NATIONAL PARAMETER STREAMENT



Three Clinic-Based Social Media Initiatives Engaging PLWHA

from the Special Projects of National Significance (SPNS)

Howard Brown Health; Chicago, IL

The MetroHealth System; Cleveland, OH

Washington University St. Louis; St. Louis, MO

Disclosures

The Washington University in St. Louis staff have no conflicts of interest or financial relationships to disclose.

The Howard Brown Health staff have no conflicts of interest or financial relationships to disclose.

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Important Acronyms/Phrases

LGBTQ- Lesbian, Gay, Bisexual, Transgender, Queer

TWOC- Transgender Women of Color

MSM/YMSM- (Young) Men who have Sex with Men

Latinx- Gender neutral terminology for Latino/Latina identified persons

LTC- Linkage To Care

HRSA- Health Resources and Services Administration

HAB- HIV/AIDS Bureau

Gap in Care- No medical visit within the last 6 mon. of the year

ADAP- AIDS Drug Assistance Program (Ryan White B)

Viral Suppression/Undetectable- A viral load of <200 copies/mL

STI- Sexually Transmitted Infection



E-volution: Connect, Engage Thrive



E-Volution Project Team

Katie Plax MD - Principal Investigator

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School of Medicine

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Stacey Slovacek LCSW – Assistant Project Coordinator

Julia Schlueter MPH – Evaluator

Maria Freshman MA – Data Manager





Background: Mobile Health (mHealth)

Text messaging can be an effective tool to improve patient outcomes along the HIV care continuum.

Cell phones have become indispensable tools - 1 in 3 adolescents sends more than 100 text messages a day.

Pew Research Center on Internet and Technology in 2015 reported 73% of teens own a smart phone and 85% of African American teens own a smart phone.



Local Eligibility Criteria

Between the ages of 18 and 29; AND

HIV-positive; AND

Receive care from a Washington University Infectious Diseases Clinic; AND

Have access to a private mobile device with texting capabilities; AND

Meet at least one of the following additional criteria:

- 1. Newly diagnosed OR
- 2. Not linked to care OR
- 3. Out of care/not fully retained in care (6 month gap in last 2 year OR
- 4. Not virally suppressed (200 copies/mL at last lab test)



Participant Demographics and Risk Factors at Consent (n=102)

Demographics	N (%)
Race	
Black	95 (93.1)
White	7 (6.9)
HIV Acquisition Category	
Male-to-Male Sexual Contact	83 (81.4)
Male to Male Sexual Contact & Intravenous Drug Use	1 (1.0)
Heterosexual Contact	11 (10.8)
Perinatal	7 (6.9)
Age*	22.33 (2.08
Psychosocial Risk Factors	
Depression (PHQ-2 ≥ 3)	28 (27.5)
Experienced Physical Intimate Partner Violence	30 (29.4)
Experienced Sexual Assault	35 (34.3)
Traded Sex	23 (22.5)
Received Payment for Sex	29 (28.4)
Paid for Sex	6 (5.9)

^{*} M (SD)



Patient C

25-year-old black male diagnosed with HIV 6 years ago

Due to challenges with medication adherence, missed medical appointments, and detectable viral load, he was assigned to a specialized Lost to Care Case Manager

MCM referred the client to E-VOLUTION and he was enrolled in November 2017.

Inclusion criteria: Not Virally Suppressed

Screened positive for Depression on PHQ-2



Medical Case Manager to Client

- Shift to preferred method of communication for clients
- Built HIV-Specific Module which includes:
 - Medication Reminders (Daily)
 - Appointment Reminders (As Needed)
 - General Mood Check-Ins (Twice Weekly)
 - Housing/Bills Needs (Monthly)
- Needs trigger alerts
- Weekly collection of text dialogue and qualitative analysis of content

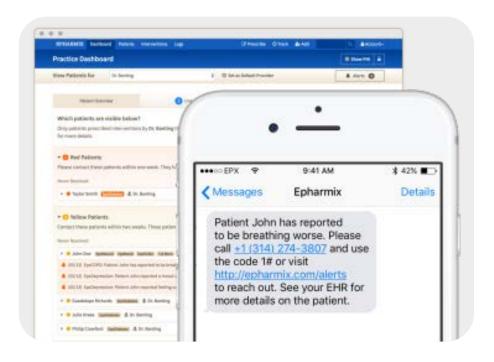




Intervention Description

Automated Text Messaging

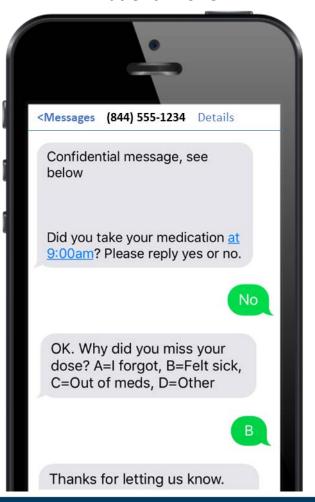
- Medication Reminders
 - "Did you take your medication at 9:00am? Please reply yes or no."
- Appointment Reminders
 - "Your appointment with The SPOT is in 2 days, on 12/28. If you cannot make the appointment for any reason, reply 1."
- Mood Check-Ins
 - "We are always here to help. How are you doing today? Reply 1 if better than usual, 2 if same, 3 if worse than usual."
- Social Service Needs (Housing/Bills)
 - "You once mentioned concerns about housing. Do you think you'll have trouble with any upcoming bills? Please reply yes or no."





