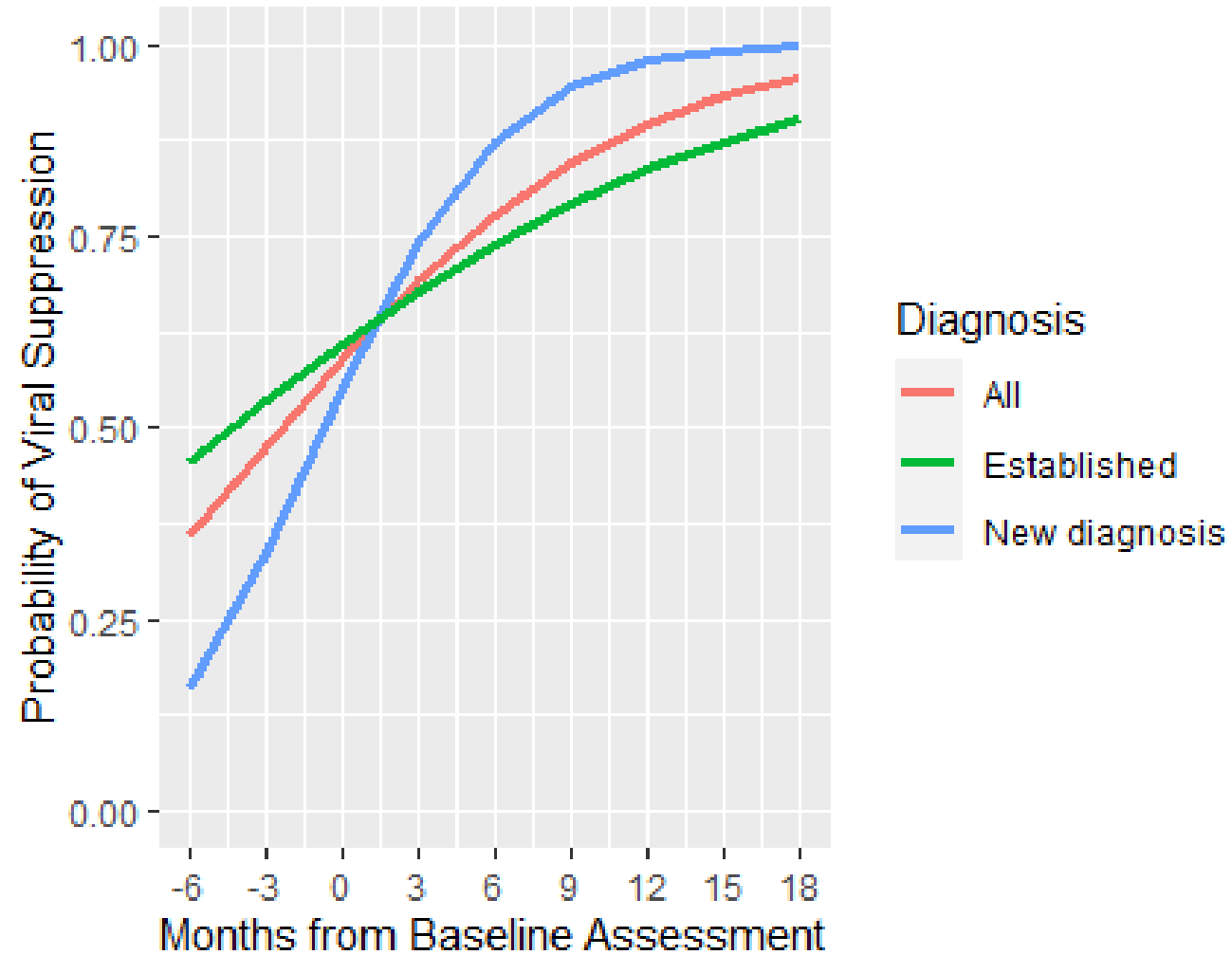
Analysis Results

Take away message ...

- Statistically significant improvements in HIV care continuum outcomes after baseline (and leveling off after 6 months)
 - Most pronounced improvements for participants with new HIV diagnosis
- One exception to improvements over time for self-reported ART adherence measure
 - Fairly flat mean outcome levels over time
- Improvements visualized on following slides by plots of estimated mean outcome levels over time
 - Estimates obtained from random effects logistic models

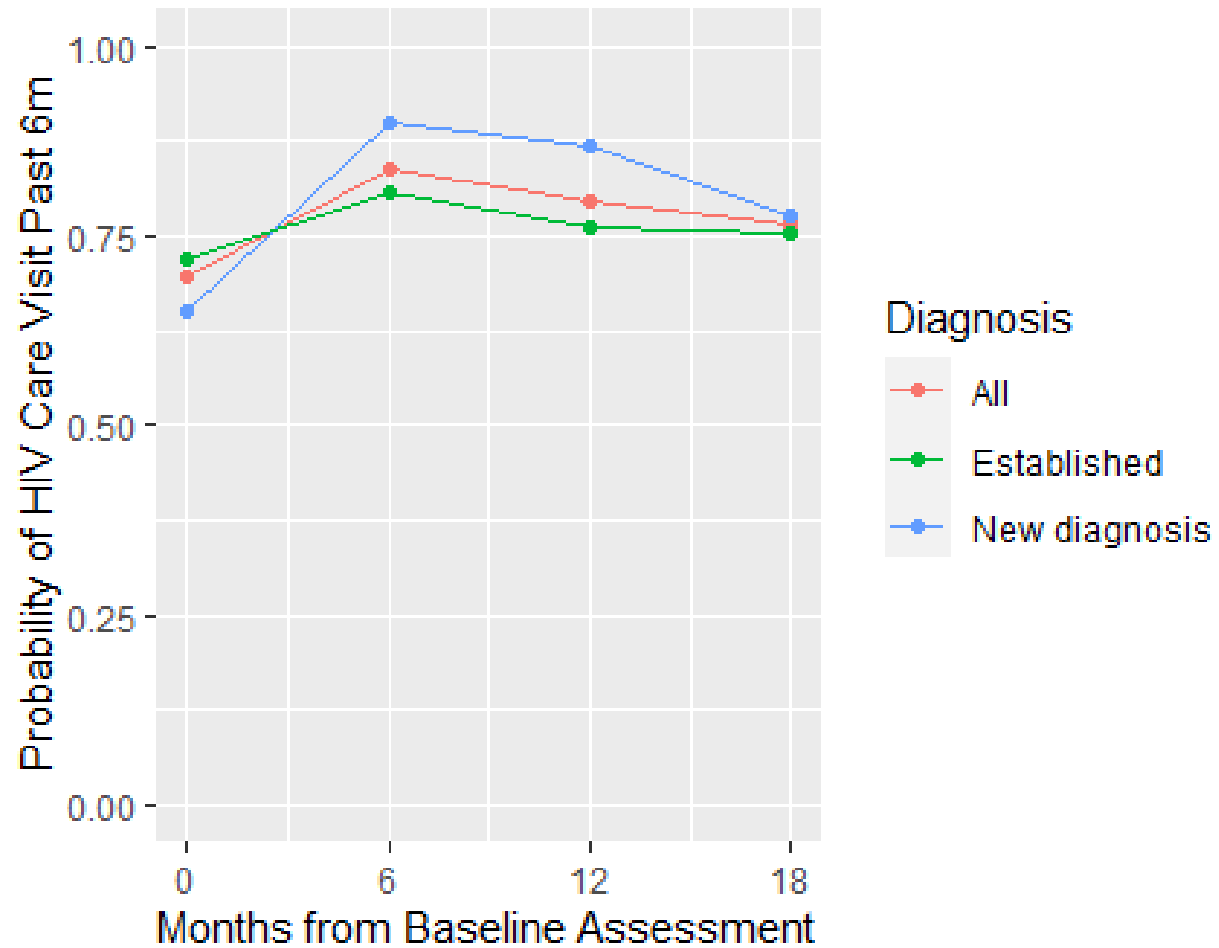


Viral Suppression By Diagnosis Type



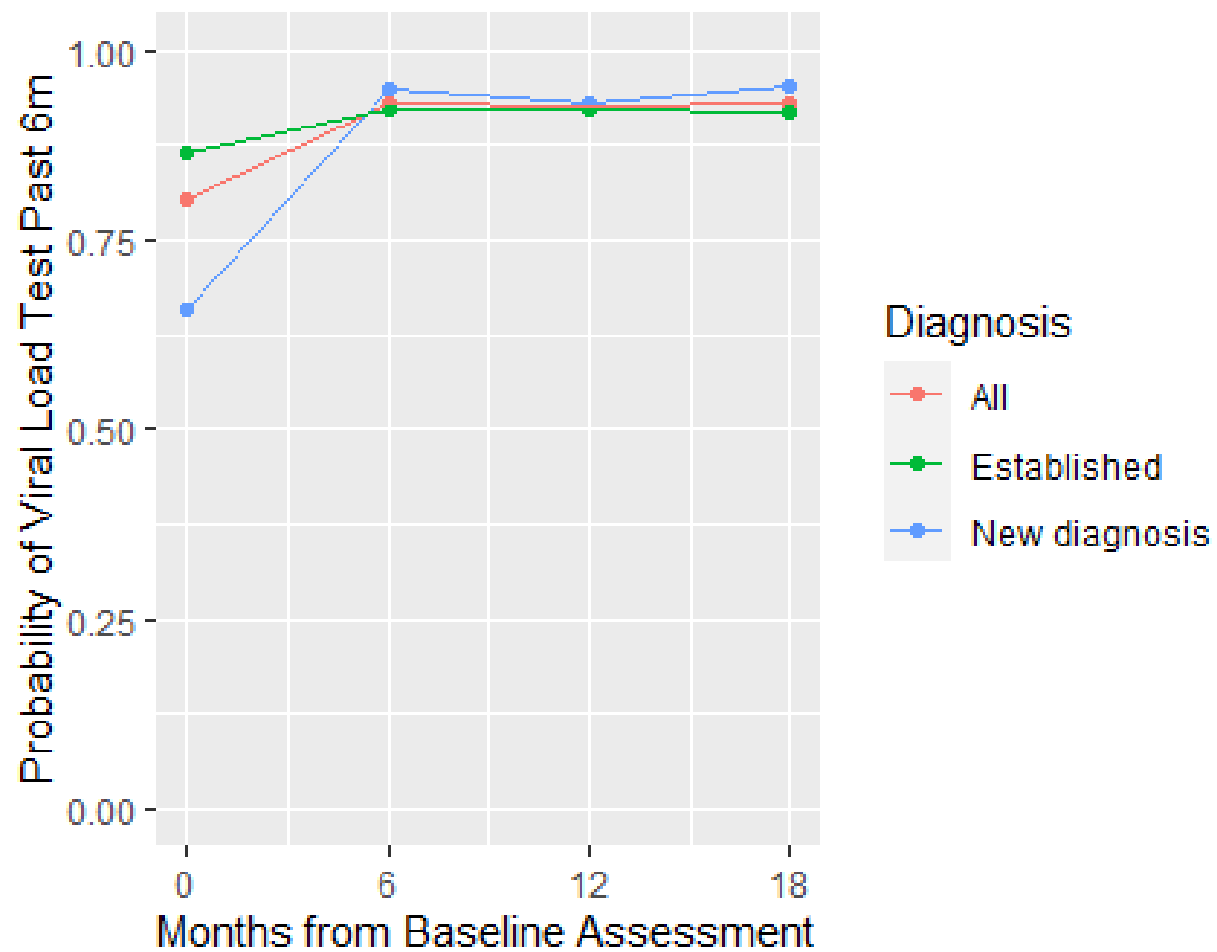


Medical Visit for HIV Care Past 6 Months



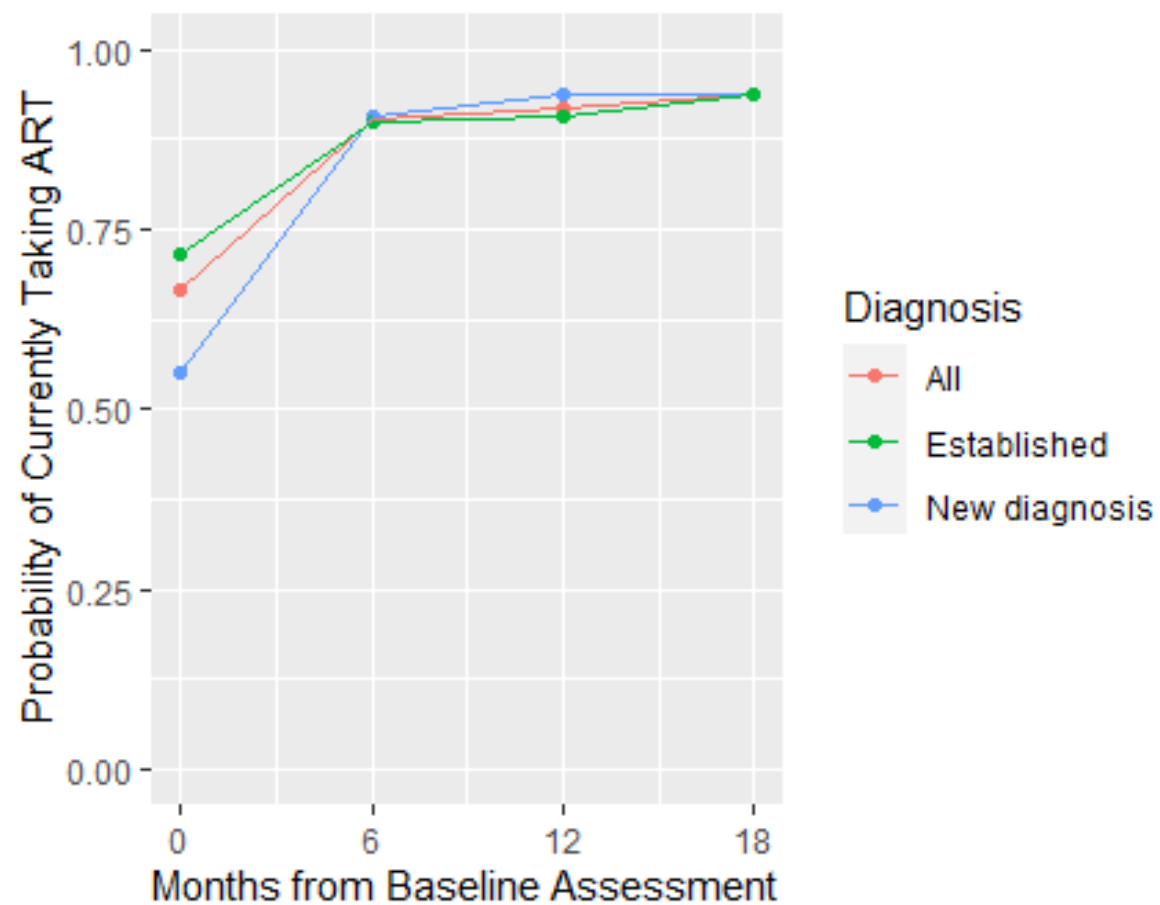


Viral Load Test in Past 6 Months





Currently Taking ART





Adherence to ART Among Those Taking ART

Binary outcome variable based on the following assessment question:

During the previous month, please rate your ability to take all your HIV medications as prescribed.

