

**Houston Area HIV Services Ryan White Planning Council**  
**Office of Support**  
**2223 West Loop South, Suite 240, Houston, Texas 77027**  
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[www.rwpchouston.org](http://www.rwpchouston.org)

**Memorandum**

To: Members, Positive Connections Ad Hoc Committee:  
David Benson, Co-Chair                      Rodney Mills  
Steven Vargas, Co-Chair                     John Poole  
Ted Artiaga                                        Cecilia Ross  
Evelio Salinas Escamilla                     Crystal Starr  
Tracy Gorden

Cc: Carin Martin                                     Amber Harbolt  
Heather Keizman                                Diane Beck  
Nancy Miertschin                               Shelley Lucas  
Sha'Terra Johnson-Fairley                   Megan Canon  
Camden Hallmark                                Raven Bradley

From: Cecilia Ross, Chair, Ryan White Planning Council

Date: Monday, November 6, 2017

Re: Meeting Notice

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We look forward to seeing you at our third meeting of the Positive Connections Ad Hoc Committee. At this meeting you will look at data points being collected for the University of Virginia study and determine information that the Council will need to evaluation the Houston project. Meeting details are as follows:

**Positive Connections Ad Hoc Committee**  
**12 noon, Monday, November 13, 2017**  
Ryan White Office of Support  
2223 W. Loop South, Room 532  
Houston, Texas 77027  
Lunch will be provided

Please contact Rod Avila to RSVP, even if you cannot attend. She can be reached at [Rodriga.Avila@cjo.hctx.net](mailto:Rodriga.Avila@cjo.hctx.net) or by telephone at 713-572-3724. If you have questions, feel free to contact Tori Williams at the same telephone number or by email at [Victoria.williams@cjo.hctx.net](mailto:Victoria.williams@cjo.hctx.net).

We look forward to seeing you next week.



Houston Area HIV Services Ryan White Planning Council

**Positive Connections Ad Hoc Committee Meeting**

12 noon, Monday, November 13, 2017

Meeting Location: 2223 West Loop South, Room 532, Houston, TX 77027

**AGENDA**

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- I. Call to Order David Benson and  
Steven Vargas, Co-Chairs
  - A. Welcome and Moment of Reflection
  - B. Introductions
  - C. Announce who will be Chairing the Meeting
  - D. Adoption of the Agenda
  - E. Approval of the Minutes
  - F. Review of October Meeting Activities Tori Williams
  
- II. Public Comment  
(NOTE: If you wish to speak during the Public Comment portion of the meeting, please sign up on the clipboard at the front of the room. No one is required to give his or her name or HIV status. All meetings are audio taped by the Office of Support for use in creating the meeting minutes. The audiotape and the minutes are public record. If you state your name or HIV status it will be on public record. If you would like your health status known, but do not wish to state your name, you can simply say: "I am a person living with HIV", before stating your opinion. If you represent an organization, please state that you are representing an agency and give the name of the organization. If you work for an organization, but are representing yourself, please state that you are attending as an individual and not as an agency representative. Individuals can also submit written comments to a member of the staff who would be happy to read the comments on behalf of the individual at this point in the meeting.)
  
- III. Ad Hoc Committee Tasks Chair, Ad Hoc Committee
  - A. Design the Evaluation Measures
  - B. Establish Project Timeline
  
- IV. Next Meeting (Goals, Date and Time)
  
- V. Announcements
  
- VI. Adjourn

\* HRSA = Health Resources and Services Administration, the federal agency that administers the Ryan White Program



## Houston Area HIV Services Ryan White Planning Council

### Ryan White Positive Connections Ad Hoc Committee Meeting

12:00 p.m., Wednesday, October 18, 2017

2223 W. Loop South, Room 240; Houston, TX 77027

### Minutes

<u>MEMBERS PRESENT</u>	<u>MEMBERS ABSENT</u>	<u>OTHERS PRESENT</u>
Steven Vargas, Co-Chair	Tracy Gorden, excused	Francis Hodge, HRSA (via phone)
David Benson, Co-Chair		Megan Canon, HHD
Ted Artiaga		Raven Bradley, HHD
Evelio Salinas Escamilla	<u>OTHERS PRESENT</u>	Carin Martin, RWGA
Rodney Mills	Akeel Taylor, UVA	Heather Keizman, RWGA
John Poole	Becca Dillingham, UVA	Sha'Terra Johnson-Fairley, TRG
Crystal Starr	Ava Lena Waldman, UVA	Tori Williams, Office of Support
	Dr. Tom Giordano, HHS	Amber Harbolt, Office of Support
	Nancy Miertschin, HHS	Diane Beck, Office of Support

HHD=Houston Health Dept.; HHS=Harris Health System; UVA=University of Virginia

**Call to Order:** Steven Vargas, Co-Chair, called the meeting to order at 9:38 a.m. and asked for a moment of reflection. He then asked everyone to introduce themselves.

**Adoption of the Agenda:** Motion #1: *it was moved and seconded (Escamilla, Artiaga) to adopt the agenda. Motion carried.*

**Approval of the Minutes:** Motion #2: *it was moved and seconded (Benson, Artiaga) to adopt the agenda. Motion carried.*

**Public Comment:** None.

**Message from HRSA:** Frances Hodge, HRSA Project Officer for the Houston EMA, said that HRSA is very supportive of the project. She is pleased that the Houston EMA is using MAI funds to underwrite the cost of this exciting and innovative project.

**Project Overview:** See attached information sheet for the UVA Positive Links program. Giordano said that he attended the premier conference for linkage which happens yearly in June and Dr. Dillingham presented data from the app. It was very impressive, it is the holy grail of apps because it has a lot of things that people want but, until now, have not known how to do. He was surprised and pleased to hear that the Planning Council wants to test pilot the app in Houston. The app is cutting and enhances the way people interface with the system.

Dillingham presented information on the Positive Links Program and Waldman discussed how the program will be implemented in Houston. See attached PowerPoint presentation. Taylor spoke about his use of the app as a client of the clinic.

**Determine Composition of the Study Group:** UVA said that they asked providers to recommend clients that they felt would benefit from the program. Most of those who were referred were newly diagnosed, recently returned to care or had problems with adherence. Committee members agreed by consensus that the number of people that will be enrolled in the 2017 Positive Links study group will be 50. Between November 1, 2017 and February 28, 2018, enrollees will be limited to black or Hispanic HIV-positive individuals since the project will be funded with Minority AIDS Initiative dollars during that timeframe. The goal of the project will be to improve retention in care among minority populations and that those considered for enrollment in the study will come from provider referrals.

**Motion #3:** *it is moved and seconded (Benson/Artiaga) that eligibility for the 2017 Positive Links study group will be as simple as possible, as long as it meets the funding criteria. Regarding the enrollment process, the implementation site is encouraged to give priority to the special populations designated in the 2017 Comprehensive Plan, which are: youth, homeless, incarcerated/recently released, injection drug users, men who have sex with men, transgender and gender non-conforming, women of color and aged 50 years and older.* **Motion carried.**

**Design the Evaluation Measures:** The committee would like to wait on this task until the next meeting so that they can review the data elements and evaluation measures that the University of Virginia has already established to see if there is anything to add that will be meaningful to the Houston planning process. In March 2018, the committee would like a report from the pilot site about the implementation process, participants recruited, staffing requirements, etc.

**Establish Project Timeline:** The project is for one year - Part A will fund through February 28, 2018 and then State Services-R funds and funding from the City of Houston will continue the project for the remainder of the year.