Intervention Description – Medication Reminders

Patient Phone

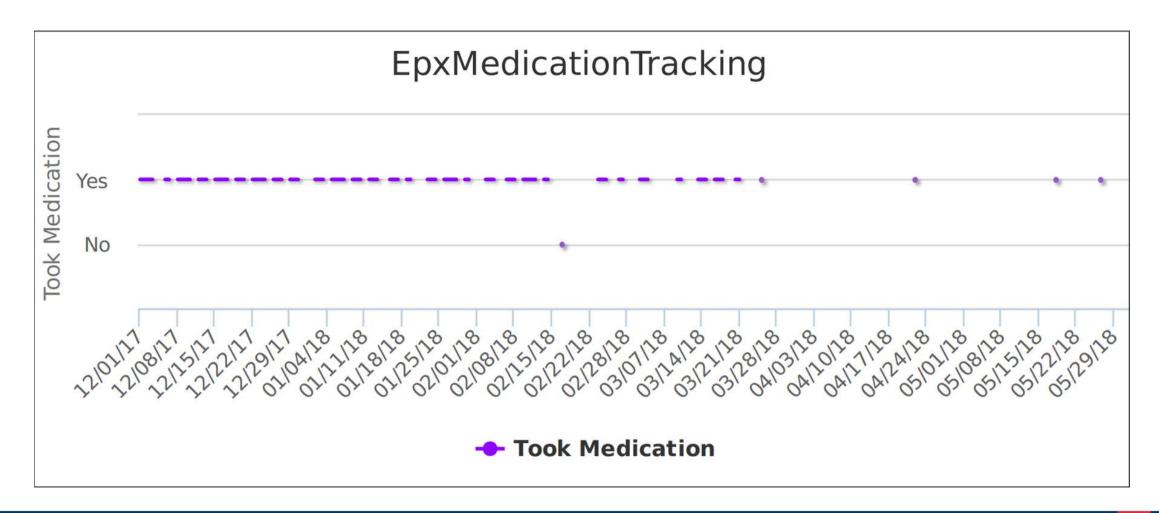


Care Team Member Phone





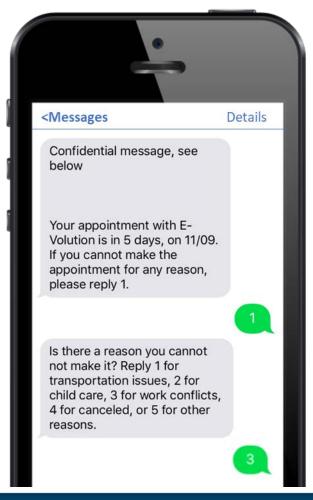
Patient C Medication Tracking Dashboard





Intervention Description – Appointment Reminders

Patient Phone



System alerts the case manager that the patient will miss the next appointment via:

- Text message direct to CM's Phone,
- Emails the CM (can be set to immediate, daily, or weekly), and
- Alert appears on the Dashboard

A callback automatically goes to the clinic's scheduling phone number to reschedule.



Alerts

"Easy to talk to someone if I have a problem and response is usually pretty quick"

Number of Alerts

- Appointment Reminders = 115
- Medication Tracking (includes mood check ins and social service needs) = 280
- Total Alerts = 395

Top 3 alerts for medication tracking

- Need for help with housing/bills = 89
- Did not take medication (Reason: Other) = 64
- Did not take medication (Reason: Out of Meds) = 58
- + Number of alerts for Not Feeling Well (with requested follow-up) = 42

Top 3 reasons for missing medical appointment

- Miss due to work = 37
- Miss due to other reasons = 31
- Miss due to transportation = 15