1 = Very poor

2 = Poor

3 = Fair

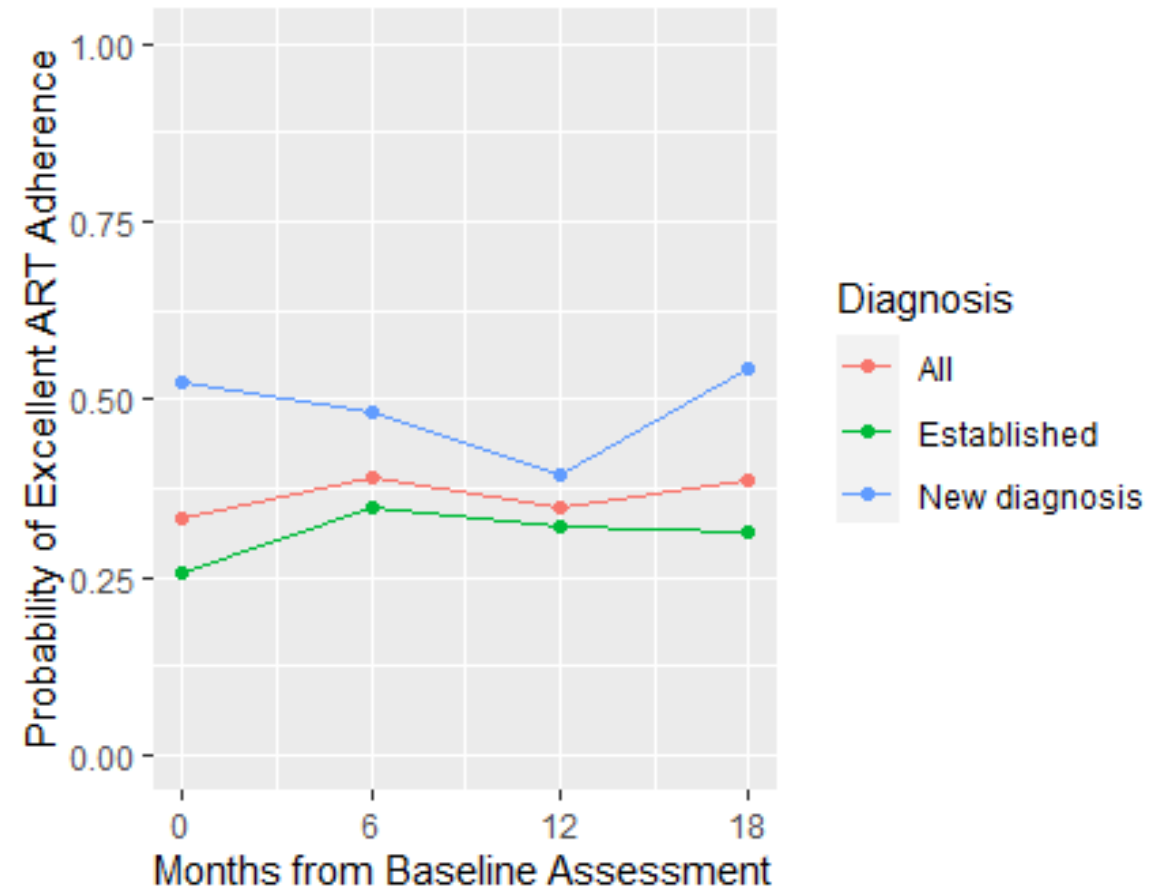
4 = Good

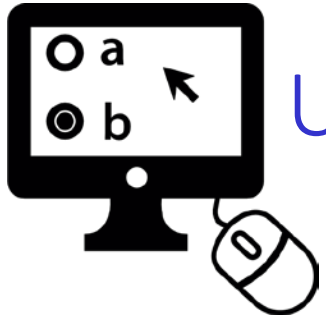
5 = Very good

6 = Excellent

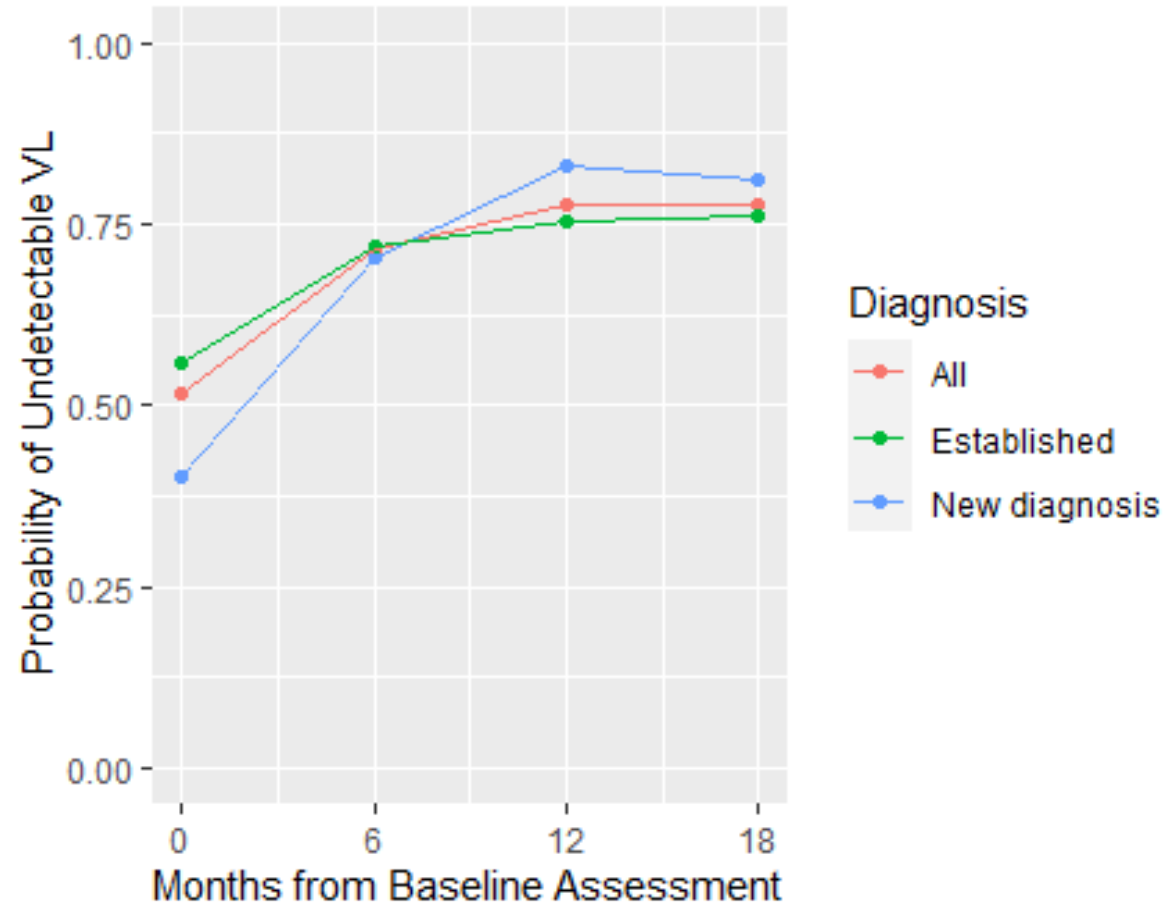
8 = Refuse to Answer

38% reported Excellent adherence





Undetectable on Last Viral Load Test (Y vs N/DK)



Conclusions

- The social media and digital technologies show promise in improving the HIV health outcomes of youth and young adults living with HIV.
- Presented aggregate results across sites
- Note variability in effects by individual demonstration sites (not shown here)
 - For interventions showing positive outcomes, next steps will be to scale up these interventions with providers working with HIV-positive youth and young adults.

What is Positive Peers?

Positive Peers is an app, with companion social media & a website, that aims to engage young people in holistic HIV care within a private, stigma-free, supportive online community.



positivepeers.org

@PositivePeers4U

Positive Peers is made possible through a U.S. Department of Health and Human Services Health Resources and Services Administration, HIV/AIDS Bureau Special Projects of National Significance (SPNS) Grant to The MetroHealth System.



What is Positive Peers? 2



Setting:

- Created & tested (n=128) by the MetroHealth System in **Cleveland, OH.**
Now available nation wide.
- Available **across platforms.**
- Functional on smartphones with **data or wifi** service.

Target:

Young people living with HIV (**YPLWH**) who:

- Are 13 - 34 years old.
- Possess a smartphone
- Live in the United States

Delivery:

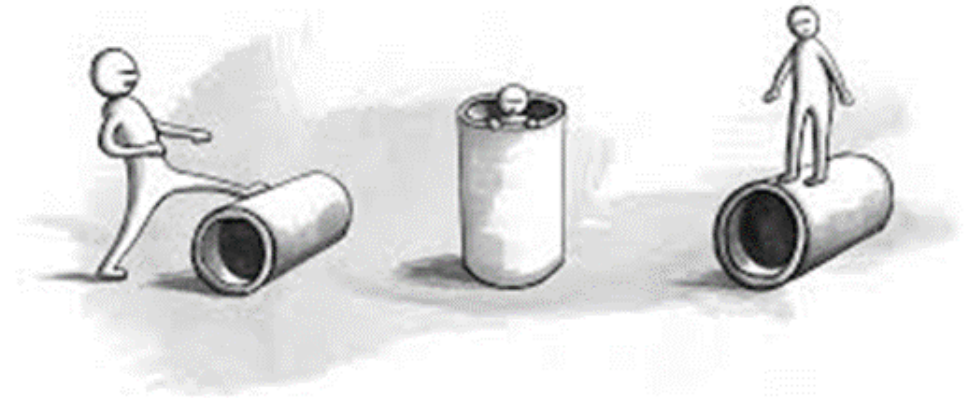
- The mobile application is the intervention, which was **integrated into overall wrap around HIV services** for young people.
- **On-line enrollment has expanded the app to all YPLWH in the U.S. in 2020**

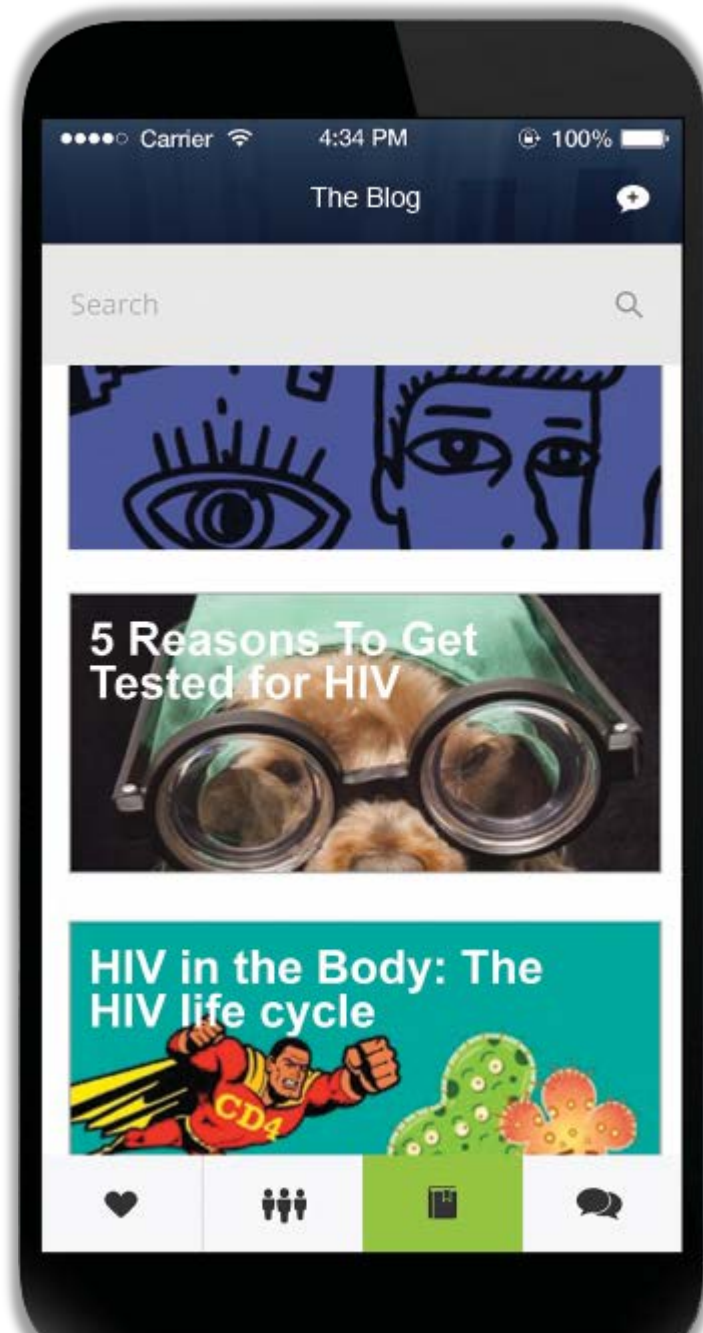
Theoretical Model: Affordance Theory

Affordances refer to **features of user/technology interaction** that offer gratification of perceived needs.