**Next Meeting:** Monday, November 13, 2017 at 12:00 p.m. The goal of the meeting will be to design the evaluation.

**Announcements:** None.

**Adjournment:** The meeting adjourned at 1:45 p.m.

Submitted by:

Approved by:

\_\_\_\_\_  
Tori Williams, Director

\_\_\_\_\_  
Date

\_\_\_\_\_  
Committee Chair

\_\_\_\_\_  
Date

# Content Analysis and User Characteristics of a Smartphone-Based Online Support Group for People Living with HIV

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Erin Plews-Ogan, BA<sup>1</sup>, Ava Lena Waldman, MHS, CHES<sup>1</sup>,  
George Reynolds<sup>2</sup>, Wendy F. Cohn, MEd, PhD<sup>1</sup>,  
Mary Catherine Beach, PhD<sup>4</sup>, Karen Ingersoll, PhD<sup>1</sup>,  
and Rebecca Dillingham, MPH, MD<sup>1</sup>

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## Abstract

**Background:** Although there is growing interest in mobile applications and online support groups to enhance chronic disease self-management, little is known about their potential impact for people living with HIV (PLWH). **Introduction:** We developed an innovative online support group delivered through a community message board (CMB) within a clinic-affiliated smartphone application Positive Links (PL). We analyzed characteristics of posters and nonposters to the CMB and evaluated content posted to the CMB. **Materials and Methods:** For this study, 38 HIV-infected patients received cell phones with the PL application that included the opportunity to interact with other users on a CMB. Logistic regressions investigated associations between participant characteristics and posting. CMB messages were downloaded and analyzed qualitatively. **Results:** 24 participants posted to the CMB; 14 did not. Participants had lower odds of posting if they were white ( $p=0.028$ ) and had private insurance ( $p=0.003$ ). Participants had higher odds of posting if they had unsuppressed viral loads ( $p=0.034$ ). Of the 840 CMB messages over 8 months, 62% had psychosocial content, followed by community chat (29%), and biomedical content (10%). **Discussion:** Psychosocial content was most prevalent on this CMB, in contrast to other online forums dominated by informational content. Participants who posted expressed support for each other, appreciation for the community, and a perception that the app played a positive role in their HIV self-management.

**Conclusions:** This CMB on a clinic-affiliated mobile application may reach vulnerable populations, including racial/ethnic minorities and those of lower socioeconomic status, and provide psychosocial support to PLWH.

**Keywords:** HIV/AIDS, qualitative analysis, online support groups, mobile app, m-health, behavioral medicine

## Introduction

People living with HIV (PLWH) face many challenges, including unmet needs for support and information from peers. Online support groups have the potential to overcome barriers to meeting these needs. Prior studies of online support groups for a variety of chronic diseases have shown that the online support group content generally focuses on informational support and illness experience.<sup>1-5</sup> Online support groups can promote patient empowerment,<sup>6-8</sup> but may also present risks.<sup>8-11</sup> Lack of nonverbal cues can lead to misunderstandings, while lack of quality control may allow misinformation to disseminate. Negative postings or inappropriate interactions may undermine users' sense of support. PLWH may be particularly vulnerable to the risks of online support groups, due to the stigma surrounding this illness and the sensitivity of disclosure. At the same time, stigma may make online support groups particularly valuable for PLWH, as a means of accessing support while maintaining anonymity.

Our study examines an online support group delivered through a community message board (CMB) within an innovative smartphone application (Positive Links [PL]) designed to promote linkage and retention in HIV care. The app was developed in-house by the study team and is available only to participants referred by project partners. In addition to the CMB, the PL app includes daily queries of stress and medication adherence, appointment reminders, tailored educational resources, and access to the study team for individualized counseling and assistance. The CMB within the PL app provides a unique data set for content analysis of an online support group for PLWH. In addition to users' posts, our app study includes demographic and clinical data on our participants not available in prior studies in HIV, which used online recruitment

of anonymous support group users or publicly accessible postings.<sup>2,10,12</sup> Furthermore, the app targets a population not previously studied. Prior work on online support groups in HIV and other chronic diseases has focused on Caucasian highly educated groups.<sup>10,12-15</sup> Our group may be more representative of the HIV-positive population in the United States, which disproportionately affects disadvantaged persons, including racial/ethnic and sexual minorities and those of lower socioeconomic status.

To our knowledge, there are no HIV medical apps that offer an anonymous online CMB. To address this gap, we developed the PL app and are conducting a pilot study on its impact. In the current analysis of the CMB, our objectives were to (1) compare characteristics of posters and nonposters to the CMB and (2) evaluate content posted to the CMB. We hypothesized that posters would be more likely to be female, younger, and with a longer time period since diagnosis, based on the literature about posting behaviors in other chronic diseases.<sup>13-15</sup> In the content analysis, we anticipated a predominance of biomedical content, similar to the patterns found in other online support groups. Ultimately, an online CMB (provided within an app) may be an opportunity to reach vulnerable PLWH, connect them with information and support from peers, and help them link to and remain in medical care, fostering better health outcomes.

### Materials and Methods

#### COMMUNITY MESSAGE BOARD

The PL app was developed using an iterative formative phase, in which we gathered input from our patient population to identify features that would be relevant, useful, and appealing.<sup>16</sup> Formative phase participants welcomed the idea of a CMB and emphasized the importance of anonymity and access to support.

For the current phase of the study, enrollment began in September 2013. Eligibility criteria were as follows: a score of 40 on the Wide Range Achievement Test (WRAT-4) or passing a subsequent reading test and HIV diagnosis since January 2012 OR at risk of falling out of care, as determined by their care provider. Participants were adults, age 18 years and older. There were no additional explicit exclusion criteria. We recruited participants through provider referrals at our local university-based Ryan White Clinic and from area AIDS service organizations and HIV testing sites. During enrollment, individuals consented to participate in the study, completed the WRAT-4 literacy test, answered baseline questions, and learned how to use the phone and PL app. Samsung Galaxy 2 or Galaxy 3 phones were provided and included a voice/data plan with unlimited minutes, texting, and data for the study

duration. Phones were encrypted and password protected and had a remote locate and wipe functionality. The app was also password secured. After enrollment, each participant will be included in the study for 18 months. Due to staggered enrollment, the total duration of the study is projected to require 2 years for all participants to complete study procedures and follow-up. The current analysis has been performed after 8 months of study duration, to evaluate preliminary findings in app usage to inform further iterative development of the app and, in particular, the CMB.

Participants had the opportunity to interact on the CMB through user names that they selected for themselves, to protect anonymity. Participants could start new conversations on the board or respond to older conversations. The PL team also introduced new conversation topics on HIV or general well-being and posted weekly funny videos, as had been suggested by formative phase participants. The team monitored the board for incorrect information or inflammatory comments and could also communicate with participants privately, as needed. This study was approved by the Institutional Review Board.

#### QUANTITATIVE ANALYSIS

Participants' characteristics were collected at enrollment by self-report. Demographic characteristics included age, gender, race, transmission risk behavior, time since diagnosis, and religious belief. Participants were categorized as "newly diagnosed" if they were enrolled in the study less than 3 months after their HIV diagnosis. Socioeconomic variables included education, insurance status, food security, employment status, and self-reported income. Participants also completed the WRAT-4 to assess literacy,<sup>17</sup> the Perceived Stress Scale,<sup>18</sup> and the Berger Stigma Scale.<sup>19</sup> Clinical data were extracted from the electronic medical record. Characteristics were compared between posters and nonposters to the CMB with Fisher's exact tests for categorical variables and *T*-tests for continuous variables. We performed logistic regressions to investigate associations between participant characteristics and posting on the CMB. All analyses were done using STATA 11 (StataCorp, College Station, TX).