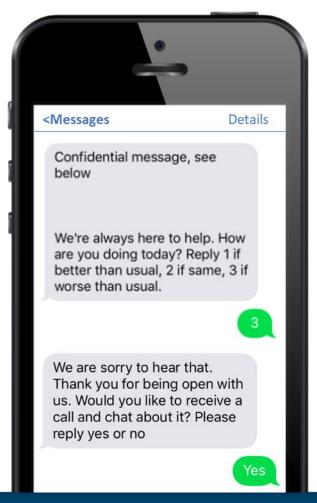
Patient C - Alerts

	<u>Date/Time</u>	Body of the Message
	12/4/2017 5:00	Patient C reported feeling worse than usual and requested a call.
	12/31/2017 10:58	Patient C would like to chat about housing issues.
1/8/2018 7:02 Patient C reported feeling worse than usual and requested a call.		Patient C reported feeling worse than usual and requested a call.
	1/31/2018 6:10	Patient C would like to chat about housing issues.
	2/26/2018 12:25	Patient C will miss the upcoming appointment at 02/27 due to work.
	2/28/2018 7:14	Patient C would like to chat about housing issues.
7/9/2018 12:22 Patient C reported feeling wo		Patient C reported feeling worse than usual and requested a call.
	7/12/2018 10:29 Patient C will miss the upcoming appointment at 07/17 due to wor	
	9/5/2018 6:45 Patient C did not take their vitamins. Reason: 'Other'	

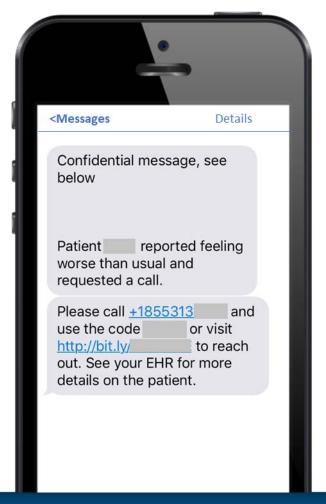


Automated Text Messaging - Alert

Patient Phone

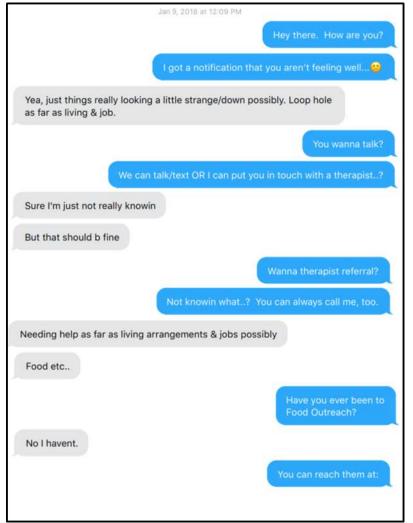


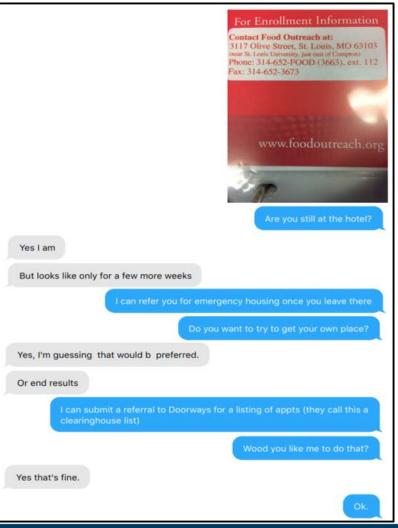
Care Team Member Phone





Live Text Messaging – Follow-up from CM





TL;DR

- Clarification of need:
 - In crisis (offer therapist referral)?
 - Asking for resources?
- Food Insecurity
- Issues with housing/employment
- Provides referral for food and emergency housing



Participant Feedback

Q: What did you like about this service? Feel free to write as much as you would like.

"They care that someone else cares for me and trying to make sure I'm on top of my needs."

"All the help that I didn't know was available to use for people with illness/sickness. How everyone is so caring and energized and the doctors are awesome."

"It's something I can rely on if I don't have anyone else or if I forget."

"The service was excellent. Thanks to [my case manager] and her keeping me updated with appointments and messaging me I received the treatment necessary."

Preliminary Evaluation Results

Differences in Proportion of Suppressed vs. Unsuppressed Participants at Consent and 6 Months

Sample (N)	Suppressed v. Not Suppressed VL	X ²	p-value
Baseline (102)	50 v. 52	5.60	.018
6 mos (89)	59 v. 30		

Excludes those that did not participate in the program for at least 6 months.



Preliminary Evaluation Results

Average Viral Load – Difference in Mean (SD) Viral Load at Consent and 6 months

Sample (N)	Mean Viral Load (SD)	z score	p-value
Baseline (102)	23,843.17 (72,661.09)	-2.45	.014
6 mos (83)	6,834.06 (26,002.05)		

Excludes those that did not participate in the program for at least 6 months.



Patient C – Follow-up

At last medical visit, Patient C reports he was virally suppressed.

"I've always struggled with my viral load. It goes up and down. I've tried hard but haven't been able to become undetectable, really.

And finally I did with this project.

I do. I credit my undetectable status to the [E-VOLUTION] project."