Affordances emerge from interaction with technologies (Leonardi, 2011).

- Experimentation and adaptation shape user's perceptions of how technology can work for them
- Relational actions occur *among* users with technologies (Leonardi & Barley, 2008; Faraj & Azad, 2012).





Positive Peers Provides

Accurate, easy-to-understand HIV health and wellness education information & curated community resources.

positivepeers.org

The screenshot shows a web browser window with the URL <https://positivepeers.org/the-plus-side/blog/>. The website header includes the 'pp' logo and navigation links: GET THE APP, BLOG, TALES OF TRIUMPH, RESOURCES, KEY HEALTH PARTNERS, ABOUT US, and APP HELP.

The main content area features three blog posts:

- What you need to know about gonorrhea**
by Positive Peers
SEPTEMBER 25, 2019
We've talked about Sexually Transmitted Infections (STIs) before and laid out how important it is to get tested regularly. Today, we're going to dive into one of the most common STIs in the United States: [...]
- Vitamin C and why it's good for you**
by Positive Peers
SEPTEMBER 6, 2019
Growing up, your mom or another close relative may have told you to drink your orange juice. That's because orange juice is packed with vitamin C, which is an essential nutrient. According to the National [...]
- HIV and HAND**
by Positive Peers
AUGUST 27, 2019
Let's do a little HIV refresher first. It may seem silly, but it will make understanding HAND a lot easier, we promise! So, HIV weakens the immune system over time, which can make people living [...]

On the right side, there is a mobile app download section with the 'pp' logo, a 'PRIVATE' button, and a 'REGISTER NOW!' button.

Below the app section is a 'Recognition' section with the following text:

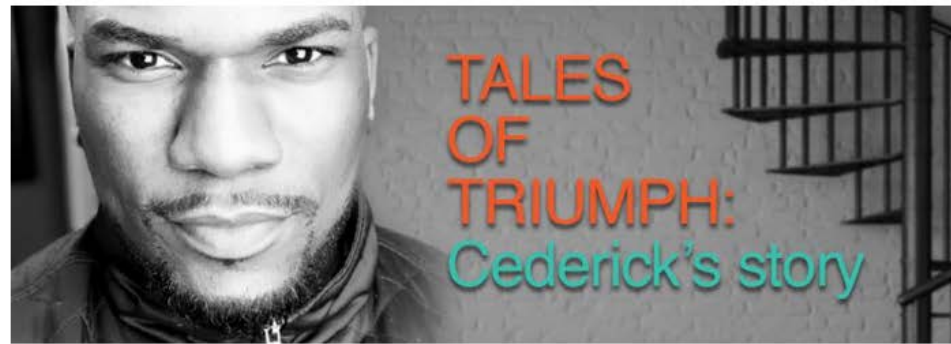
- Medical News Today named Positive Peers one of the top 10 best blogs on HIV/AIDS in 2018!
- MyTherapy listed Positive Peers as 10 of the Best HIV and AIDS Blogs in 2019!
- FeedSpot named Positive Peers one of the

The Windows taskbar at the bottom shows the system tray with the date 1/23/2020 and time 9:39 PM, and a taskbar with icons for various applications.



April 2nd

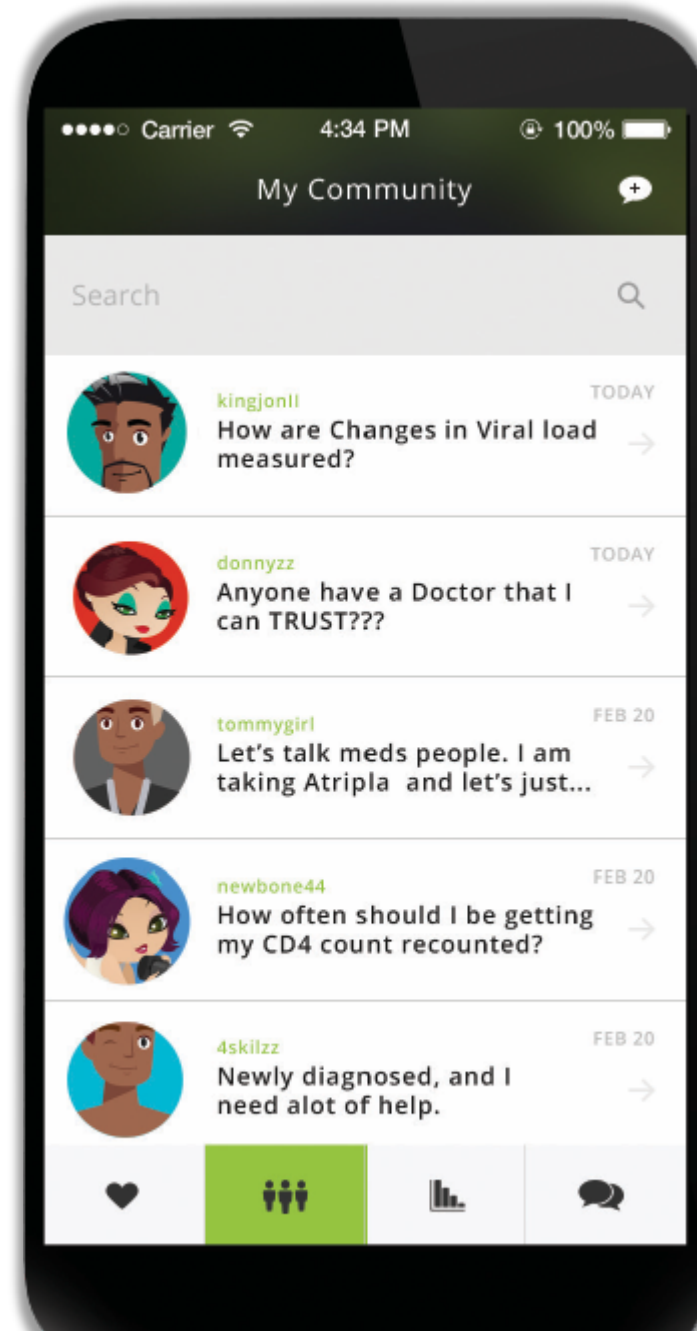
Tales of Triumph: Cederick's Story



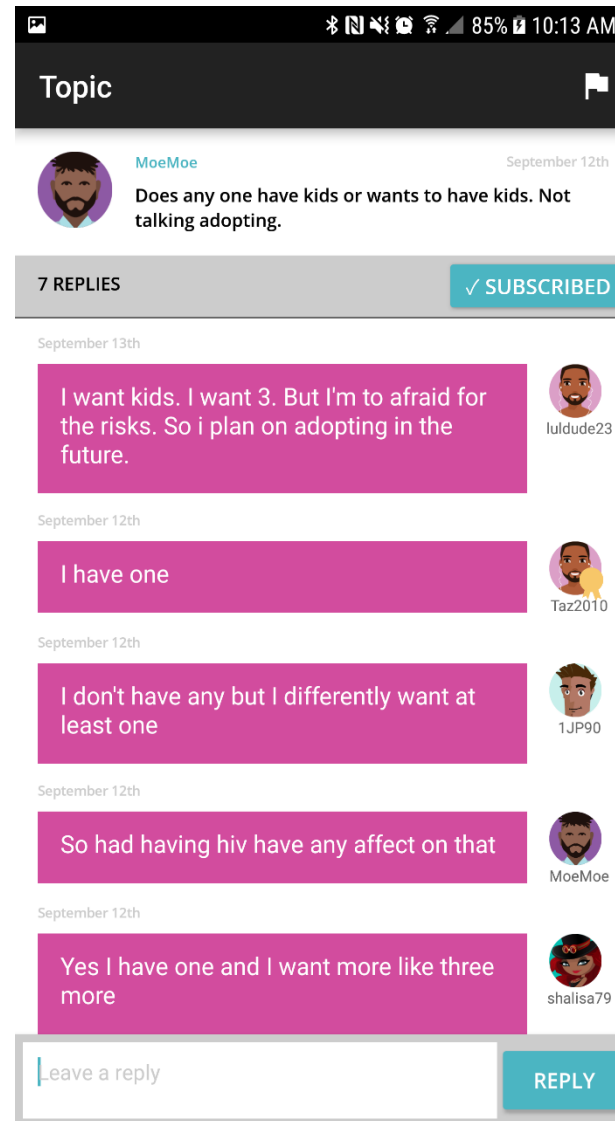
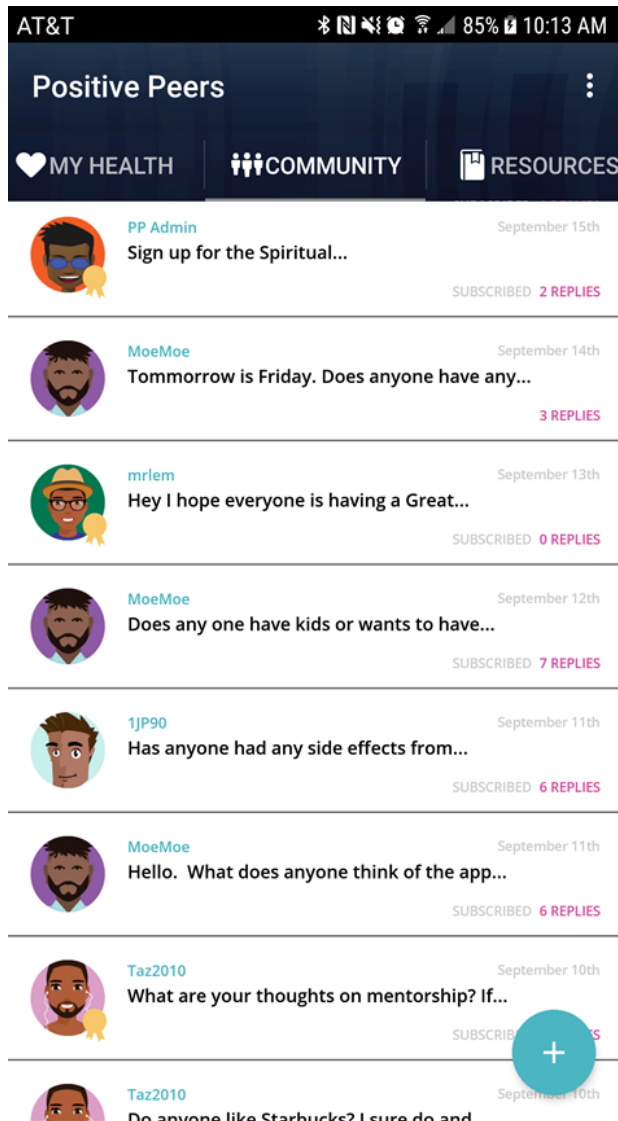
Cederick was 24-years old when he was diagnosed with HIV. He was feeling weird while visiting a friend in Florida. He wasn't eating well and thought it was due to the heat. Then,

Positive Peers Provides

Social networking in a community conversation & private chats

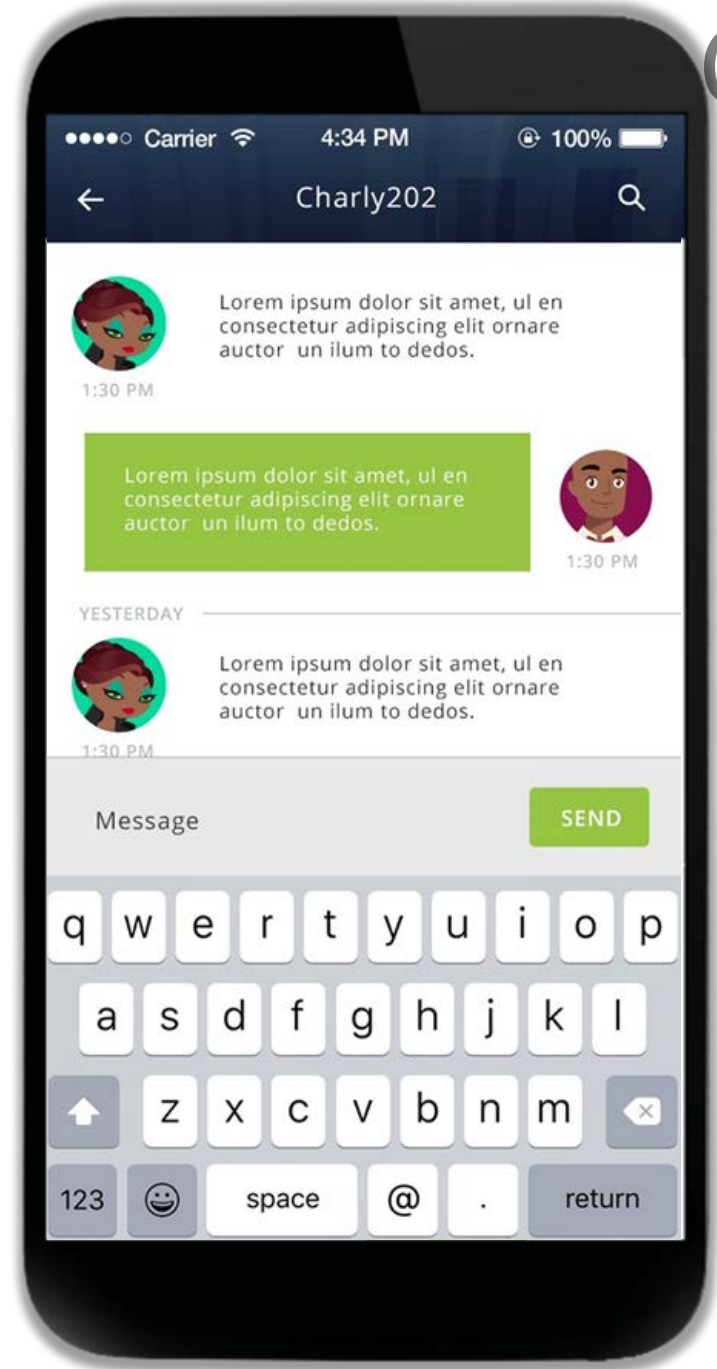


My Community



- Similar to posting on a Facebook wall
- Everyone shares one wall
- Everyone can see and reply to posts
- Can add in links to external or in-app content
- Can use emojis 😊 and GIFs
- Cannot upload and share pictures or videos