#### QUALITATIVE ANALYSIS

After the PL study had been ongoing for 8 months, the CMB messages were downloaded and imported into NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012). Using a Grounded Theory approach,<sup>20</sup> two independent coders assigned codes to every post to categorize themes expressed by participants. Individual codes were grouped into



three broad types of content: biomedical, psychosocial, and community chat. The codebook was refined until intercoder agreement reached a kappa statistic of 0.93. After thematic saturation was achieved with no additional topics identified by either coder, the codebook was applied to the entire data set of posts, so that the frequency of each topic category could be evaluated.

## Results

### CHARACTERISTICS OF POSTERS AND NONPOSTERS

Among the 38 participants in this analysis, mean age was 34.1 years (SD 11.5). Twenty-eight participants were male (74%), 9 were female (24%), and 1 transgender male to female (3%). Seventeen participants identified as black, non-Hispanic (45%), 13 as white, non-Hispanic (34%), 3 as Hispanic (8%), 3 as multiple races (8%), 1 as African American/Caucasian (3%), and 1 refused to answer (3%). *Table 1* shows differences in participant characteristics between the 24 who posted to the CMB (posters) and 14 who never posted (nonposters). Posters were more likely to be nonwhite, with 76% of nonwhite participants posting and only 38% of white participants ( $p=0.035$ ). The majority of nonwhite participants (68%) self-identified as "Black, non-Hispanic". Participants with public insurance or uninsured were more likely to post than those with private insurance (79% vs. 20%,  $p=0.002$ ). Participants with unsuppressed viral loads were also more likely to post than those who were suppressed (82% vs. 48%,  $p=0.043$ ). Several other trends were suggested by the data, such as posters being younger and more likely to be newly diagnosed with HIV than nonposters, but these findings were not statistically significant. There were no differences in gender, literacy scores, perceived stress, or stigma scores.

*Table 2* shows the results of unadjusted logistic regression analyses investigating associations between participant characteristics and posting on the CMB. Participants had lower odds of posting if they were white [OR 0.20 (0.05–0.84),  $p=0.028$ ] and had private insurance [OR 0.07 (0.01–0.41),  $p=0.003$ ]. Participants had higher odds of posting if they had unsuppressed viral loads [OR 5.13 (1.13–23.30),  $p=0.034$ ]. When race, insurance status, and viral load were included in one multivariable model, race was no longer significant, but insurance status and viral load remained significant ( $p=0.020$  and  $0.047$ , respectively). The association between viral suppression and posting was attenuated when adjusted for newly diagnosed status, but a trend remained [OR 4.44 (0.87–22.56),  $p=0.073$ ]. When race, insurance status, viral load, and newly diagnosed status were all included in multivariate analysis, only insurance status remained statistically significant [OR 0.09 (0.01–0.71),  $p=0.023$ ].

### CONTENT AND THEMES POSTED ON THE CMB

In total, 840 messages from participants posting on the CMB were analyzed. Posts on the CMB were most commonly psychosocial content (62% of posts), followed by community chat (29%) and biomedical content (10%). *Table 3* shows each category from the codebook with frequency of occurrence and examples. Posts could be assigned more than one code if several different topics were expressed.

### PSYCHOSOCIAL CONTENT

Of psychosocial content, posts frequently described stressors, offered support for and affirmations of other users, described users' state of mind, and discussed coping strategies. Posts describing stressors represented 9.3% of total posts ( $N=840$ ) and 15.2% of posts with psychosocial content ( $n=515$ ). Participants reported many sources of stress, including from relationships outside the CMB and HIV-related concerns, including disclosure, stigma, and both geographic and social isolation. Many posts expressed more than one stressor and, either explicitly or implicitly, asked the CMB community for advice. It should be noted that posters frequently used abbreviations common in text messages, such as "u" for "you," and additionally used nonstandard grammar, punctuation, and spelling, perhaps consistent with the skew toward lower educational attainment in this sample.

Among coping strategies identified, participants most frequently used the CMB for coping, in 31.6% of total posts and 51.5% of posts with psychosocial content. Participants reached out to the community for help with statements such as "Im so mad and not sure what to do ... Need someone to talk to." Participants also discussed coping methods that had helped them and could help others, which included prayer, music or dance, maintaining positive thinking, and maintaining positive relationships outside the CMB. Non-CMB coping methods were shared in 9.8% of total posts and 16.0% of posts with psychosocial content.

Posts expressing the user's state of mind represented 10.6% of total posts and 17.3% of posts with psychosocial content. Positive posts endorsed optimism, contentment, perseverance, and gratitude. Negative emotions were also shared, including anger, frustration, depression, grief, embarrassment, worry, or anxiety. These negative posts were generally met with encouragement and empathy, such as "I know how u feel ... but one thing I can say there is light at the end of the tunnel." However, some negative posts appeared to be disturbing or disruptive to the community. In particular, posts expressing suicidal thoughts caused tension on the CMB. The PL team reached out privately to participants expressing mental health concerns, including suicidal thoughts, to provide assistance.

## SMARTPHONE-BASED ONLINE SUPPORT GROUP FOR HIV

**Table 1. Characteristics of All Participants, and Comparing Posters Versus Nonposters to the Community Message Board**

CHARACTERISTIC	ALL PARTICIPANTS (N= 38)	POSTERS (N= 24)	NONPOSTERS (N= 14)	p
Age in years: mean (SD)	34 (11.5)	33.5 (11.8)	35 (11.3)	0.680
Gender: n (%)				0.715
Male	23 (74)	17 (61)	11 (69)	
Female	10 (26)	7 (70)	3 (60)	
Race: n (%)				0.035
White, non-Hispanic	16 (44)	5 (38)	8 (62)	
Not white (all other categories)	25 (66)	19 (76)	6 (74)	
Transmission risk: n (%)				0.740
Men who have sex with men (MSM)	21 (55)	14 (67)	7 (93)	
Not MSM	17 (45)	10 (59)	7 (41)	
Religious practices: n (%)				0.611
Religious	16 (42)	9 (56)	7 (44)	
Spiritual	15 (39)	11 (73)	4 (27)	
Neither	7 (19)	9 (57)	3 (49)	
Education: n (%)				1.000
Did not complete 12th grade	7 (18)	5 (71)	2 (29)	
Completed high school	31 (82)	19 (62)	12 (69)	
Insurance: n (%)				0.002
Private	10 (26)	2 (20)	8 (60)	
Does not have private insurance	28 (74)	22 (79)	6 (21)	
Employment status: n (%)				0.168
Employed	15 (39)	7 (47)	8 (53)	
Unemployed	23 (61)	17 (74)	6 (26)	
Poverty: n (%)				1.000
Income below 100% federal poverty level	17 (45)	11 (65)	6 (35)	
Income above 100% federal poverty level	21 (55)	13 (62)	8 (38)	
Food security: n (%)				0.329
High	26 (61)	13 (57)	10 (43)	
Less than high	15 (39)	11 (73)	4 (27)	
Owens a cell phone: n (%)				0.383
Owens a cell phone	32 (84)	19 (59)	13 (41)	
Does not own a cell phone	6 (16)	5 (83)	1 (7)	
Literacy level (WRAT score): mean (SD)	55.8 (8.7)	54.6 (8.1)	57.3 (9.8)	0.462
Perceived stress score: mean (SD)	25.8 (8.9)	25.3 (8.8)	26.9 (9.4)	0.608
Stigma score: mean (SD)	100 (19.8)	99 (20.7)	101 (18.7)	0.7415

continued →

**Table 1. Characteristics of All Participants, and Comparing Posters Versus Nonposters to the Community Message Board** *continued*

CHARACTERISTIC	ALL PARTICIPANTS (N= 38)	POSTERS (N= 24)	NONPOSTERS (N= 14)	p
Enrollment type, n (%)				0.198
Newly diagnosed	10 (26)	8 (80)	2 (20)	
Not newly diagnosed	28 (74)	16 (57)	12 (43)	
CD4 count, n(%)				0.268
Participants with CD4 <200	10 (26)	8 (80)	2 (20)	
Participants with CD4 >200	28 (74)	16 (57)	12 (43)	
Viral load, n (%)				0.043
Suppressed VL (VL <50)	21 (55)	10 (48)	11 (52)	
Unsuppressed VL (VL >50)	17 (45)	14 (82)	3 (18)	

SD, standard deviation; VL, viral load.