- Patient C





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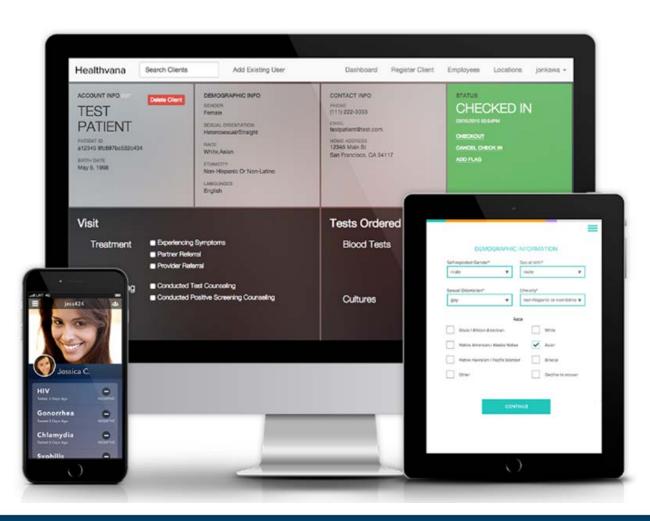
Howard Brown Health

"Howard Brown Health exists to eliminate the disparities in healthcare experienced by lesbian, gay, bisexual and transgender people through research, education and the provision of services that promote health and wellness."

- One of the largest LGBTQ organizations in the country, Howard Brown Health spans 10 locations across Chicago and serves more than 34,000 clients.
- In 2017, Howard Brown served over 4,100 People Living with HIV/AIDS.



Healthvana



- Healthvana is a secure platform that provides users access to portions of their medical chart.
- Clients can view STI results, locate nearby testing centers, and get info on common STIs from any smart device.
- Since being implemented in 2013 over 7 thousand clients have created an account.



S.M.A.R.T.E.E

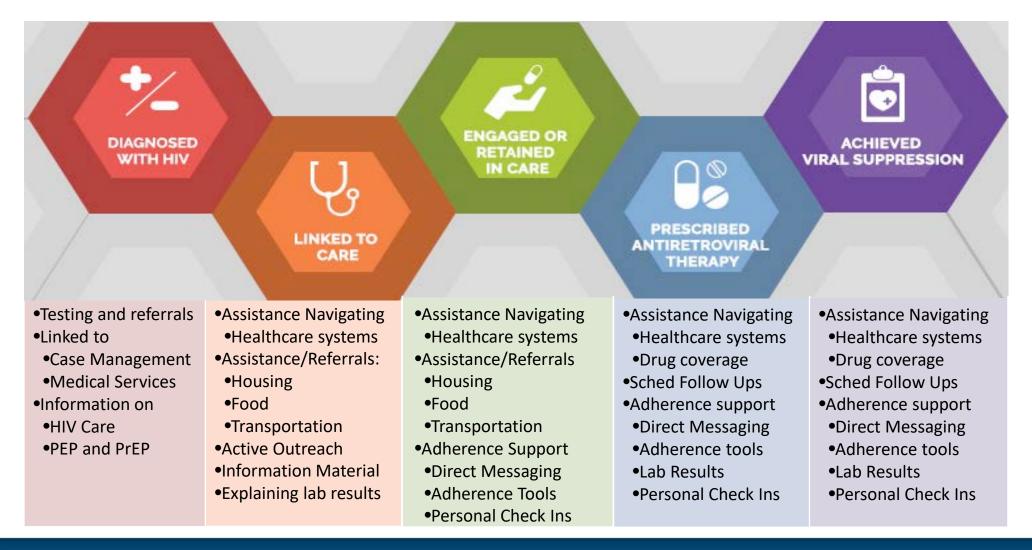
Social Media App for Retention, Treatment, Engagement and Education

- Enabled direct messaging
 - Facilitate LTC
 - Understand barriers to treatment adherence
 - Increase use of support services
- Released VL and CD4 Results
 - Support ART adherence and increase viral suppression
 - Allow self tracking/monitoring
- Provided more in depth health information
 - Advance health literacy
 - Promote HIV testing/Awareness





SMARTEE Care Continuum





Messaging Examples



Hi Your application for medication assistance was approved through Your labs came back and you are back to undetectable and your CD4 percentage is up to 39%. Great job staying on top of your care! I'll send you a reminder about your upcoming appointment on September 21 at 1pm with Cori a few days before your appointment. Let me know if you need anything before then. -James

JAMES ZUNIGA 08/22/2018

Thank you so much J trying to .. the work outs not to stress out

08/22/2018

You're doing great! I know its hard not to stress out but you've worked hard to improve your health and it shows. I'm sure Cori will be excited to hear this next month.

JAMES ZUNIGA 08/22/2018



Good morning ! Just a friendly reminder about your upcoming appointment scheduled for Monday, October 1st at 4 pm here at Sheridan with Michelle. Let me know if you need to cancel or reschedule. Have a great weekend!