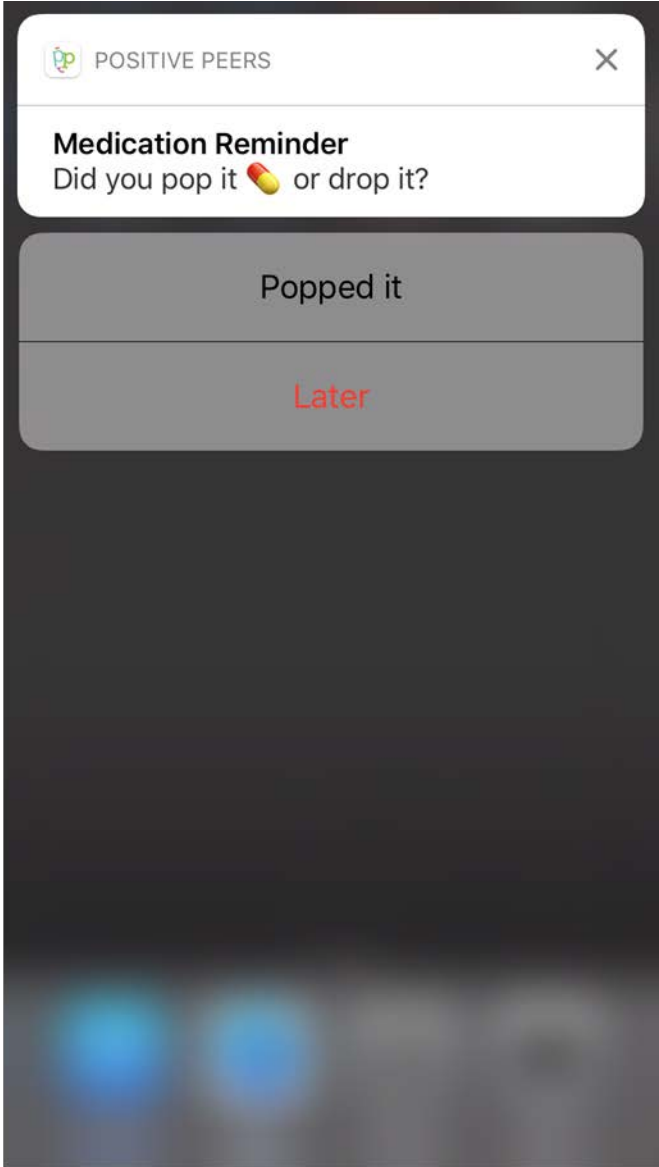
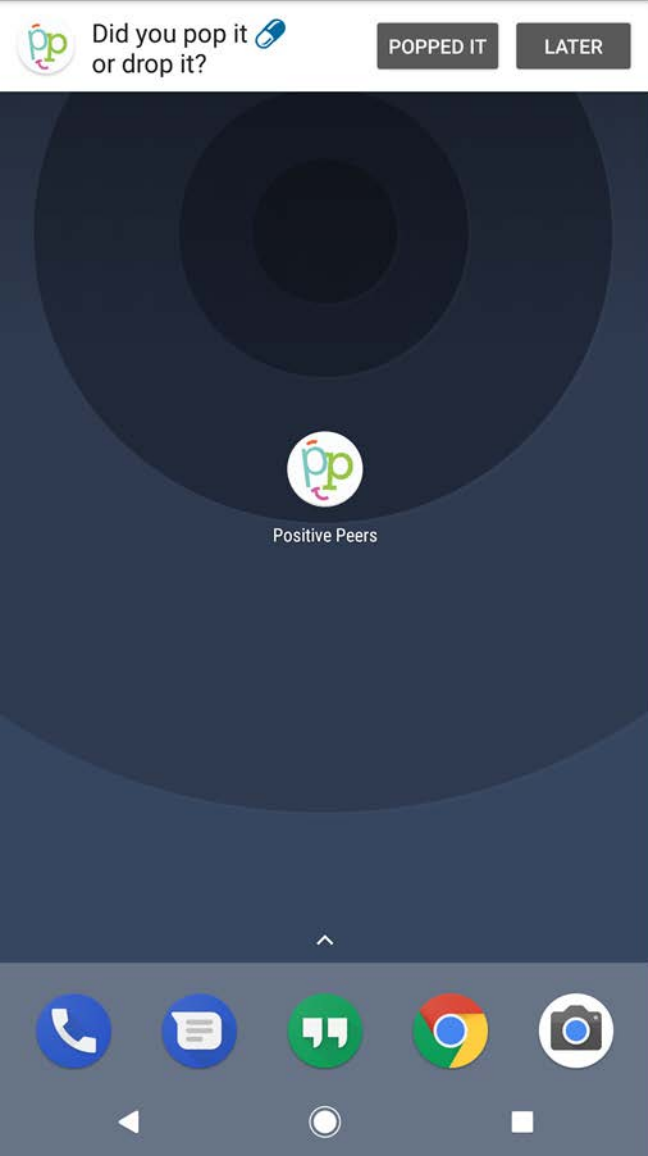
Chat

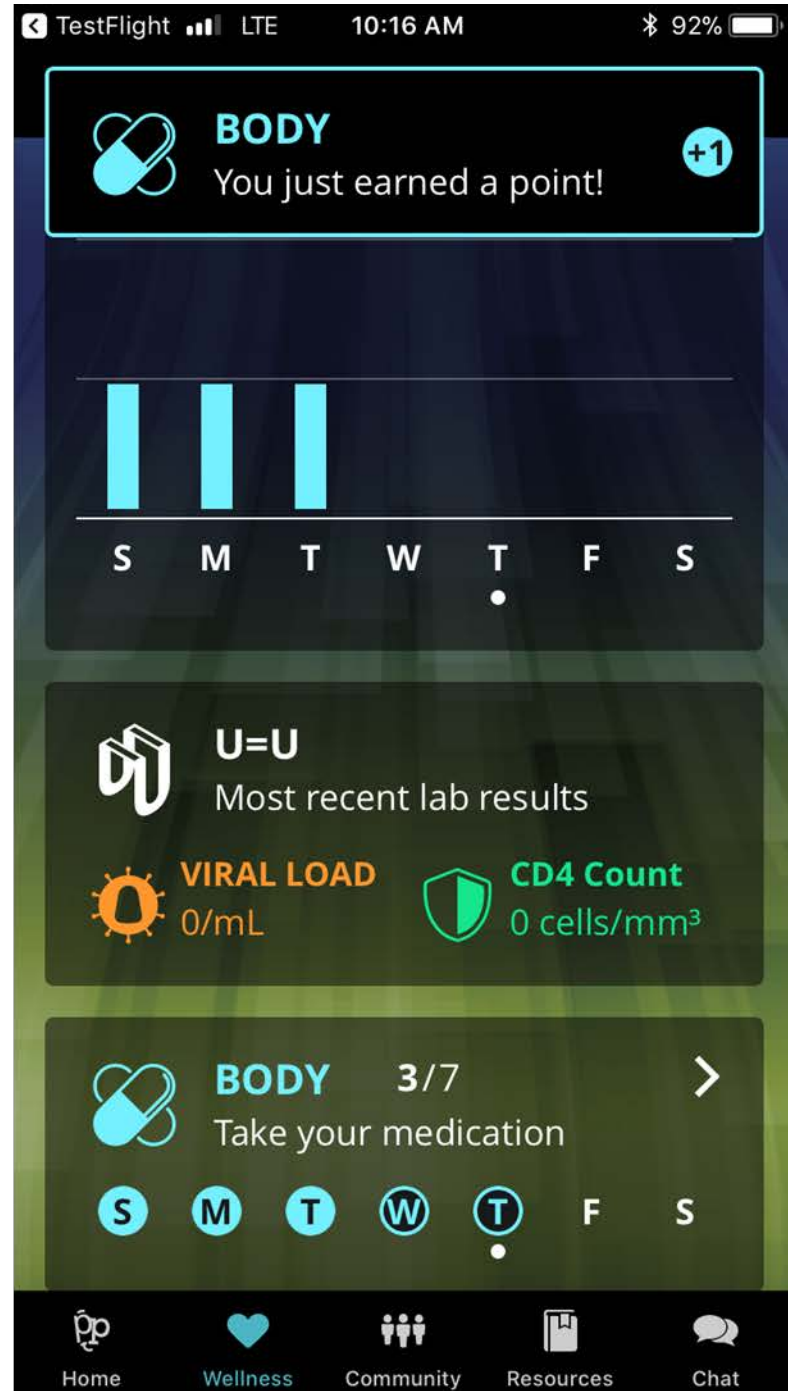


Direct Messaging

- Users can message one another
- Completely private
- Divided by age (13-17 vs 18-34)
- Admin is available on app for DM too
- Similar to Facebook Messenger

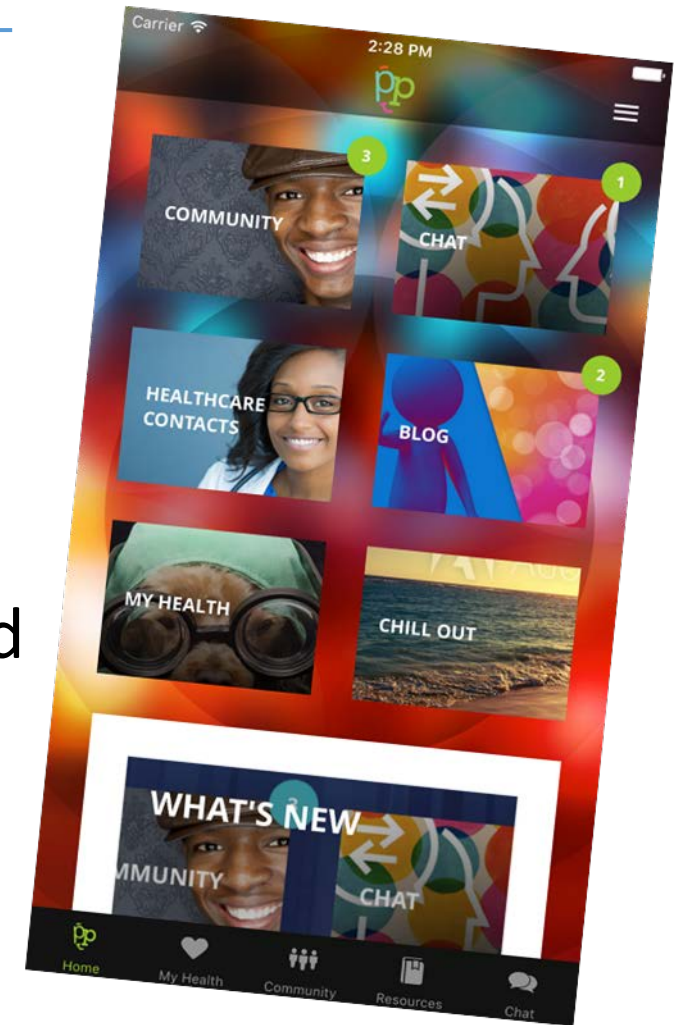
Interactive Med Notification!





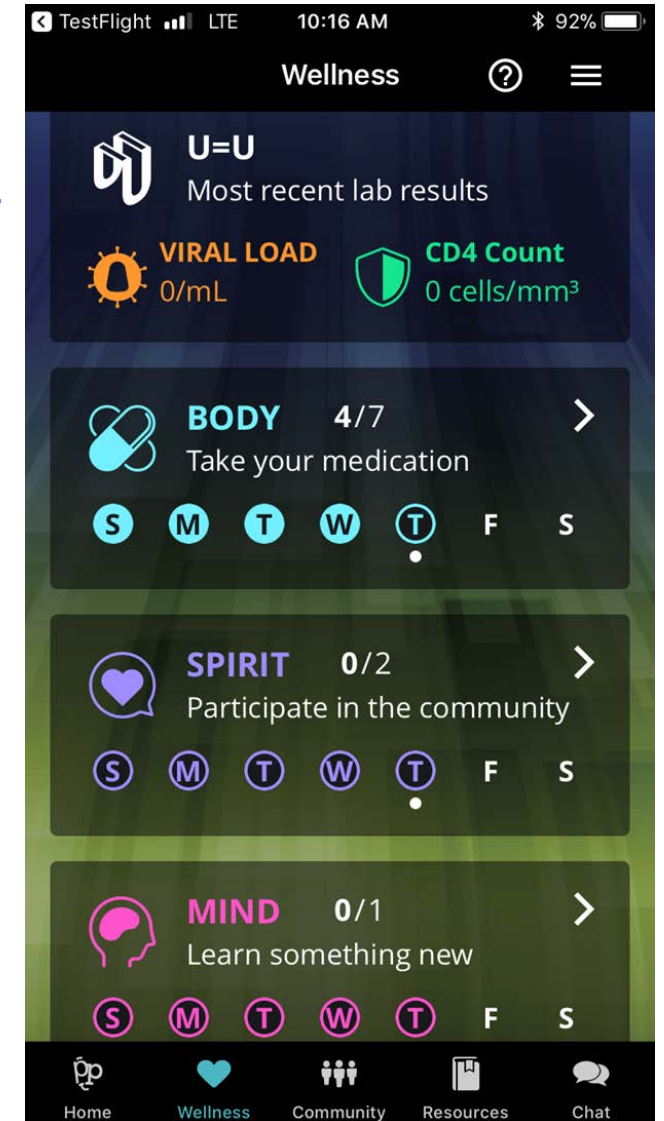
Positive Peers impacts viral suppression

- A retrospective matched cohort showed **Positive Peers users are 3.2 times more likely to sustain viral suppression** than non-users.
- Subsequent data analysis shows viral suppression effects remain for those who enrolled and had higher use of the app than those who enrolled and didn't use the app at all.