**COMMUNITY CHAT CONTENT**

Community chat was defined as content that was not related to psychosocial or medical information or concerns. This category was initially termed “chit-chat” because it contained seemingly superficial content such as comments on the

weather and holidays. However, these interactions appeared to serve a more significant function, as a means of community building, and were renamed “community chat”.

In this category, greetings were most common, found in 8.3% of total posts (N= 840) and 29.1% of posts with community chat content (n=240). Greetings included messages welcoming new members, greetings to individual users, and greetings to the entire group. Participants discussed events in their lives unrelated to HIV in 7.8% of total posts and 27.3% of posts with community chat content. Community chat also included religious or spiritual posts not related to a particular problem or coping strategy, such as “its all good don't forget God loves YOU,” in 1.8% of total posts and 6.3% of posts with community chat content. Participants appeared to regard the CMB as a community, with group-related messages in 6.8% of total posts and 23.8% of posts with community chat content. These messages included such posts as “I don't know if many of you realize it, but each and every one of us who uses this app is making a difference in someone else's life battling every day of this new journey.” One participant suggested a name for the community as the Positive Links Posse (PLP). This was adopted by other members as well, with such as expressions as “PLP 4 LIFE” or “PL Family.”

**Table 2. Odds of Being a Poster (Versus Nonposter) by Participant Characteristics**

CHARACTERISTIC	ODDS RATIO (95% CI)	p
Age	0.99 (0.98-1.05)	0.673
Male gender	0.66 (0.14-3.12)	0.603
White, non-Hispanic	0.20 (0.05-0.84)	0.028
Men who have sex with men (MSM)	1.40 (0.37-5.27)	0.619
Did not complete 12th grade	1.58 (0.26-9.43)	0.617
Private insurance	0.07 (0.01-0.41)	0.003
Employed	0.61 (0.08-4.22)	0.094
Income below 100% federal poverty level	1.13 (0.30-4.26)	0.859
High food security	0.47 (0.12-0.94)	0.298
Literacy level (WRAT score)	0.97 (0.89-1.05)	0.428
Perceived stress score	0.98 (0.91-1.06)	0.590
Stigma score	0.99 (0.96-1.03)	0.740
Newly diagnosed	2.63 (0.54-16.77)	0.211
CD4 Count >200	0.93 (0.08-11.86)	0.211
Unsuppressed VL (VL >50)	5.13 (1.13-23.30)	0.034

WRAT, wide range achievement test.

**BIOMEDICAL CONTENT**

Of biomedical content, most posts discussed medications, 4.1% of total posts (N=840) and 40.5% of posts with biomedical content (n=85). Other frequent topics were seeing a healthcare provider (2.2% of total posts, 21.7% of posts with biomedical content) and laboratory results (1.5% of total posts, 14.8% of posts with biomedical content). Posts on medications were centered on the importance of adherence and support for

## SMARTPHONE-BASED ONLINE SUPPORT GROUP FOR HIV

**Table 3. Community Message Board Content with Categorized Themes, Examples, and Frequencies**

CATEGORY AND DEFINITION	EXAMPLE	FREQUENCY (% OF TOTAL POSTS)
Biomedical Content		10.1
Alternative medicines: describes options of alternative medical treatments or experiences with them.	"All they can do is treat me with acupuncture and injections and medication to help with the pain."	0.1
Laboratories: describes different laboratories or results; can include an individual's initial laboratory results, changes, or current values.	In response to another user's concern about their cd4 count: "I've been fine but when I got emitted to the hosp my cd4 was 8 and my viral was in the mill. Kinda scary but I'm good now."	1.5
Comorbidities: describes a different health problem (outside of HIV) that a user has; it can also describe treatments or visits to a provider regarding the problem. Can include comorbidities related to HIV, such as opportunistic infections or neuralgias.	"...they said that my skull is actually smaller than my brain so they are sending me to a neurologist. I'm still in pain my neck and back still sore hopefully I will get better soon."	1.0
Drug use: discusses how drug(s) might affect user or HIV medication efficacy.	"Is it good to smoke weed on HIV meds or even at all?"	0.4
HIV symptoms: discusses how user experienced initial symptoms of HIV; does not include descriptions of how laboratory results have changed.	Describing time before diagnosis: "My last six months began to make sense. I have lost 120 lbs in two months and found myself getting sicker more than I have ever in my life."	0.4
Medications for HIV/AIDS: includes details of and coherence to treatment plan, initiation of medications, and side effects of medications.	In response to another user asking about side effects of ATRIP/AAV: "I asked the doctor about the side effects to my med and got her to print out all of the info on them. U should do so as well. One needs to know exactly what is possible so they can adjust accordingly."	4.1
Seeing a healthcare provider: discusses appointment (planned or upcoming meeting with care provider) or emergency appointment (going or possible going to emergency department or hospital).	In response to another user discussing headaches: "I hate 2 hear ur not feeling well with a headache...not good if this headache continues go back 2 hospital!!! This is important!!! Keep me posted!!!"	2.2
Sex and protection: discusses sex practices and concerns about transmitting HIV to partners; also includes suggestions and concerns about sex practices.	In response to another user's fear about inserting their partner: "I feel ya. I'll still have sex w/ ur condoms and as long as u and ur partner are comfortable it will get better. My wife and I are very active so talk to ur partner and see how he feels."	0.5
Community chat		28.6
Group-related content: expresses appreciation for the board and community support, as well as interest in meeting other members of the group.	"I don't know if many of you realize it but each and every one of us who uses this app is making a difference in someone else's life battling every day of this new journey... We all are making a difference together... 1 day one app and one click at a time."	6.8
Greetings: participant-to-participant or participant-to-group greetings; also includes personal introductions to group and "welcome" messages to group.	"I just want to say hello. I hope everyone has a good weekend in week. I love ya!!!"	8.3
Miscellaneous: chitchat that is nonspecific, such as jokes and riddles.	"Did u check out the riddle I throw out there."	4.0
Outside events and activities: includes posts about current events, participant hobbies, personal activities, seasons and weather, and holidays.	"Happy Halloween everyone!!!"	7.8
Religious: has religious content that is written in a nonspecific manner or noncoping manner.	"It's all good don't forget God loves YOU."	1.8