JAMES ZUNIGA

09/27/2018

Thanks James! :) I'll be there.

09/27/2018

Patient read on 9/27/2018 at 11:07am CDT



Scopes and Recruitment

Eligibility

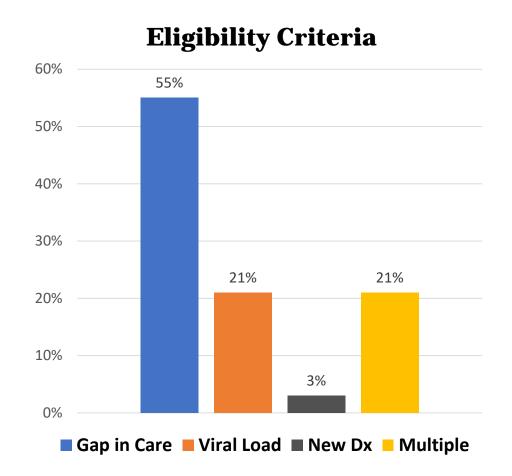
- Age 13-34
- Identify as MSM or TWOC
- Receive HIV care at HBH
- And at least 1 of the following:
 - Have a gap in care
 - Be newly diagnosed
 - VL >200 copies

Recruitment

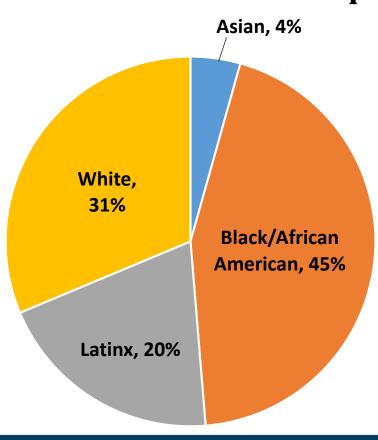
- From January of 17 through May 18
- HAB measures to identify clients
- Internal referrals for new diagnoses
- 115 participants were enrolled
 - Mean age: 28
 - 96% identified as MSM
 - 4% identified as TWOC



Participant Demographics



Racial and Ethnic Makeup



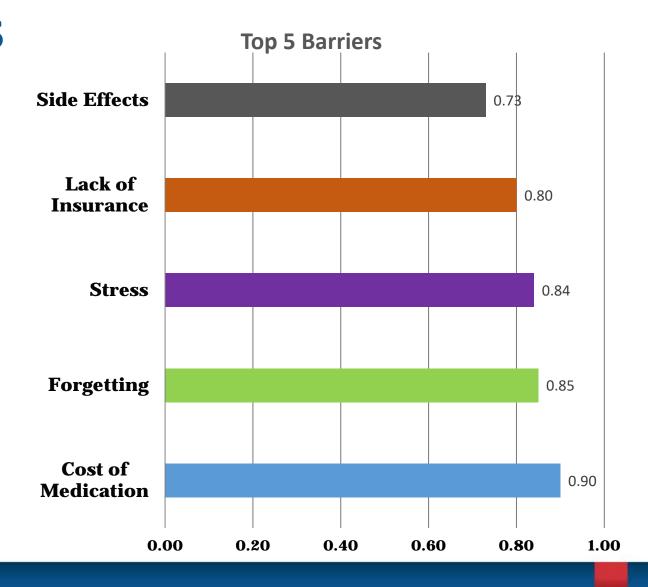


Barrier Assessment

Barriers	Highly concerned	Slightly concerned	Not at all concerned
Frequent changes to daily routine			\
Cost of medication	✓		
Side effects		✓	
Drug or alcohol use			✓
HIV stigma		✓	
Sexual or gender identity stigma			✓
No or poor access to transportation		✓	
No or poor access to food			✓
Unstable housing			✓
Unemployment	✓		
Lack of health insurance	✓		
Depression		✓	
General stress		✓	✓
Lack of support from family			✓
Lack of support from friends			✓
Lack of support from significant other			✓
Tired of taking medications		✓	
Forgetting to take medications		✓	
Distrust of medical providers			✓
Unwilling to accept HIV diagnosis			✓
Forgetting to refill prescription		✓	
Feeling medications are not necessary			✓
Forgetting dosage or how to take medication			✓

Top Reported Barriers

- Cost and Insurance
 - 75% had Rx. Coverage
- Forgetting in some context
- Perception vs Experience
 - Discussions revealed level of concern was often projected
 - Reflective of political climate
 - Dismissive of contributing factors causing side effects





You win some...You lose some

- 25 participants are inactive
 - 1 withdrew
 - 4 relocated/transferred care
 - 13 are in care, but not engaged in the study
 - 7 have been lost to follow up
- Mean age: 28
- Mean VL at baseline: 7942 copies/mL
- 64% (11) had a gap in care and 52% (13) had a detectable VL
- 28% (7) met multiple criteria