Positive Peers and Stigma

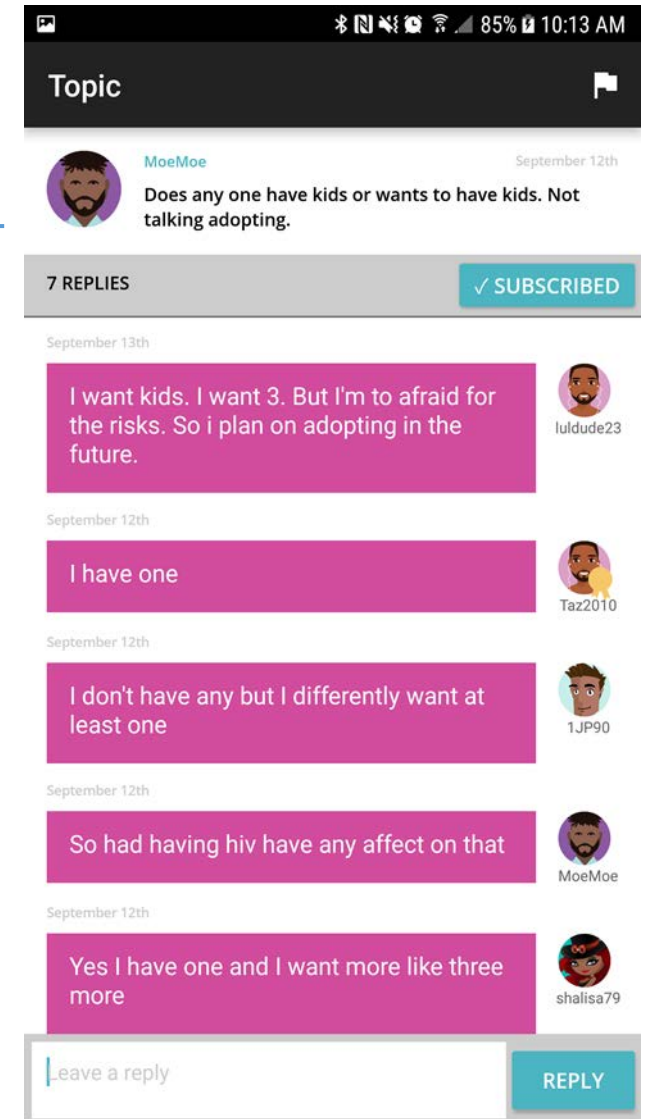
- Less overall, personal, disclosure, self image, & perceived public attitudes (PA) stigma reported by Black participants at baseline and over time
- Overall and PA stigma lessened for all over time points
- >25 YO reported less disclosure stigma over time ($p=.06$; $p=.03$)
- 30+ reported less PA stigma over time ($p=.01$)
- Trending inverse relationship for broad use app activity and disclosure stigma ($p =.09$)



Positive Peers creates interpersonal connections

Qualitative interview responses suggest **interpersonal connections** within this virtual community are important and users demonstrate a desire for building relationships through the app, even among some participants who log-in infrequently.

- *“It's important to just, regardless of how much you actually make the choice to use it, I think it's important to know it is there for that time when you really, really do need it.”*
- *“It taught me to accept that I have HIV and there's other people out there that have it and I can talk to the people in the app and they understand some of my questions and concerns.”*



The screenshot shows a mobile app interface for a discussion thread. At the top, the status bar displays the time as 10:13 AM and battery level at 85%. The app header is dark with the word "Topic" and a flag icon. The main post is by user "MoeMoe" on September 12th, asking "Does any one have kids or wants to have kids. Not talking adopting." Below the post, it shows "7 REPLIES" and a "SUBSCRIBED" button. The replies are listed chronologically:

- September 13th: User "luldude23" replies, "I want kids. I want 3. But I'm to afraid for the risks. So i plan on adopting in the future."
- September 12th: User "Taz2010" replies, "I have one"
- September 12th: User "1JP90" replies, "I don't have any but I differently want at least one"
- September 12th: User "MoeMoe" replies, "So had having hiv have any affect on that"
- September 12th: User "shalisa79" replies, "Yes I have one and I want more like three more"

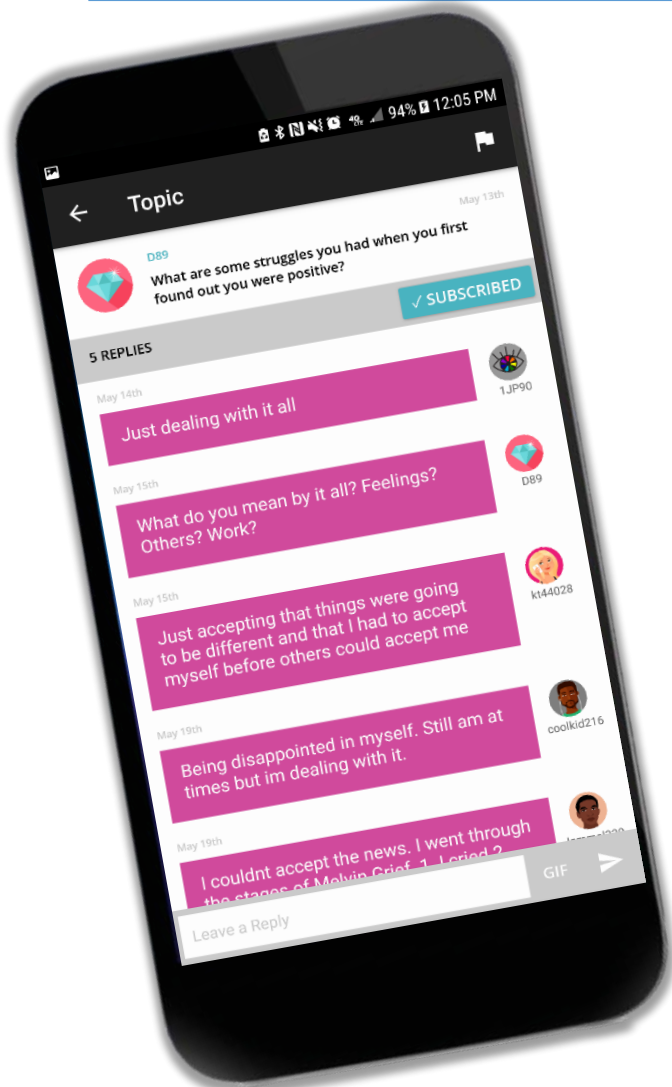
At the bottom, there is a text input field with the placeholder "Leave a reply" and a "REPLY" button.

Lessons Learned

- Building an app is an expensive and lengthy process
- Evolve with technology / needs / learning
- Build your own backend tracking
- Test and test and test
- User-controlled privacy settings are key
- Size **does** matter...when it comes to apps

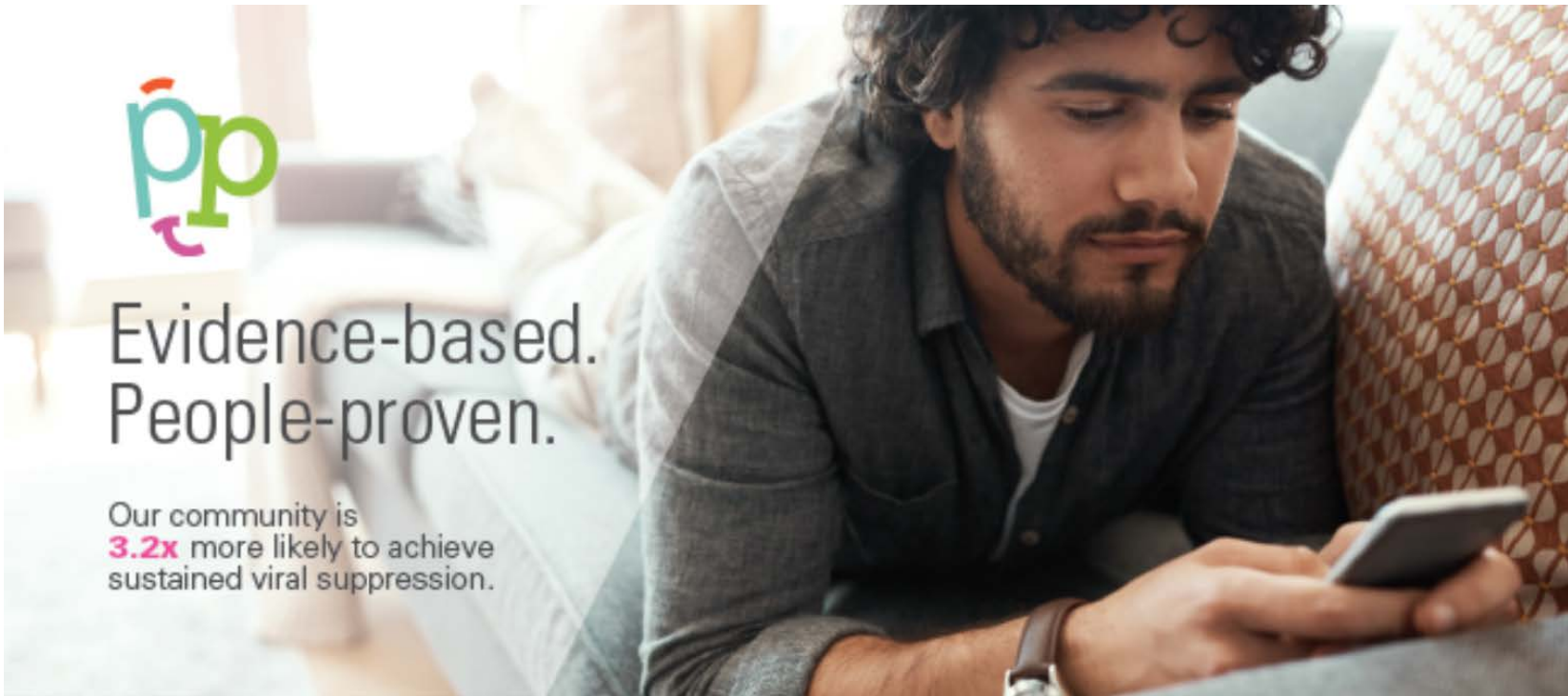



Lessons Learned



- **Multidisciplinary magic**
 - Clinical, social science, creative, technology
 - CAB involvement from conceptualization to creation to implementation
- **Audience-centered messaging**
 - Deep/continuous audience evaluation/input
 - Timely, frequent, and diverse (not always HIV-related)
 - Funny, useful, attractive
- **mHealth is best approached by thinking of it as HUMAN CONNECTION extended into a VIRTUAL SPACE.**

Sustainability Plans





Evidence-based.
People-proven.

Our community is
3.2x more likely to achieve
sustained viral suppression.

Become a Positive Peers Key Health Partner

Positive Peers is a private peer-led support app helping **end the epidemic** for the especially vulnerable populations of 13-34 year-olds and MSM of color.

Key Health Partner Benefits

Admin access

Up to 4 professionals of your choice will gain access to interact directly with users in your geo-location

- Post and reply to all Positive Peers users within the community forum
- Send private chats & push notifications

Provide regional content for your community

Curate a regional calendar for local events, add your community resources, and post additional success stories about your local YPLWH in Tales of Triumph.

Local, aggregate data

Get data about local YPLWH in areas such as substance abuse, self-efficacy, incarceration history, and stigma.

Promotional materials

Spread awareness of the app within your community with posters, marketing handouts, promotional pins, and stickers we provide.

Receive training

Guidebooks are provided and, upon request, a MetroHealth staff person will conduct on-site training to ensure bringing Positive Peers to your area is as easy as possible.

Give input on new features

Your local app users and healthcare professionals can join Cleveland's YPLWH Community Advisory Board to provide feedback and spark new ideas.



Register for the Positive Peers App

Start your registration below to join the Positive Peers Community!

[SKIP DOWN TO REGISTRATION](#)



Questions?

Thank you!



U=U

**UNDETECTABLE
=
UNTRANSMITTABLE**

POSITIVE PEERS 4 HIV CARES

“Undetectable = Untransmittable” isn’t something you keep to yourself. It’s something to shout from the rooftops!