continued →

**Table 3. Community Message Board Content with Categorized Themes, Examples, and Frequencies** *continued*

CATEGORY AND DEFINITION	EXAMPLE	FREQUENCY (% OF TOTAL POSTS)
<b>Psychosocial content</b>		61.3
<b>Coping strategies</b>		9.8
Activity-based coping: participant describes their own coping strategy. Includes spirituality; also includes maladaptive behavior, such as violent thinking	"I went out today and did some African drumming... then went on a walk and listened to nothing but some uplifting music. And not one thought crossed my mind."	
Relationships outside of the board: describes how participant uses partners, family, or friends outside of the board for coping	"I was blessed to have [X]. He accepted it from the beginning... but sometimes I question why. Never the less, he stands by my side. I do thank God!"	
Strategies suggested by the Positive Links Team: suggestions from the Positive Links Team that receive participant endorsement	"Just tried the auditory resource when I actually needed it. It seemed to have an even better effect than normal. Please remember them, they do help."	
<b>Coping by using the board</b>		31.6
Coping by using the board: user describes a problem or stressor; can ask for help with the problem	"I'm so mad and not sure what to do... Need someone to talk to."	
Support for another user: community or another user's suggestions on activities for coping or on using outside resources. Can also include compliments or affirmations for the original user	"CONGRATS [X]!! I am happy 4 U!! I have faith that you will move mountains... u go girl!"	
<b>Describing participant's state of mind</b>		10.6
Negative state of mind: describes feelings such as anger, frustration, depression, grief, embarrassment, worry, or anxiety	"Hi community its [X]... Not really feeling in the best mood right now inside I want to cry times over, not easy doing it on my own."	
Positive state of mind: describes feelings such as contentment, optimism, perseverance, gratefulness, or otherwise improved state of being	"I appreciate the welcome... I have full assurance that one day this will be eradicated and people will say I never knew you were HIV positive and my response will be!! It was because I know for me HIV means Heavens in View."	
<b>Stressors</b>		9.3
Drug use: describes relapses, wanting to come off drugs and not feeling able to, or previous drug use that user finds disappointing	"I will told myself one day that I would fall deep... and now I'm falling in relapsing in so many diff way and I can't stop! I would do things for fun now its a habit I can't break and I don't know what to do it sucks."	
Financial and work stress: conveys stress about working, making enough money to pay for expenses, and information about financial expenses	"... thank U [X] trying to stay on my meds but its hard with no food to eat."	
Geographic isolation: describes living away from others or family	"... when I think about my family in Jersey city I get all down... im just a lil homesick u know."	
HIV-related psychosocial stress: describes a user's appointments, how they contracted HIV, disclosure of their status to others or a partner's status to others, feelings about their health status or insurance, and social isolation and stigma	"How can I feel good to talk about my HIV status with my roommate who is also a best friend to me."	
Relationship stress: includes stress resulting from family, friends and roommates, and partners	"Why don't I have a husband that don't do anything but play on his phone he don't can cook nothing im tired of doing it by myself."	

others who might be having difficulty: "Keep your head high, everything will b okay. Just remember your lifeline .... Your Meds!!!!!" One participant who was newly diagnosed reached out to the CMB community with concerns about starting medications. Others responded with encouragement, advice about how to find more information on treatment, and personal stories of success.

In addition to seeking biomedical information from health-care providers, participants asked their questions to the CMB community. Many questions addressed issues of substance use (4.0% of biomedical content) and sexual behavior (4.9% of biomedical content). One participant asked: "Is it good to smoke weed on HIV meds or even at all?" Another inquired about risks of transmission and received advice, such as "I still have sex but I use condoms and as long as u and ur partner are comfortable it will get better." The PL study team also provided posts addressing biomedical questions, if an incomplete or incorrect answer was offered by the community or conflicting opinions were posted.

## Discussion

This study of a CMB within a smartphone app for PLWH revealed several unexpected findings. First, we found that posting behaviors did not vary with gender or age, and posters did not have more illness experience, in contrast to studies of online support groups in other chronic diseases.<sup>8,13,14</sup> In fact, there was a trend toward those newly diagnosed with HIV being more likely to post on the CMB, although this did not reach statistical significance. Participants in this sample who were white, had private insurance, and had suppressed viral loads were significantly less likely to post to the CMB. Second, we found that the CMB contained more psychosocial than biomedical content. Again, this contrasts with published data on other online support groups, in which biomedical content is predominant.

The population targeted in this study has been underrepresented in prior work on online support groups, which have generally focused on well-educated Caucasian groups. This is an ongoing pilot project with a small number of participants, therefore, firm conclusions cannot be drawn. However, our findings suggest that our CMB is being used by participants from racial/ethnic minority groups and lower socioeconomic status, who tend to be disproportionately affected by HIV and are at risk for health disparities. The lower rate of viral suppression among the CMB posters (compared to nonposters) also suggests that the intervention may target those who need it most, that is, those who are at risk for poor clinical outcomes. Furthermore, the app may reach a population with relatively low literacy. Nonstandard spelling and grammar were more

prominent on our CMB than other qualitative studies of online support groups. This may be a function of the mobile medium, in which autocorrect and shorthand tend to be more accepted than other settings. However, an informal style of exchange could encourage participation from those with lower literacy and this will be investigated with participant interviews.

There was much more psychosocial content and community chat than biomedical content on this CMB. Most other studies have identified informational support as the primary content on online forums for chronic illness.<sup>1-5</sup> Possible explanations for this difference might be that participants in our study have other sources of biomedical information (such as their healthcare providers), users are less readily able to look up or share biomedical content on their cell phones, or that an important usage of the app is social interaction with peers. Participants who posted on the CMB expressed support for each other, appreciation for the community, and a perception that the app was playing a positive role in their daily struggles with HIV. Even the community chat content, which did not relate to a specific problem or concern, appeared to serve an important function of support and community building.

Despite the generally positive nature of interactions on the CMB, there are potential dangers. Negative posts could be disruptive to other CMB users or result in the poster not seeking adequate help. Posts with personal identifiers (which were specifically prohibited during the enrollment and app training process, but did rarely occur) might pressure users who wish to remain anonymous. Last, while no misinformation was observed on this CMB, the potential for misinformation must be considered in online forums.<sup>21,22</sup>

This study has several limitations to consider. As there was a small sample size and potential for truncated age ranges or limited variance in other characteristics, we may have been unable to detect some true differences between posters and nonposters. Second, the value of the CMB to "lurkers" (those who read others' posts, but do not contribute their own) was not assessed, although we are conducting interviews with participants that may address this question. Third, the app functions in close coordination with the PL study team and with connections to the participants' HIV care setting. Some potential dangers, such as negative interactions or misinformation, may have been mitigated by the study team, which included licensed clinicians. Monitoring the CMB and reaching out to participants who appeared to need additional help were accomplished by the PL study team and in coordination with the participants' care providers. The functioning of the app and particularly of the CMB would likely be different if delivered through a publicly available app marketplace and without the link to a care setting.

Next steps will include further evaluation of the CMB, such as investigation of support mechanisms and community dynamics, and longitudinal assessment of users and evaluation of outcomes of the PL app and CMB participation. Investigation of barriers to CMB participation may also help adapt the CMB to reach nonposters. The app will be refined, using participant input and additional formative work, and integrated further with the users' clinical care. After this next demonstration project is complete, plans for offering the app to other users or care settings will be pursued.

To our knowledge, this is the first study to examine an online support group delivered through a CMB as part of a smartphone app for PLWH. Results indicate that the CMB may be able to reach a previously understudied vulnerable population. Exploratory analysis reveals a predominance of psychosocial content, possibly indicating that the CMB is meeting a previously unmet need for information and support from peers. Online support groups have the potential to address challenges faced by PLWH, including social isolation, while protecting anonymity. Further development of this smartphone application and its CMB will include investigation of possible benefits in improving social support, linkage and retention in HIV care, and health outcomes for PLWH.

### Acknowledgments

This project was supported by the M.A.C.AIDS Fund and AIDS United. These sponsors had no role in study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

### Author Disclosure Statement

No competing financial interests exist.

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Received: August 26, 2015


Revised: January 5, 2016

Accepted: January 7, 2016





# Social Support in a Virtual Community: Analysis of a Clinic-Affiliated Online Support Group for Persons Living with HIV/AIDS

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**Abstract** Social support can improve outcomes for people living with HIV (PLWH) and could be provided through online support groups. The Positive Links smartphone app is a multicomponent intervention that allows users to interact in a clinic-affiliated anonymous online support group. We investigated how social support was exchanged in a group of 55 participants over 8 months, using an adaptation of the Social Support Behavior Code. Participant interviews assessed their experiences and perceptions of the app. Of 840 posts analyzed, 115 (14 %) were coded as eliciting social support and 433 (52 %) as providing social support. Messages providing support were predominantly emotional (41 %), followed by network (27 %), esteem (24 %), informational (18 %), and instrumental (2 %) support. Participants perceived connection and support as key benefits of the app. Technical issues and interpersonal barriers limited some participants in fully using the app. Mobile technology offers a useful tool to reach populations with barriers to in-person support and may improve care for PLWH.