Preliminary Progress for VL

- 32 active participants with a VL >200, 30 have reached 6 mon. of enrollment
- Of 30 who had been enrolled for at least 6 mon.
 - 70% (21) had a reduction in VL
 - 70% (21) achieved viral suppression
- Of 20 who have been enrolled for at least 12 mon.
 - 60% (12) maintained viral suppression (2 consecutive undetectable VLs)
 - 10% (2) are pending 12 month follow up labs
- 17% (5) have inconsistent viral trends or no major change



Retention in Medical Care

- At this point retention in medical care cannot be gauged uniformly since not all participants have been enrolled for the same length of time.
- We can report that 83% of active participants have completed a medical appointment within the last 6 months.
- Of those who have not completed a medical visit, 6% completed labs.
- 11% are due for a medical visit.



Participant Feedback: The Good

19 completed the study; 18 completed feedback assessments

- Which features in the app were most helpful?
 - 65% Direct messaging
 - 53% Lab tracking
- What do you like <u>most</u> about the app?

"That messages was being sent to me as friendly reminders to take meds, take care of myself, those kind words always made my day and not to forget."

"Direct messaging and Rey's thoughtful daily tips."

"Easier to access lab results and be able to contact staff or schedule appointments."



And: The....Not So Good

- Which features in the app were **least** helpful?
 - 23% Direct Messaging
 - 31% Lab Tracking
- What did you like <u>least</u> about the app?

"Having to log in and kept forgetting." (kept forgetting password)

"Getting weekly emails about stuff that I could care less about."

"Additional messages not directly related to my care or appointments."



Additional Comments

"They really will go above and beyond to assist you with other needs besides HIV meds, they help with housing, etc."

"Always there to remind me about my labs check up, insurance and ADAP. Totally helpful because I can't keep up without them."

"Thank you! I'm not just trying to be nice, I think this has a profoundly positive effect on my life!"



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Positive Peers Overview



Positive Peers

is a web-based, mobile application (app) that aims to engage young people in holistic HIV care while creating a private, stigma-free, supportive community.

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. For more information about the SPNS grant initiative, visit:

http://hab.hrsa.gov/abouthab/special/socialmedia.html#5

Eligibility

Health Ambassador

- Be between the ages of 13 34
- Be living with HIV
- Be undetectable and retained in care
- Be a MetroHealth System patient
- Have a smartphone (Apple or Android)

*Referred to project coordinator by provider/case manager because they have the potential to be a peer mentor on the app.

Multisite Study Participant

- Be between the ages of 13 and 34
- Be living with HIV
- Meet at least one of the following
 - Newly diagnosed: 1st tested positive within 1 year from enrollment
 - Not linked to care
 - Out of care/not fully retained in care: diagnosed with HIV more than 1 year ago, but has a gap in care greater than 6 months, within the last 2 years
 - Not virally suppressed: having a viral load ≥
 200 copies/mL at last lab test.
- Be a MetroHealth System patient
- Have a smartphone (Apple or Android)



^{*}Enrolled in the local study only.

Health management tools that chart improvement, track activities, and set medication & appointment reminders.

These features are built to have a game-like feel and are housed under the My Health tab.

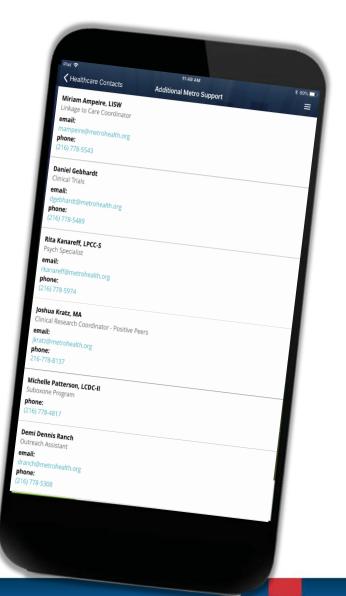






Accurate, easy-to-understand HIV health and wellness education information & curated community resources.