What does it mean? It means that scientists are certain that if your viral load is undetectable and has been for six months or more (200 copies/ml or less), **you cannot pass on the virus to anyone else.**





Positive Peers App



PI: Ann K Avery, MD
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Director: Jen McMillen Smith, MSSA, LISW-S
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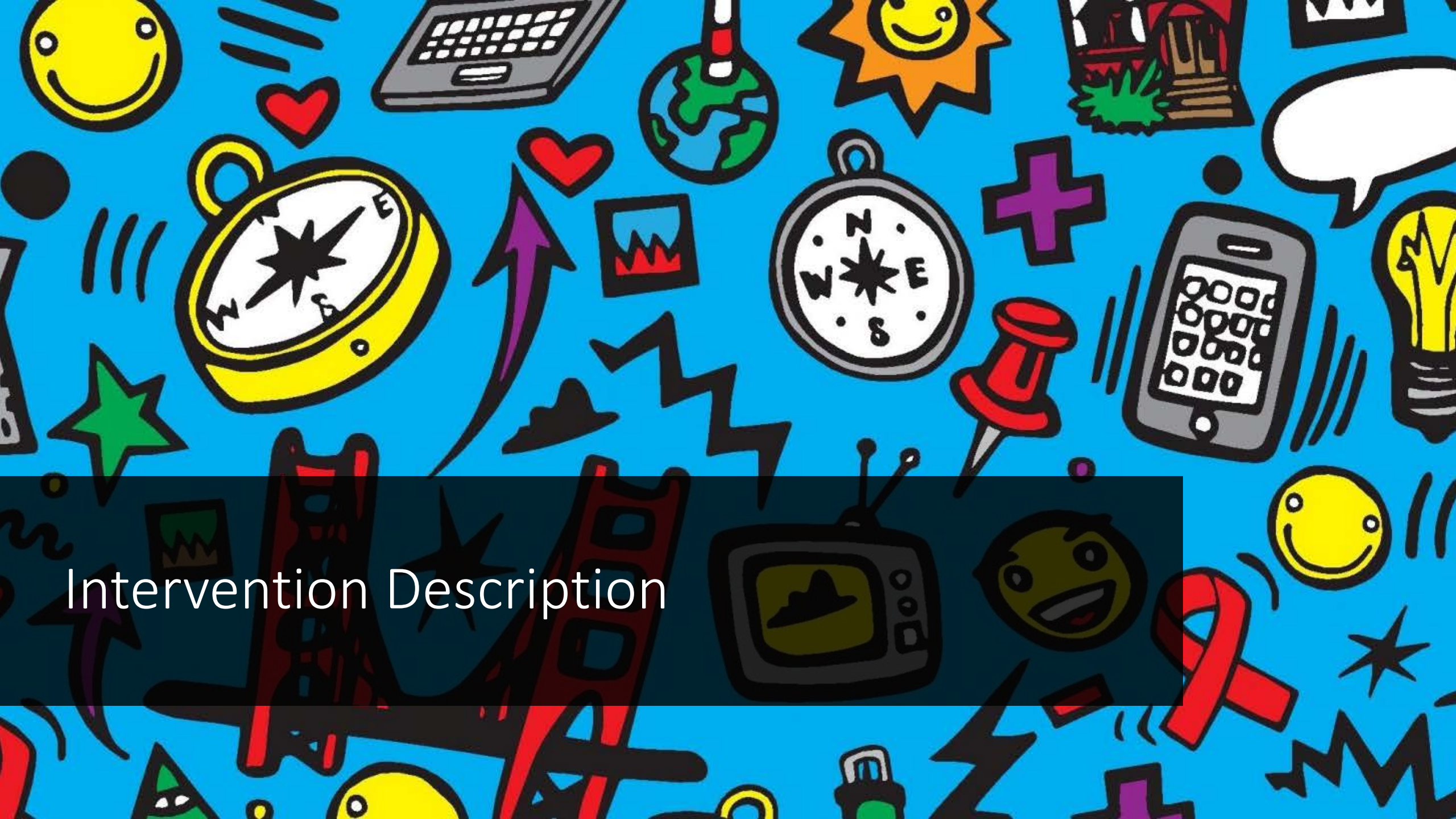
Evaluator: Mary M. Step, PhD
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Eval Assist: Theodore Russell, BSPH
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Intervention Description

Description of Health eNav

- Conceptual Framework
 - Patient-Centered Medical Home (PCMH) Model
 - Chronic Care Model
 - Peer Navigation
- Intervention Components
 - Short-term mobile phone access
 - Delivering asynchronous, non-traditional digital navigation through text messaging
 - Collecting ecological momentary assessment (EMA) data and integrating that into the digital navigation system in real-time
 - Using comprehensive social medial contact information to locate and retain participants in care

Digital HIV Care Navigation

Social Support

- Emotional
- Informational
- Instrumental

DIGITAL HIV CARE NAVIGATION

Linkage

Engagement

Retention

- Personalized, In Context
- On-Demand/Real-time
- 2-way text messaging

Motivational Interviewing

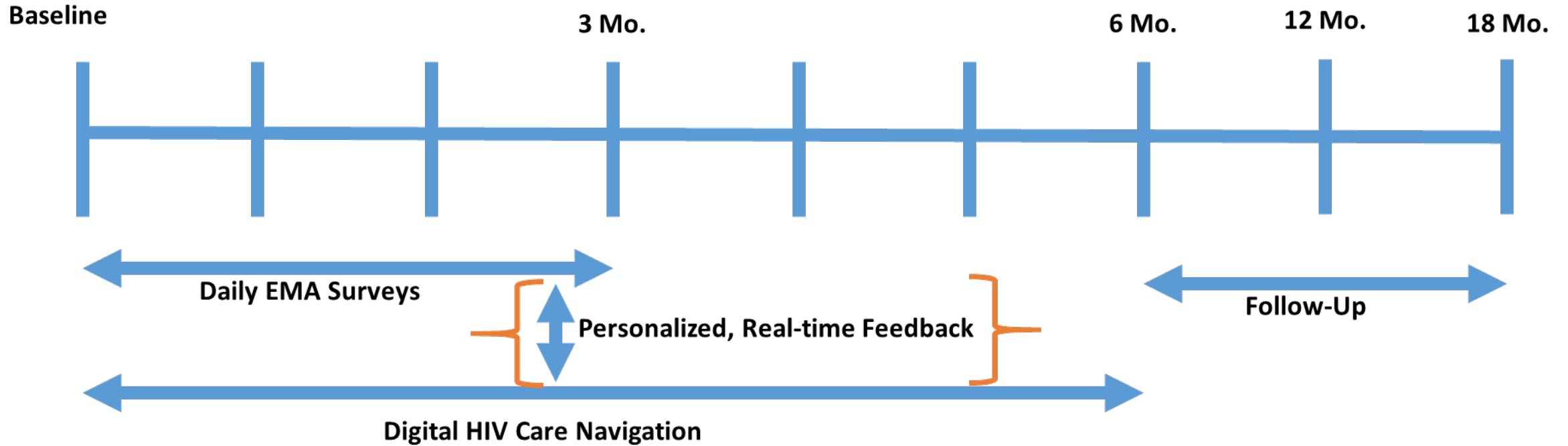
- Behavior Change
- Mental Health
- Substance Use

Ecological Momentary Assessments



- 90 Daily Text Message Surveys
- Affect, Sexual Behaviors, Substance Use, Treatment Adherence, Social Support.
- \$1 earned per completed survey

Study Design



Description of Health eNav

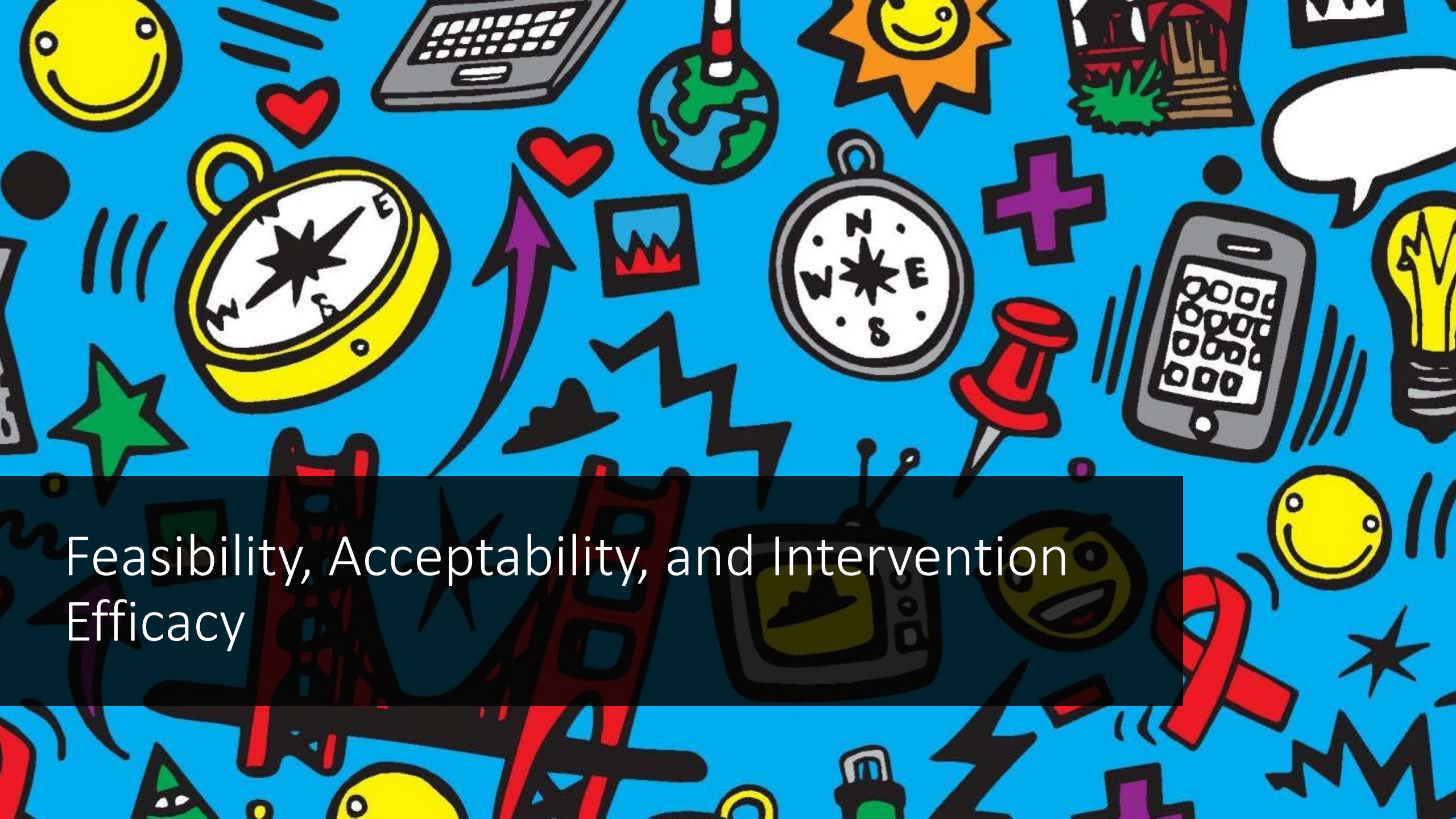
- **Intervention Setting**
 - Virtual (on-going); and in-person visits at the San Francisco Department of Public Health (SFDPH) (at baseline, 6-, 12-, and 18-mo)
 - Digital safety net spanning San Francisco's HIV prevention and care network (e.g. HIV testing sites, SFDPH clinics, etc.)
- **Target Population**
 - Young People Living with HIV ages 18-34
 - Identify as an MSM or a trans woman
 - Be a resident of San Francisco and speak English
 - Be either: 1) newly diagnosed, 2) out of care, or 3) not virally suppressed
- **HIV Care Continuum Outcomes**
 - Linkage, engagement and retention in HIV care
 - Adherence to ART and viral suppression

Sources of Data Collection

- Multi-Site Evaluations
 - Comprehensive psychosocial assessments (@ Baseline, 6-, 12-, and 18-months)
- Client-Level Data
 - Medical chart abstraction (6-mo prior to baseline and throughout the study period)
- Costing Data
 - Monthly costing data related to project delivery

Sources of Data Collection

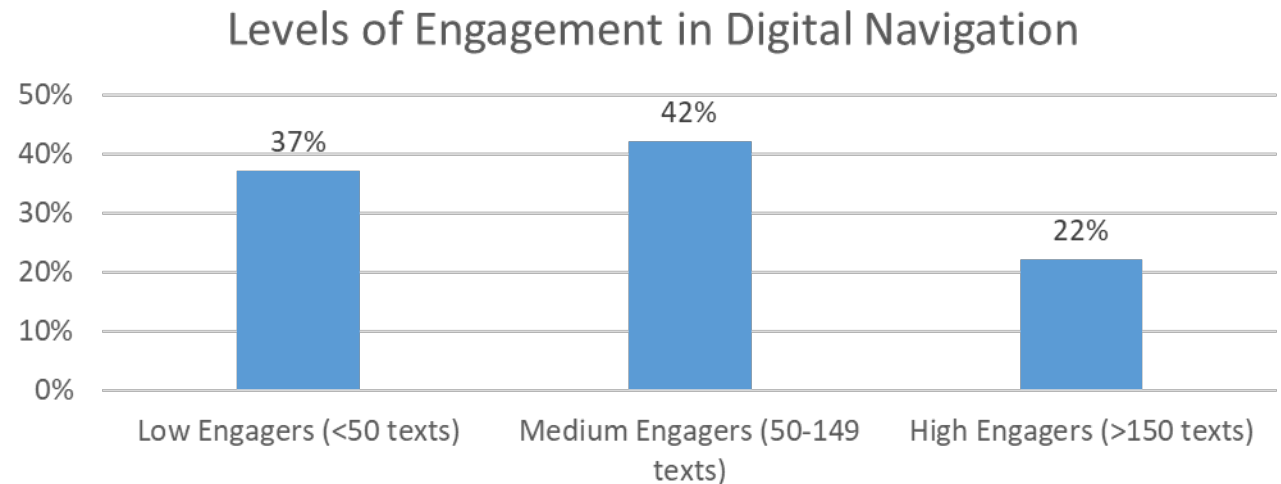
- Ecological Momentary Assessments
 - Daily short text message surveys for 90 consecutive days
 - Measuring potential barriers to HIV care – mood, mental health, sexual behaviors, substance use (and concurrent sex), social support, and treatment adherence
- Digital HIV Care Navigation (Intervention Exposure)
 - Backend data (e.g. time, date) and ALL text messages exchanged during digital HIV care navigation
- Qualitative Primary Data Sources Collected in Intervention Delivery
 - Behavioral change goals, objectives and activities; case notes; etc.



Feasibility, Acceptability, and Intervention Efficacy

Digital Navigation – Feasibility

- Feasibility (n=120)
 - Racially diverse sample
 - 85% MSM; 15% trans women of color; 20% were recently incarcerated; 32% were diagnosed within the last year
 - 12,423 total text messages sent, ranging from 1-467 texts
 - Average # of text messages per participant: 109 texts



Digital Navigation – Acceptability

- Acceptability (n=16)
 - 81% found Digital Navigation acceptable
 - 70% felt that 6 months of Digital Navigation was a good amount of time
 - 19% were interested in more than 6 months
 - 100% felt that Digital Navigation positively impacted their engagement in HIV care
 - Structural inequity = primary barrier to participation

Digital Navigation – Acceptability

Qualitative Participant Feedback

“...I was in the waiting room and actually in the doctor’s office texting the digital navigator and discussing the questions that I was going to ask the doctor and some of the information that I wanted to make sure to tell her. I needed the digital navigator to help me remember the questions that were important for me to ask...that was the first time I actually went to my doctor’s appointment prepared.”