**Keywords** HIV/AIDS · Online support group · Mobile app · Social support

## Introduction

Despite recent advances in care, many patients continue to face significant challenges in coping with HIV/AIDS. Social support can help to improve outcomes for people living with HIV/AIDS (PLWH) and has been associated with more active coping strategies, improved medication adherence, better immune function, and higher quality of life [1–4]. Perceived social support can improve both physical and mental health for PLWH, through direct and indirect mechanisms, including relief of depressive symptoms [5], which are a common barrier to adherence and retention in care [6]. PLWH are more likely to achieve suppressed viral loads if they perceive informational and emotional support to be available [7]. Informational support refers to the sharing of information or advice, while emotional support refers to the sharing of concern, encouragement, or the expression of caring for others. Social support can also take the form of esteem support (the expression of respect for others or confidence in them), network support (the concept of belonging to a group with similar concerns or experiences), or instrumental support (providing tangible assistance, such as performing a task or willingness to help others in a practical way) [8].

Online support groups may help provide social support and improve psychosocial function for patients coping with illness. Virtual connections may be particularly valuable to patients with barriers to seeking in-person groups, such as geographic or social isolation. In serious, life-threatening diseases such as cancer, patients seek both emotional and informational support online [9–13]. In many chronic

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diseases, informational support tends to dominate online forums [14–16]. However, evidence of benefit is mixed, due to lack of high quality studies and studies that include online support as part of more complex interventions [17, 18].

For PLWH, use of the internet to seek health information and social connection is becoming increasingly common [19–21]. There is growing evidence that online tools using peer-to-peer support can help patients struggling with adherence to antiretroviral therapy (ART) [22], encourage risk reduction [23], and promote patient empowerment and psychological health [24, 25]. Social support in online networks appears to increase with the frequency of contacts between participants [26]. In one prior study of social support within a publically accessible online support group for PLWH, the most frequent types of posted messages were related to information support, followed by emotional, esteem, network support, and tangible assistance [27]. More evidence is needed to guide the development of technological interventions to promote social support for PLWH [28].

The Positive Links project offers a unique opportunity to observe social support mechanisms within a private, clinic-affiliated online support group, with assessment of user and non-user perspectives. The Positive Links smartphone app was developed with the input of patients seeking HIV care at a university clinic and includes the ability for users to interact on a community message board through anonymous user names. In this exploratory analysis, our research questions were (1) How is social support exchanged in a clinic-affiliated online support group for PLWH? (2) How do users and non-users of the online support group perceive its benefits and limitations as a source of support?

## Methods

### Development of the Community Message Board

Positive Links is a Smartphone app developed as part of a multi-component intervention intended to improve linkage and retention in care for PLWH in southwestern Virginia. Key features of the app include tailored educational resources; daily queries of stress, mood and medication adherence; appointment reminders; access to the study team for individualized counseling and assistance; and the opportunity for participants to interact anonymously on a community message board (CMB). Participants selected user names for themselves to protect anonymity, although participant's chosen user names were known to study investigators. This allowed the investigator team to monitor the board regarding posts that reflected mental health concerns, including suicidal content, as well as for

misinformation or inflammatory comments, and to communicate with participants privately, as needed. Positive Links staff members monitored the board daily by reading all posts. If a concern was identified, the staff member referred the issue to a licensed clinician to follow up with the participant and address the issue, for example, offering the participant individualized counseling or case management. The study team was able to link participants' user names to their study identification numbers, in order to facilitate analysis of users' demographic and clinical information. However, participant identities remained private on the board. Under their anonymous user names, participants could start new conversations on the board or respond to older conversations. The Positive Links team also introduced new conversation topics on HIV or general well-being. Participants could receive notifications on their app's main screen letting them know that a new post had been made.

During an iterative formative phase, patients seeking care at the university-based Ryan White HIV Clinic provided input on app design and features. During the current pilot phase of the study, participants were recruited from the clinic and from area AIDS service organizations (ASOs) and HIV testing sites. Eligibility criteria were focused on ability to use the app (either a score of 40 on the Wide Range Achievement Test (WRAT-4) or passing a subsequent reading test) and risk of falling out of HIV care (either HIV diagnosis since January 2012 OR at risk of falling out of care as determined by their care provider). The reading test corresponded to a fourth grade reading level and design of the app was tailored to accommodate low literacy. Providers assessed risk of falling out of care based on their experience with patients' missed appointments, difficulties with adherence, and psychosocial barriers to retention in care. Providers referred patients to the program by contacting the study team, who then made contact with patients to assess eligibility. Participants were given Samsung Galaxy 2 or Galaxy 3 phones with the app installed and a voice/data plan with unlimited minutes, texting, and data for the 18-month study period. Phones were encrypted and password protected and had a remote locate and wipe functionality. The app was also password-secured. The study team continued to refine the app using the feedback of participants. IRB approval was obtained for the study.

### Participant Characteristics

Enrollment for the current phase of the Positive Links study began in September 2013 and was ongoing through the study period. During enrollment, individuals consented to participate in the study, completed the WRAT-4 literacy test, and answered baseline questions. Participants were

then instructed in how to use the phone and Positive Links app. Participant training in using the phone and the app took approximately 10 to 15 min. Participants were not prompted to use the board at any particular time or frequency. They were informed of how to use it at enrollment and had the option to use it if they wished to do so. Participants then completed usability interviews after 3 weeks of enrollment to address any technical difficulties and obtain feedback on use of the app. Overall, participants were followed for 18 months and completed assessments at 6, 12, and 18 months. They received \$25 for completing the 12-month assessment and \$25 for completing the 18-month assessment. They did not receive any compensation for using the community message board. The project budget allowed for recruitment of 75 participants, which was our ultimate enrollment target. Enrollment took place on a rolling basis, with total recruitment of 77 participants achieved over the course of September 2013 to May 2015. This paper concerns our interim analysis performed on data collected up to May 2014. At that time, enrollment included 55 participants. This interim analysis timing was chosen as approximately half-way in the study follow-up period for the earliest enrollees. This time point was far enough into the study so that participants had the opportunity for interactions to occur on the CMB but early enough that changes could be made to the CMB app feature if it did not appear to be functioning as intended. The approach used was consistent with the study principles of following an iterative, user-driven process to optimize the app for participants.

Participants' demographic characteristics included age, gender, race, transmission risk behavior, time since diagnosis, and religious belief. Socio-economic variables included education, insurance status, employment status, and self-reported income. Participants also completed the Wide Range Achievement Test (WRAT-4) to assess literacy [29], the Perceived Stress Scale [30], and the Berger Stigma Scale [31]. Social support was evaluated using the Social Support Appraisals (SS-A) Scale, which has demonstrated good reliability, convergent and divergent validity with other social support measures, and predicted associations with psychological wellbeing [32]. Religious belief was assessed by self-report as an exploratory question of the role of religious belief in coping with HIV. During the formative phase of app development, religious and spiritual themes were frequently cited by clients of the clinic as important aspects of their HIV experience. Stigma was assessed using the Berger Stigma Scale, which has been previously validated and shown to be a possible mediator of engagement in care [31]. Participants were categorized as "newly diagnosed" if they were enrolled in the study less than three months after their HIV diagnosis.

Clinical data were extracted from the electronic medical record.