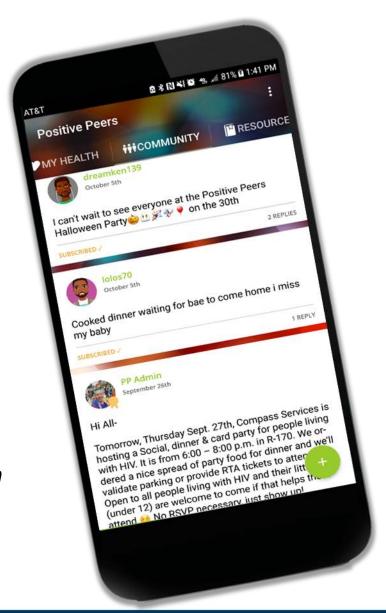


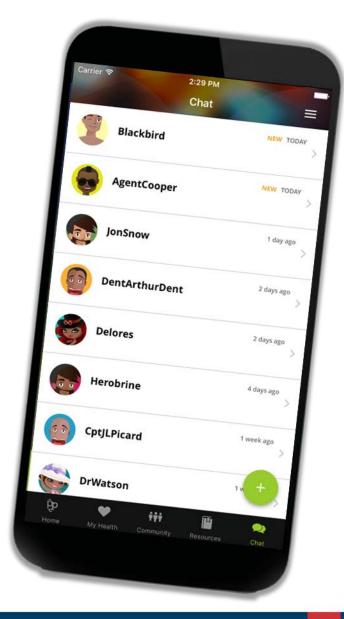




Local social networking in a community conversation & private chats

*Private chats limited to 2 age groups: 13-17 year olds can only chat with each other, 18-34 year olds can only chat with each other

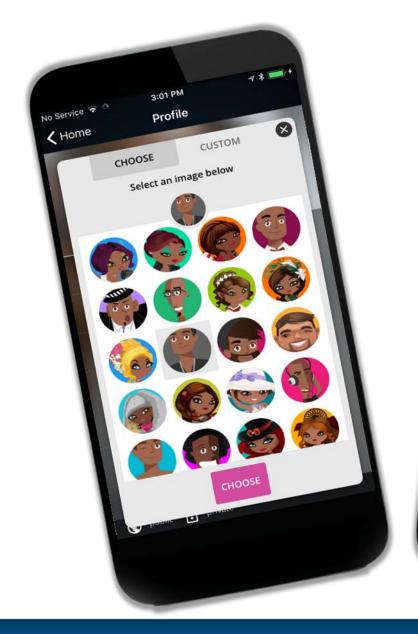






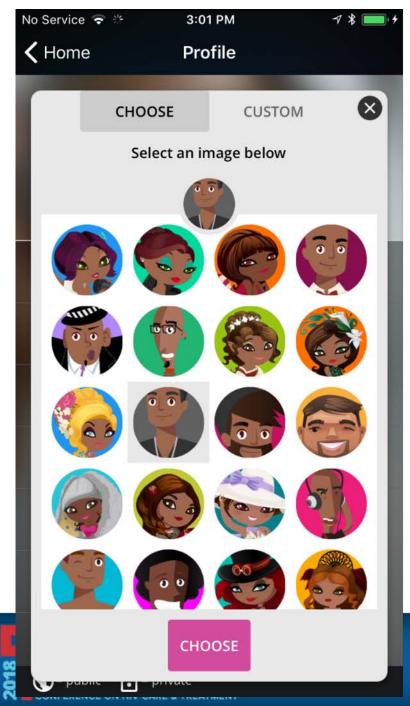
Personalization & Privacy.

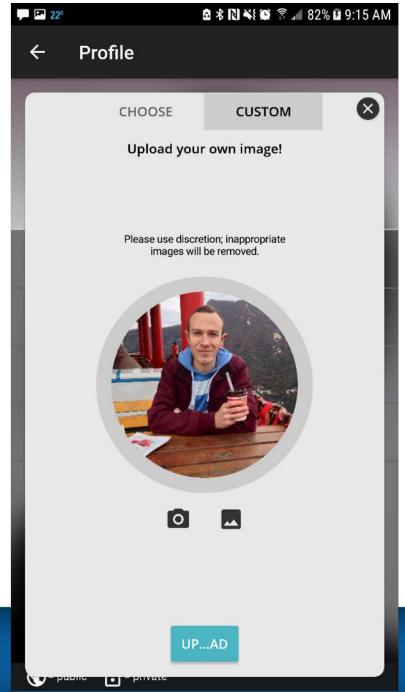
Participants create their own username, choose an avatar, and a skin (color scheme of the app). Personalized calendars and medication/appointment reminders are available too.













Baseline Sample Characteristics (n = 128)

Characteristic	N(%) or M(sd)*
Participant Type Health Ambassador Criteria Eligible	14 (10.9) 114 (89.0)
Age* 13-17 18-24 25-29 30-34	26.15 (3.9) 2 (1.5) 42 (32.8) 58 (45.3) 26 (20.3)
Race African American White Multiracial or Other Hispanic	87 (67.9) 25 (19.5) 16 (12.5) 15 (11.7)
Education Not a HS Graduate HS Graduate Some College	25 (19.5) 44 (34.3) 59 (46.0)