Digital Navigation – Acceptability

Qualitative Participant Feedback

“It made me more consistent and it always gave me reminders...I could say, ‘This is what’s going on and what I need’ and the response would be this is what I think you should do; and that doesn’t happen every day, you don’t always have someone with that type of experience like my digital navigator had. I think about the community impact, and I think many people who are diagnosed with HIV in the community need it [Digital Navigation].”

Intervention Efficacy

- 6 Month Compared to Baseline
 - 2.07 fold greater odds of viral suppression
 - Decrease in mean mental health problems
- 12 Month Compared to Baseline
 - 2.98 fold greater odds of viral suppression
- 12 Month Dose-Response Effect
 - Every one-text increase in engagement was associated with an increased odds of undetectable viral load

Lessons Learned

- Social media contact information is stable over time (vs. phone number)
- Use non-HIV related messages to develop rapport and build trust
- Carve out time to engage in a more lengthy text message session in real-time
- Technology is not just a means to an end – it is inherently social → meaningful interactions
- LOW Tech, HIGH Touch interventions can be powerful
- Analyzing intervention exposure is challenging

The background features a dark blue gradient with a complex pattern of white and light blue circular elements. On the left side, there is a large circular scale with numerical markings from 140 to 260 in increments of 10. Several concentric circles and dashed lines with arrows are scattered across the image, creating a technical or scientific aesthetic.

OPT-IN FOR LIFE

JOHN ZURLO, MD

PENNSSTATE HEALTH (*THOMAS JEFFERSON UNIVERSITY*)

CYNTHIA WHITENER, MD

PING DU, MD, PH.D

CHRISTINE QUIMBY

MATT MAHONEY

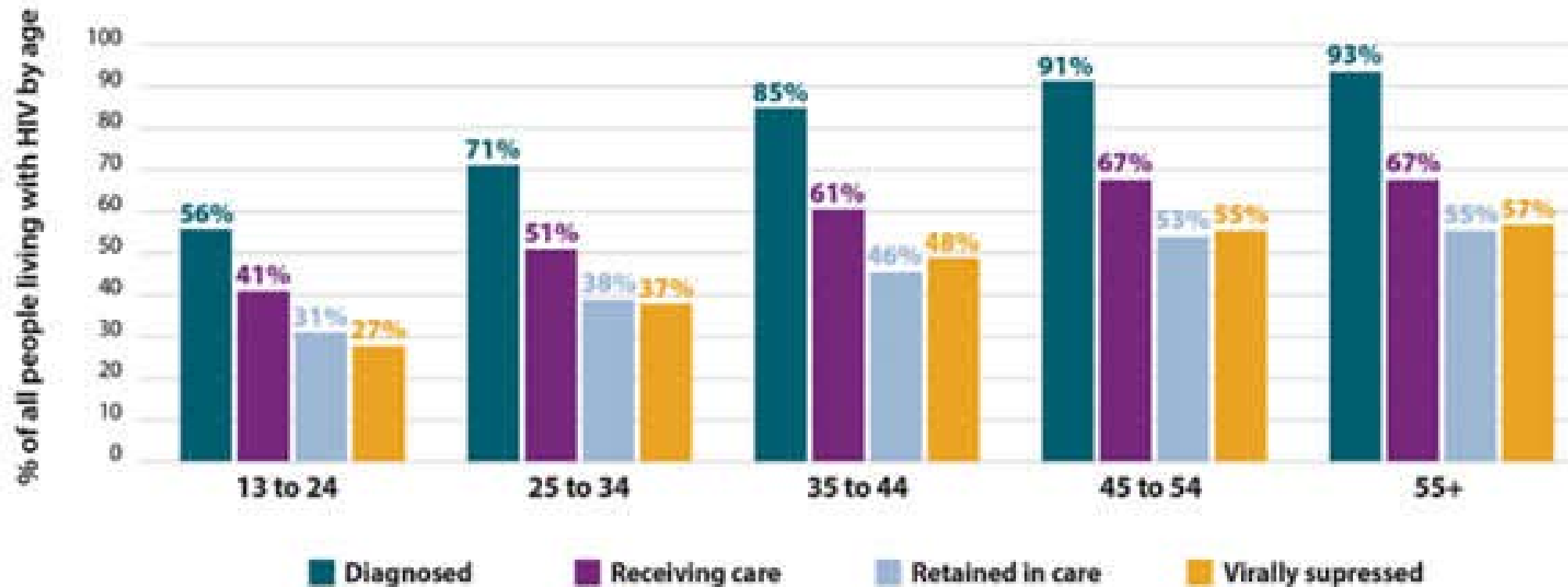
ALEX HAYNOS

YARITSA VARGAS

DAGAN COPPOCK, MD

BACKGROUND – HIV CARE CONTINUUM

HIV Care Continuum, by Age, U.S., 2014



Source: Centers for Disease Control and Prevention

BACKGROUND – APPS AND SOCIAL MEDIA

Pew Research Poll 2014

- 74% of online adults used social media sites
 - Highest in age group 18-29 (89%); 30-49 (82%)
 - No difference by sex, education or earnings (< or > 30K annually)
- Smartphone penetration in 2014
 - 90% of adults reported having a mobile phone; 58% smartphone
 - The majority of our youth and young adults reported owning a smartphone

SPNS INITIATIVE (2015). USE OF SOCIAL MEDIA TO IMPROVE HIV CARE CONTINUUM OUTCOMES OF YOUTH AND YOUNG ADULTS WITH HIV

- Central Premise
 - Youth and young adults with HIV are least likely by age group demographic to seek/remain in care, take ARVs and therefore to reach sustained viral control.
 - Youth and young adults are fully engaged in social media of every kind.
 - Hence, can social media be used as a tool to improve outcomes?

COLLABORATORS

- Penn State Health, Hershey Medical Center
 - Division of Infectious Diseases
 - Public Health Sciences
- Pinnacle Health System
 - REACCH Program
- Hamilton Health Center
 - Hamilton HOPE Program
- Alder Health Services
- Duet Health
 - App developer

BACKGROUND – LOCAL EPIDEMIOLOGY

- HIV care model in southcentral PA
 - Small urban centers: Harrisburg metro area, Lebanon, Carlisle
 - Dauphin County (Harrisburg) – ranks 5th in PA for cumulative AIDS cases
 - Relatively large AA population (Harrisburg) and Latinos (Harrisburg, Lebanon), both disproportionately affected
 - Large rural population: 10+ counties
 - Largely Caucasian population
 - Increasing proportion of MSM, young and youngish

SPNS FUNDING

- Began 9/1/15 for a 4-year study period
- Ten sites funded nationally
 - Hershey project was the only funded site to address a large rural population
- Multiple different approaches to social media

OBJECTIVES

- Link all Ryan White-funded providers in the greater Harrisburg area in a collaborative project
- Unmet need #1
 - Extend the existing OPT-In For Life brand (<http://optinforlife.org>) to include all individuals on our web and all social media sites
 - Market/outreach the brand to at-risk, infected, and affected individuals in the age group 13-34
- Unmet need #2
 - Develop the OPT-In For Life app to target our new and existing patients, ages 13-34 for whom we have already demonstrated a high dropout rate
 - Enable secure communications across the app
 - Develop app specific features such as access to their medical data, tools, goals, information, evaluation (journaling)

INCLUSION CRITERIA

- Youth and young adults, ages 13-34 (we chose 18-34)
- Newly diagnosed (within the past 12 months)
- Last viral load >200/mL
- Missed a visit for at least one >6 month-time-period in the last 24 months

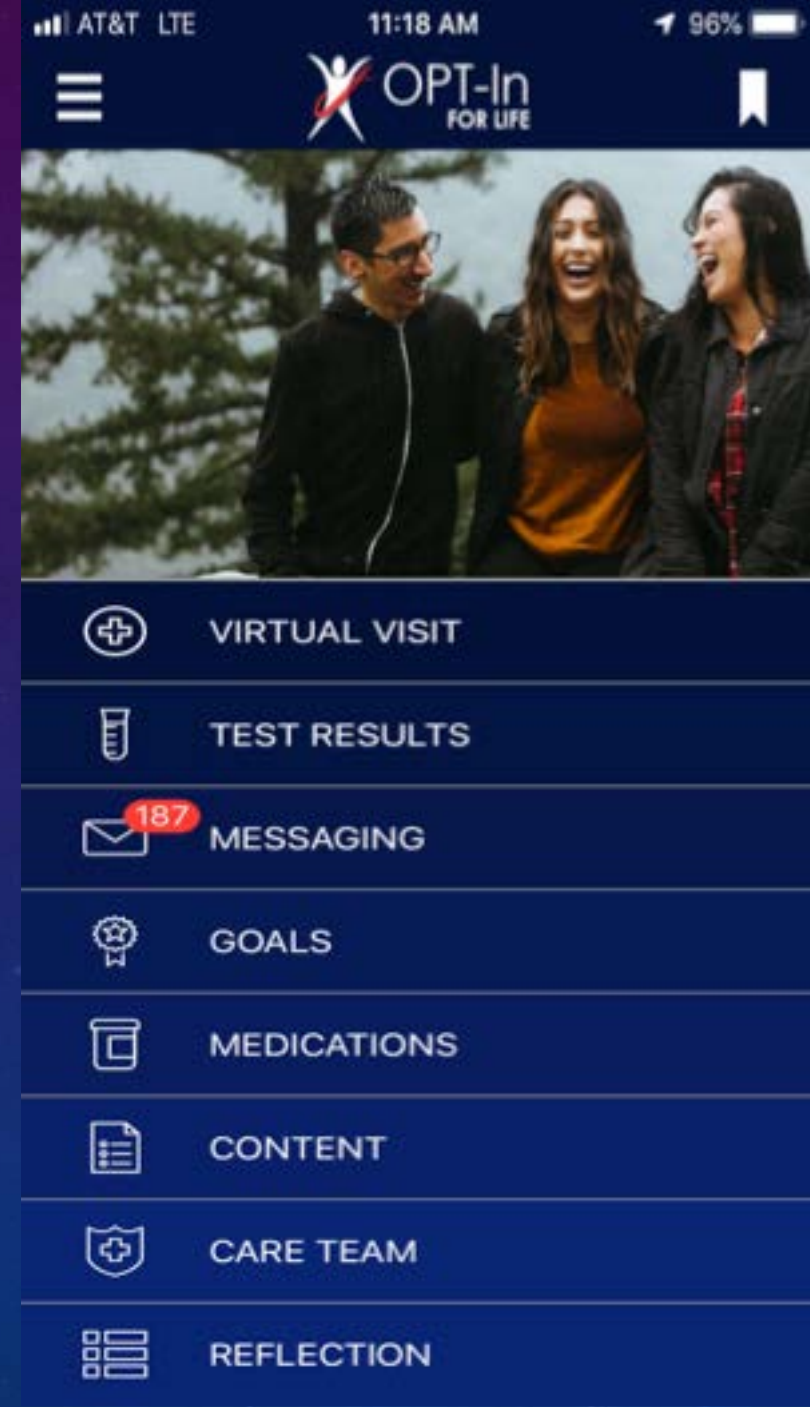
DEMOGRAPHICS

- Recruitment (N=92)

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	40 (43.5%)
White	49 (53.3%)
Other	3 (3.3%)
Ethnicity	
Hispanic	15 (16.3%)
Non-Hispanic	77 (83.7%)
Eligibility criteria	
Newly diagnosed	22 (23.9%)
Loss-to-follow up in care	54 (58.7%)
HIV RNA viral load>200	28 (30.4%)
HIV RNA viral load at enrollment	
<=200	59 (64.1%)
>200	33 (35.9%)

MOBILE APP (OPT-IN FOR LIFE)

- DUETHEALTH (MEDDATA)
- CURRENT FUNCTIONS & FEATURES



Duet Controls Communications Content Journal Editor Patient Messages Patient Alerts Logout

Module: Living with HIV Controls Ping Du **Backend data**

Ping Du Patient Initiated: 11/01/16 Living with HIV Module **PEI Score: 104**

PEI Score Tracking

Initiated	1 points
Opens	32 points
Journals	12 points
Opens Per Week	4 points
Journals Per Week	0 points
Content Views	30 points
Devices	25 points

Test Results: 4 ADD NEW

11/02/2016	CD4 : 580	Viral Load : 13
10/05/2016	CD4 : 850	Viral Load : 14
09/05/2016	CD4 : 450	Viral Load : 340
08/03/2016	CD4 : 120	Viral Load : 45,000

Messages: 414 SEND NEW

Appointment Reminder	07/13/18 3:22 PM	08/01/18 1:58 PM
New Look, Different App!	06/29/18 9:24 AM	08/01/18 1:28 PM
New Content: Medical Marijuana	05/09/18 10:01 AM	08/01/18 1:28 PM
New Reflection questions	11/14/17 11:34 AM	03/13/18 2:35 PM
Recent App Update	06/27/17 9:07 AM	10/18/17 2:05 PM

Care Team

John Zurlo, MD
Verbenia Collins, RN

AT&T LTE 11:18 AM 96%

OPT-In FOR LIFE

VIRTUAL VISIT

TEST RESULTS

187 MESSAGING

GOALS

MEDICATIONS

CONTENT

CARE TEAM

REFLECTION

Goals

My Current Goal Quit Smoking

Medications

TRUVADA	Refill in 30 days
Allegra--D 24 Hour	Refill in 0 days
Fish oil	Refill in 0 days

Content Interaction: 30

Viral Load	6
Sometimes, it's okay to quit	3
Medical Marijuana in PA	3
Indications for medical marijuana	2
We want to hear from you!	2

Reflection Journal

Are you feeling more in control of your health care since using the OPT-In For Life App?
Yes, I find certain things about the app help me.

Has the app helped you in staying regular with your medication?
Yes

Have you checked out the content section? We're trying to add information that you may find useful.
Yes. There are some useful things there.