### Analysis of the Community Message Board

After 8 months, CMB posts were downloaded and analyzed. In order to evaluate social support messages on the CMB, content analysis was performed using the Social Support Behavior Code (SSBC) developed by Cutrona and Suhr [8]. This coding framework categorizes content intended to provide five types of support: information support (information or advice), esteem support (expressing respect or confidence in others), network support (belonging to a group with similar concerns or experiences), emotional support (expressions of concern or empathy), and instrumental support (providing tangible assistance). Subcategories were adapted from coding methods used in prior analyses of social support on a publicly accessible online support group for PLWH [27] and a Facebook group for HIV-infected youth [33]. We added further subcategories during our codebook development to capture additional types of expression that were prominent on the CMB: community companionship (as a subcategory of network support) and prayer (as a subcategory of emotional support). We also adapted coding methods used to assess posts seeking social support in three categories of information, emotional, and instrumental support [34].

Validity of the coding method was enhanced by using a previously established system for categorization of social support (the Social Support Behavior Code) and by expert consensus of the study co-authors on the adaptation of this coding system to our data set. Our expert team included the perspectives of an HIV care physician (RD), a clinical psychologist (KI), and an investigator in public health sciences with expertise in evaluation methods (WC). Team members were part of the Positive Links project and had access to the data. Reliability was assessed by using 2 independent coders (TF and CD) and an iterative process for development of the codebook. Analysis of the codes was performed by a primary analyst (TF) in discussion with a secondary analyst (CD), and presented for further discussion with the expert team (RD, KI, WC) in order to assess the validity of interpretation during the analysis process. This analysis categorized the types of support expressed and examined the context in which support-related posts occurred, focused on the interactions between posts seeking support and subsequent posts providing support in response. Team meetings during the analysis phase included updates on the themes elicited, categorization of themes, and synthesis of findings, as well as resolution of any discrepancies between the primary and secondary analysts. Final results were composed by the primary analyst (TF) and reviewed by all co-authors.

## Analysis of the Participant Interviews

Usability interviews for the participants (both users and non-users of the CMB) were transcribed for analysis. The focus of analysis in this study was to assess perceptions of potential benefits and barriers to the CMB as a source of social support. The interview guide included open-ended questions asking what users liked most about the app, which features they used, what problems they might have experienced, and what suggestions they might have for further improvements to the app. The interviewers explored responses further with clarification questions. The analytic method for the usability interviews used a constant comparisons approach to identify emerging themes from the qualitative data. Relevant themes to this analysis were categorized as perceived benefits of the app, negative aspects of the app, and barriers to using the app. Validity of this coding scheme was assessed by expert consensus, as described above. Reliability was assessed by using two independent coders and an iterative process for development of the codebook.

For both phases of analysis, codebooks were refined until excellent reliability was achieved (kappa 0.90 for social support message coding and kappa 0.84 for interview coding). Analyses were performed using NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012).

## Results

### Participant Characteristics

Table 1 shows demographic and clinical characteristics of the study participants. Among the 55 participants in this analysis, mean age was 39 years (SD 11.68). Thirty-seven participants were male (67 %), seventeen were female (31 %), and 1 transgender male to female (2 %). Twenty-seven participants identified as black, non-Hispanic (49 %), 18 as white, non-Hispanic (33 %), 5 as multiple/other races (9 %), 4 as Hispanic (7 %), and 1 as Asian (2 %). Many participants were unemployed (45 %) and did not have insurance (35 %). Most participants identified themselves as religious (38 %) or spiritual (47 %). Thirty-three participants (60 %) had unsuppressed viral loads. At baseline, participants had unmet needs for social support, with mean scores of 43.51 (SD 12.38) on the Social Support Appraisal (SS-A) questionnaire [32]. This instrument measures perception of support received from family, friends, and others with a standardized scale up to a maximum score of 100. For comparison, mean scores have been reported in studies of alcohol dependence, ranging

from 37.7 to 64.7 among patients categorized as having low social support [35].

### Frequency of Posting on the Community Message Board

Of the 55 participants in this analysis, 24 posted on the board at least once. Due to rolling enrollment, participants were in the study for varying durations at the time of the 8-month interim analysis. Posters had been in the study for a mean of 23 weeks, ranging from 8 to 34 weeks. Posting frequency fluctuated over time, with the highest numbers of posts during the 28th week (71 posts, primarily among 3 users with 11, 19, and 21 posts each) and the lowest number of posts during the first 3 weeks of the study (0–2 posts). Total posts declined after the peak of 28 weeks, but use continued with 5–10 posts per week from week 30 onward. The number of posts per user per week was calculated, in order to account for the changing denominator of total users over time. On average, users posted 1.3 times per week, with a median of 0.5. The 3 highest utilizers posted on average 3.8, 4.8, and 5.1 times per week.

### Social Support on the Community Message Board

Of the 840 messages on the CMB, 115 (14 %) were coded as eliciting social support and 433 (52 %) as providing social support. Table 2 presents each category of social support messages, with definitions, examples, and frequency of occurrence. Participants' use of abbreviations and non-standard spelling and grammar has been retained in quoted messages.

Messages seeking social support were predominantly related to emotional support (74 % of messages seeking support; 10 % of total messages). These included posts asking for encouragement, comfort, congratulations, praise, empathy, concerns, or gratitude. Posts seeking information support were less common (26 % of messages seeking support; 4 % of total messages) and included posts asking for medical or health-related advice, guidance, or news. There were no posts classified as seeking instrumental support, though a small number of posts (1 % of total messages) did offer to provide instrumental support in response to messages that were primarily emotional in nature.

Messages providing social support were predominantly focused on emotional support (41 % of messages providing support; 21 % of total messages). Of subcategories of emotional support, the most common were encouragement (51 % of messages providing emotional support), expressions of care (41 %), and prayer (38 %). The subcategory of prayer was added during codebook development to

**Table 1** Characteristics of participants

Characteristic	All participants (n = 55)
Age in years: Mean (SD)	39 (11.68)
Gender (n[%])	
Male	37 (0.67)
Female	17 (0.31)
Transgender Male to Female	1 (0.02)
Race (n [%])	
Black, non-Hispanic	27 (0.49)
White, non-Hispanic	18 (0.33)
Multiple/Other	5 (0.09)
Hispanic	4 (0.07)
Asian	1 (0.02)
Education (n[%])	
Did not complete 12th grade	9 (0.16)
Completed high school	46 (0.84)
Sexual orientation (n[%])	
Has sex with men	39 (0.71)
Has sex with women	9 (0.16)
Has sex with both men and women	6 (0.16)
Declined to answer	1 (0.02)
Transmission risk (n[%])	
Men who have sex with men (MSM)	27 (0.49)
IV Drug User (IDU)	2 (0.04)
Not MSM (Includes heterosexual, Transgender)	26 (0.47)
Insurance (n[%])	
Public	24 (0.44)
Private	12 (0.22)
None	19 (0.35)
Employment status (n[%])	
Employed	30 (0.55)
Unemployed	25 (0.45)
Poverty: Mean % of federal poverty level (SD)	60.05 (78.79)
Religious practices (n[%])	
Spiritual	26 (0.47)
Religious	21 (0.38)
Neither	8 (0.15)
CD4 Count (n[%])	
Participants with CD4 < 200	13 (0.24)
Participants with CD4 > 200	42 (0.76)
Viral Load (n[%])	
Suppressed VL (VL < 50)	22 (0.40)
Unsuppressed VL (VL > 50)	33 (0.60)
Enrollment type (n[%])	
Newly diagnosed	13 (0.24)
Not newly diagnosed	42 (0.76)
Owns a cell phone (n[%])	
Owns a cell phone	43 (0.78)
Does not own a cell phone	12 (0.22)
Literacy level (Wrat Score): Mean (SD)	55 (9.25)
Perceived Stress Score: Mean (SD)	28.49 (9.16)
Social Support Score: Mean (SD)	43.51 (12.38)
Stigma Score: Mean (SD)	101.53 (17.97)