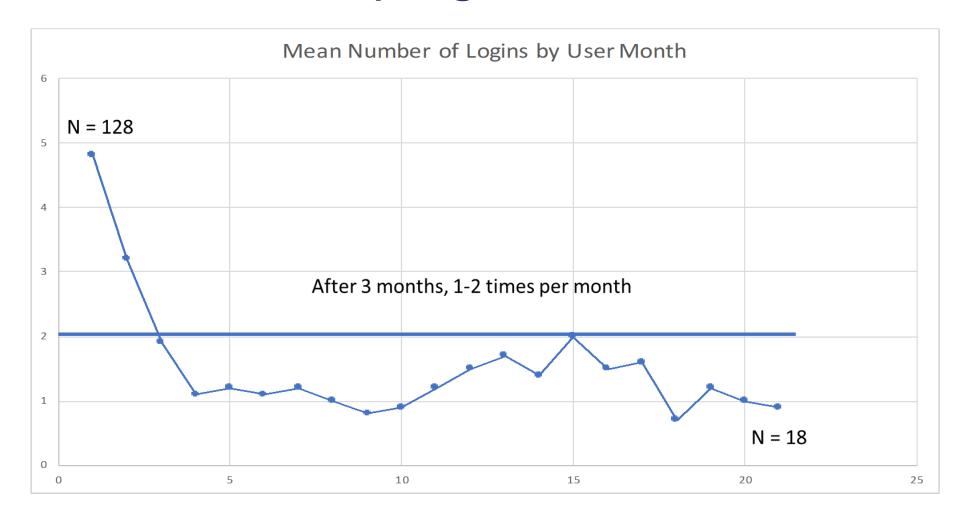
Characteristic	N(%)
Gender Male Cisgender Female Cisgender Male Transgender Female Transgender Gender Queer/Nonconform Other	101 (78.9) 20 (15.6) 1 (.78) 4 (3.1) 1 (.78) 1 (.78)
Sexual Orientation Straight Lesbian or Gay Bisexual Queer Other	31 (24.2) 60 (46.8) 27 (21.0) 3 (2.3) 7 (5.7)
Relationship Status Single or Not Dating In a Relationship	84 (65.6) 44 (34.3)
Born w/HIV	12 (9.3)

Total Application User Acts*

Variable	2017 Q1-2	2017 Q3-4	2018 Q1-2	
	Median	Median	Median	
In-app minutes	34.4	22.1	25.7	
Total number of user acts	100.0	75.0	75.0	
Number of My Health page hits	20.0	13.1	8.0	
Number of <i>Resources</i> hits	11.0	16.0	10.0	
Number of <i>Calendar</i> hits	9.0	5.0	2.0	
Number of <i>Chat</i> hits	13.0	5.0	1.0	
Number of private message	0.0	0.0	0.0	
Number of My Community hits	10.0	16.0	5.0	
Number of public user posts	0.0	0.0	0.0	
Number of public user replies	0.0	0.0	1.0	



Mean Number of Monthly Logins (Adjusted for enrollment date)



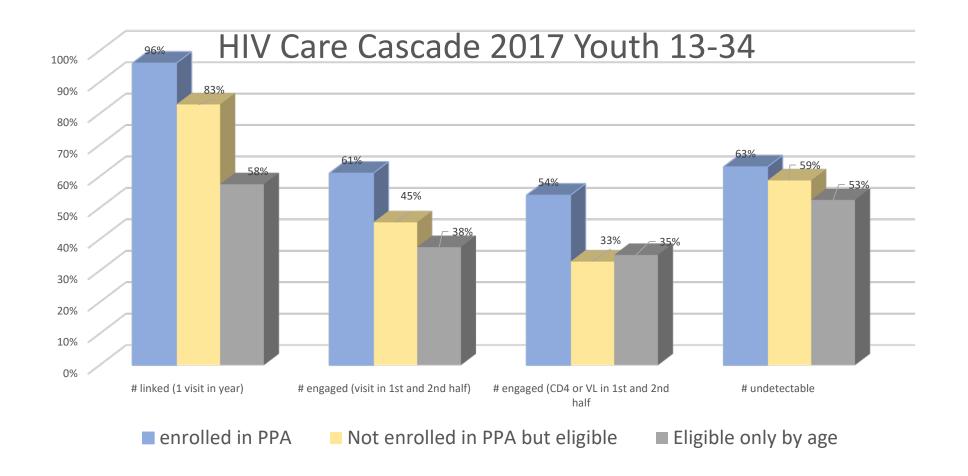


Findings

Qualitative interview responses suggest **interpersonal connections** within this virtual community are important and 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."





NATIONAL

		# linked (1 visit	# engaged (visit in	# engaged (CD4 or VL in 1st	
	Total unique #	in	1st and	and 2nd	#
PPA Status	reported in 2017	year)	2nd half)	half	undetectable
PPA = Y	100	96	61	54	63
PPA = N, PPA-Eligible = Y	368	305	167	121	58
PPA = N, PPA-Eligible = N, Age-Eligible = Y	40	23	15	14	53

Sustainability and Scale Up

New nodes with a local project coordinator

- Better local context, in-person connection

VS

Expand enrollment with virtual enrollment

- Less barriers to scale up, more control



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