What's something you would like us to address or talk about?
Healthy diet

Journal away. What's new with you? We would love to know what's going on in your world.
No

TRACKING APP USAGE

Population View Module: Living with HIV DOWNLOAD CSV

POPULATION VIEW POPULATION ANALYSIS Search by Patient Name

Name	Invited	PEI	Opens	Meds	Meal	Water	Weight	Reflecti	Activity	Some que	Content
	03/29/17	138	39	1	0	0	0	2	0	0	6
	03/29/17	0	0	0	0	0	0	0	0	0	0
	03/27/17	28	9	0	0	0	0	5	0	0	3
	03/23/17	48	18	6	0	0	0	2	0	0	0
	03/17/17	49	12	0	0	0	0	1	0	0	8
	03/09/17	51	16	0	0	0	0	1	0	0	3
	03/08/17	18	7	0	0	0	0	0	0	0	1
	03/06/17	5	2	0	0	0	0	0	0	0	0
	02/17/17	5	2	0	0	0	0	0	0	0	0
	02/17/17	15	6	0	0	0	0	0	0	0	1
	02/17/17	30	11	2	0	0	0	0	0	0	0
	02/15/17	110	48	1	0	0	0	0	0	0	2
	01/26/17	52	21	0	0	0	0	4	0	0	1
	01/25/17	468	204	3	0	0	0	6	0	0	7

PATIENT INTELLIGENCE CENTER
track the users' trends and preferences

Opt-In For Life Care Site: Penn State Hershey Medical Center DOWNLOAD CSV

ENROLLMENT

- 54 Invited
- 51 Activated
- 94 Conv. Rate (%)

ACTIVATION

- 720 Sessions
- 15,709 Clicks
- 9 Clicks / Session

ENGAGEMENT

- 46 Journal Entries
- 2,283 Messages
- 94 Audio/Video

OVERVIEW

Popularity

- MESSAGING 43%
- TEST RESULTS 23%
- CONTENT 10%
- NEWS/SOCIAL MEDIA 10%
- REFLECTION 7%
- CARE TEAM 3%
- MEDICATIONS 3%
- GOALS 1%

Messaging

- Sent 2,283
- Read 1,183

Overview Start Date End Date GO

Avg. Time / Session	02:40
Clicks from Returning Patients	15,708
Avg. Sessions / Returning Patient	13.1
Avg. Time / Video	00:00:45
Total Video Time	01:08:47
Avg. Time / Audio	00:00:00
Total Audio Time	00:00:00

QUALITATIVE ANALYSIS FOR TEXT MESSAGES

Message to [REDACTED]

Subject RE: Health Ins.

Time Sent 03/06/17 1:31 PM

Time Read 12/31/69 7:00 PM

Hey [REDACTED]

It's Laurel. I will forward your message to Micheal.

Have a great day!

:)

Original messages

Message from [REDACTED]

Subject Health Ins.

Time Sent 03/03/17 6:55 PM

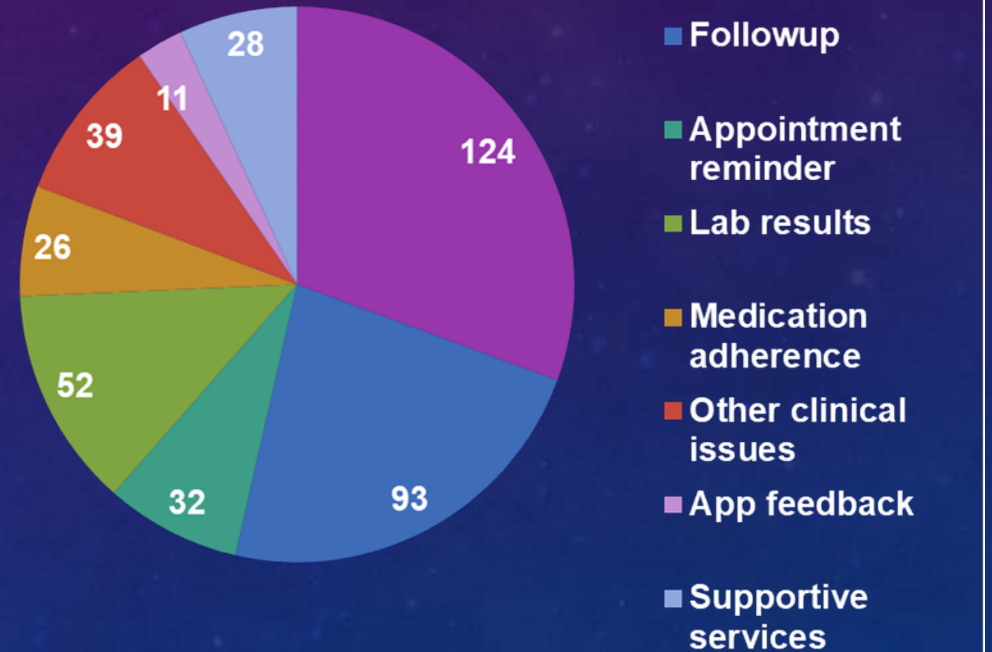
Time Read 03/06/17 1:32 PM

Hey Michael,

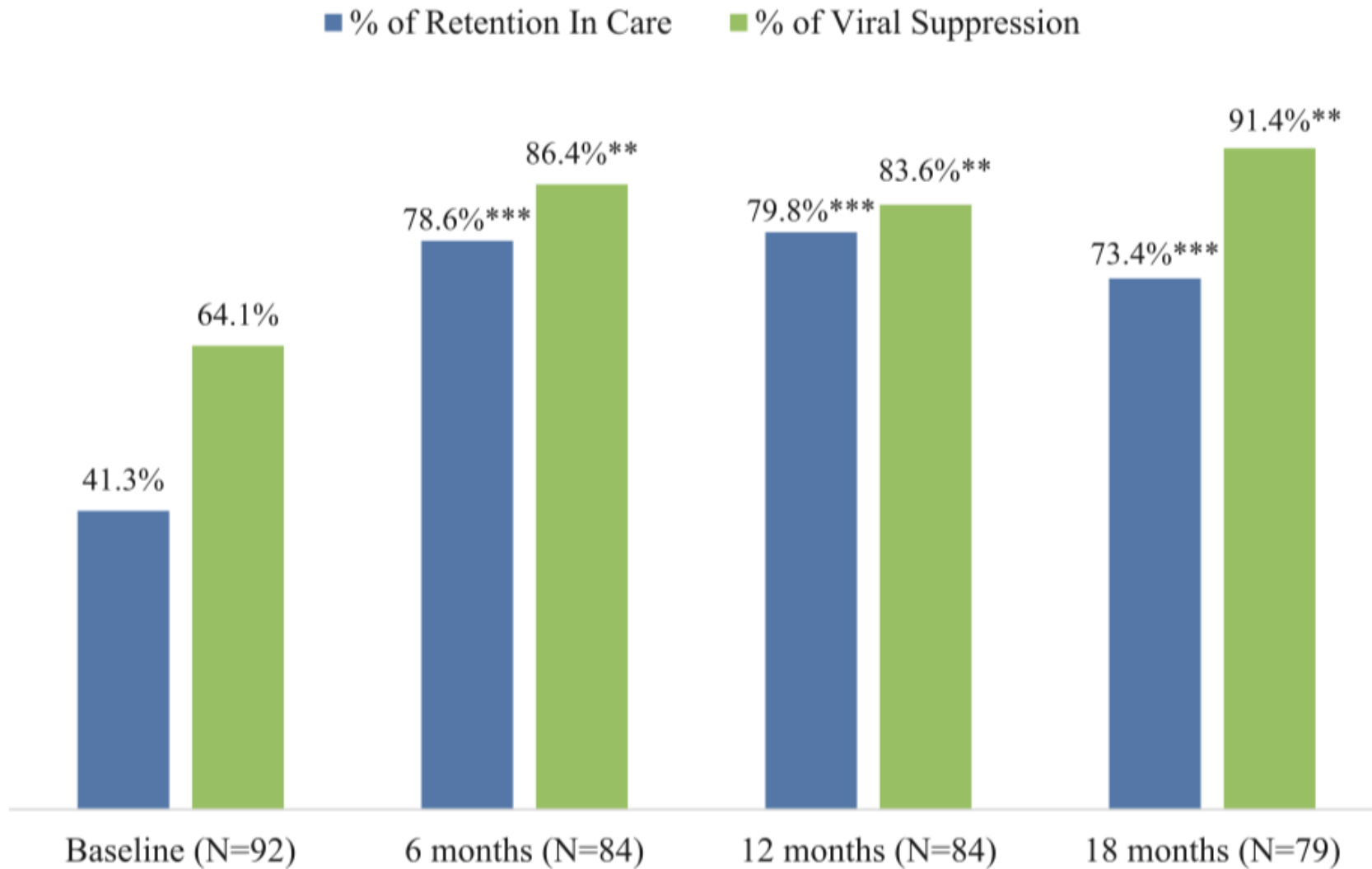
Can you please give me a call asap. I got a few letters in the mail about Health Ins. Stuff and something else I think you signed me up for and I don't understand. Plus some of it is time sensitive.

[REDACTED]

Number of messages by topics



18-MONTH OUTCOMES



PROJECT SUCCESSES AND LIMITATIONS (LESSONS LEARNED)

• Successes

- We have shown early outcome success
- App is easy to enroll, easy to use, easily scalable
- Data are stored safely and in perpetuity
- Back end allows for unlimited flexibility and analysis
- Little site maintenance required
- Telehealth capability

• Limitations

- App usage is variable, reduced over time, lower than hoped for
- Aggressiveness in getting patients back for survey completion may have skewed the data
- Uncertain relationship between content creation and usage/outcomes
- Difficult to gain traction with social media sites
- ?Patient portals

OPT-IN FOR LIFE: CURRENT STATUS

- 1 year no-cost extension (through 9/1/20)
- Expanded enrollment to include the larger population of patients served by Hershey focusing on those we deem likely of drop-out
- Continue to create content to “see what sticks”
- Develop a PrEP module

SUSTAINABILITY PLANS

- Extend the use of OPT-In For Life to a larger group of patients beginning with multiple sites across Pennsylvania
- Second phase of investigation
 - Continued focus on primary outcomes (engagement in care, antiviral suppression)
 - Determine the feasibility and scalability of mobile app technology for this population
 - Continue to explore the relationship between unique, relevant content creation and engagement in the app

INCLUSION CRITERIA

- PrEP patients
- Newly (within 1 year of diagnosis) diagnosed with HIV
- Any patient whose last two consecutive viral loads are ≥ 200 copies/mL
- All pregnant women
- All telehealth patients (HIV+ or PrEP)
- Any patient with a demonstrated history of poor adherence to ARV medications (as judged by the local site providers)
- Any patient with a h/o of frequent missed visits (as judged by the local site providers)
- Any patient that falls into a demographic group associated with high risk of lost-to-follow-up (to be defined, *e.g.* youth and young adults, trans-women, etc.)

The background is a dark blue gradient with a subtle pattern of white stars. Overlaid on this are several faint, light blue technical diagrams. On the right side, there is a large circular diagram with concentric circles and radial lines, resembling a scale or a gauge, with numerical markings from 0 to 210. Below it is another circular diagram with dashed lines and arrows. On the left side, there are smaller circular diagrams, some with arrows indicating direction. The overall aesthetic is scientific and technical.

JOHN ZURLO, MD
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**HRSA/SPNS Social Media
Initiative:
Publication and
Dissemination Activities**

More Information Available: HRSA HAB Website

➤ SPNS page on hab.hrsa.gov

<https://hab.hrsa.gov/about-ryan-white-hivaids-program/part-f-special-projects-national-significance-spns-program>



➤ Target HIV

<https://www.targethiv.org/library/hiv-care-innovations-replication-resources>



Professional Publications

Recently Published

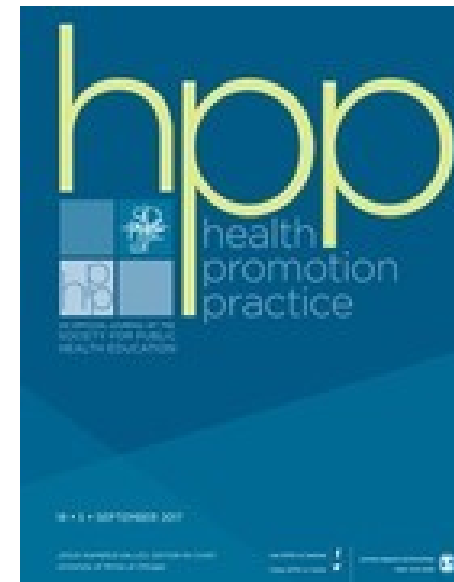


Step, M. ““Positive Peers: Function and Content Development of a Mobile App for Engaging and Retaining Young Adults in HIV Care,” *JMIR Research Protocols*, Jan 30, 2020

Trujillo, D. “Digital HIV Care Navigation for Young People Living With HIV in San Francisco: Feasibility and Acceptability,” *JMIR mHealth and uHealth*, Jan 10, 2020

Reback, C. “Technology Use to Facilitate Health Care among Young Adult Transgender Women Living with HIV,” *AIDS Care*, Aug 12, 2019

Coming: Focus Issue of *Health Promotion Practice*, September 2020 (now online August 2020)



Articles Planned for September 2020 *HPP*

E-VOLUTION: A Text Messaging
Powered Intervention –
Connection, Support and HIV 2
Eradication

Does the Use of Motivational
Interviewing Skills Promote
Change Talk among Young People
Living with HIV in a Digital HIV
Care Navigation Text Messaging
Intervention?

Supporting Health Among Young
Men Who Have Sex With Men and
Transgender Women With HIV:
Lessons Learned from
Implementing the WeCare
Intervention

OPT-In For Life: A Mobile
Technology-based Intervention
to Improve HIV Care
Continuum for Young Adults
Living With HIV

Associations between Social
Support and Social Media Use
among Young Adult Cisgender
MSM and Transgender Women
Living with HIV

Qualitative Evaluation of Social
Media and Mobile Technology
Interventions Designed to
Improve HIV Health Outcomes
for Youth and Young Adults
Living with HIV

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