**Table 2** Types of social support sought and provided on community message board, with definitions, examples, and frequencies

Support category	Definition	Example	Number of posts	% of total posts
Seeking support (n = 115)				
A. Emotional support	Post asks for encouragement, comfort, congratulations, praises, empathy, concerns, or gratitude	"How can I feel good to talk about my HIV status with my roommate who is also a best friend to me"	85	10.12
B. Informational support	Post asks for information on a particular subject, including medical or health-related advice, guidance, news, or findings	"Me to do u ever feel like u gain wait on it and do u ever think differently on it" (About a medication)	30	3.57
C. Instrumental support	Post asks for tangible aid		0	0
Providing support (n = 433)				
A. Emotional support (communicating love, concern, empathy)	Provides the recipient with hope, optimism, and confidence	"We are all blessed and can show the ENTIRE world that even though they may consider us to be less that we are stronger and even in better health than they are..."	178	21.19
Encouragement		"Thank you [X] hope all is well with you and just know that you have a friend in me"	90	10.71
Expression of care	Conveys supporter's engagement of recipient's wellbeing	"I thank the lord for another day healthy... I pray that you continue to bless... other people who deal with the same thing I do. I pray that you continue to give us the strenght to fight and get healthy again in Jesus name I pray AMEN..."	73	8.69
Prayer	Offers prayer or blessings for the recipient, reminders of faith	"[X] I'd b untruthful if I told you that I understand bc I don't but I could only speculate what's like 2 do this without someone to hold..."	68	8.10
Empathy	Expressions of understanding the situation and/or discloses similar experience in a way that conveys understanding	"We are here for you! *hugs**"	27	3.21
Virtual affection	Physical affection expressed (but virtual)	"Hey [X]... it will make you feel better to talk to someone close to you. I had to do the same it was hard but once I got it out I felt better"	8	0.95
Sympathy	Conveys sorrow for the recipient's distress		6	0.71
Confidentiality	Keeps the recipient's problem in confidence		0	0
B. Network support (communicating belonging to a group of persons with similar concerns or experiences)				
Community companionship	Indicates community's unique position to share experiences, importance of community closeness, and gratitude for community support.	"I remember when I first came on to the site [X] told me some things that actually helped me tremendously. And to this day I still think her everyday"	115	13.69
Presence	Presence of listeners and reminders that others are available to offer support	"ENJOY YOUR NIGHT MY FRIEND, IM ONE CLICK AWAY..."	71	8.45
Access	Messages that appeared to broaden recipient's social network by establishing access to new members; "welcome" messages	"[X] here welcome to the fam"	52	6.19
C. Esteem support (gives positive feedback, communicating respect and confidence in abilities)				
Compliment	Conveys positive assessments of the recipient and his or her abilities	"[X] that sounds like a great idea"	19	2.26
Validation	Acknowledges agreement or emphasizes similar views with recipient	"Ameen brother. We have HIV. It doesnt have us" (in response to another user's posting)	77	9.17
			57	6.79
			25	2.98

Table 2 continued

Support category	Definition	Example	Number of posts	% of total posts
Relief of blame	Conveys that a particular action is not the fault or complete fault of the recipient		0	0
D. Informational support (gives information on a particular subject, including medical or health-related advice, guidance, news, or findings)			55	6.55
Advice	Suggestions or guidance for coping with difficulties associated with HIV or AIDS	"[X] they have churches that helps with food check out sum churches in ur area because its very important that you stay on trac with ur meds"	21	2.50
Situation appraisal	Reassesses or redefines a situation, often in a way that makes it more positive or shows new information that could be helpful	"...that's right [X] and believe it or not it could b worst..."	17	2.02
Sharing own experience	Conveys experience in a way that demonstrates specific knowledge of particular condition, such as changes in CD4 count or viral load	"[X], my cd4 was also very low, didn't find out I was hiv positive until a month ago. I was the walkingdead, still working and didn't know why I was so tired..."	12	1.43
Referrals to experts	Includes directing the member to a specific source, community resource, or website	"I asked the doctor about the zside effects to my med and got her to print out all the imfo on them. U should do so as well"	8	0.95
Teaching	Includes feedback that gives information or facts about the disease		0	0
E. Instrumental support (provides or offers to provide performance of a task, goods, or services directly related to the stress)			8	0.95
Active participation	Offers to join the recipient in an activity; includes concrete plans or planning to do something together	"[X] Hay bro hiking sounds awesome... Lets get something started for a Spring outing..."	5	0.60
Perform a task	Member actually performs an action on behalf of the recipient or the group	"1-800-555-5555 this numer is for those who need help. I talked with her. Please call if you need help"	2	0.24
Express willingness	Expressing willingness to help recipient	"if you think I can help you then please let me know how I can help"	1	0.12
Loan	Member loans money or object to another member		0	0

capture the prominence of spiritual expressions of support on the CMB.

Network support was offered in 27 % of messages providing support (14 % of total messages). These messages included posts establishing access (such as welcome messages to new members) and posts affirming the presence of community members available to listen and help. The subcategory of community companionship (62 % of messages providing network support; 8 % of total messages) was added during codebook development to include posts demonstrating the community's unique position to share experiences, the importance of community closeness, and gratitude for community support. The original subcategory of "relationship" under emotional support was incorporated into "community companionship" due to significant overlap between these concepts in the CMB posts. An example of this was observed in the evolution of a community identity, referred to by participants as the "Positive Links Posse" (PLP) or "Positive Links family".

Esteem support (24 % of messages providing support; 9 % of total messages) included posts giving positive feedback or communicating respect and confidence in other participants' abilities. Most of these were compliments, followed by validation. The subcategory of relief of blame was included in the codebook, as part of the categorization scheme used in other studies of social support, but no messages of this type were posted on the CMB.

Informational support was offered in 18 % of messages providing support (9 % of total messages). Most of these were advice, situational appraisal, or sharing of experience. A few posts did include referral to experts, such as directing others to seek input from their clinicians or staff at local support organizations. None were classified as teaching posts.

For each message coded as seeking support, an average of three responses was posted in reply from other participants providing support. For example, one exchange among participants began with a post seeking emotional support: "times are not easy doing it on my own I try to smile to hide my pain sometimes it's not that easy it's easy to just want to give up." Within a few minutes, other participants responded with multiple forms of support, including encouragement, prayer, virtual affection, empathy and expression of care, for example: "Its okay cry, just remember that god loves you & so do I, hugs I KNOW your day will get better"; "I know how u feel I but one thing I can say there is light at the end of the tunnel but all ur troubles on god shoulders and he will get u through trust me I know". The first participant followed up with more detail on struggles with adherence and meeting basic needs: "trying to stay on my meds but it-s hard with no food to eat". Others responded with additional emotional support, such as "When u feel u feel like this burden is to

much to bare and u feel there is no hope say a silent prayer god does not gives us wat we cant handle we all have come along way and givin up is not a choice so stay strong keep the faith and lets continue to fight we will overcome our struggles", and informational support with advice, such as "they have churches that helps with food check out sum churches in ur area because its very important that u stay on track with ur meds".

### Participant Perceptions of the Community Message Board

All study participants completed usability interviews 3 weeks after enrollment, even if they did not post on the CMB or use other app features. Of the 55 participants, 51 (93 %) reported a benefit from the app, 50 (91 %) described a potential barrier to using the app, and 24 (44 %) reported a negative aspect of using the app. Table 3 shows categories of benefits, barriers, and negative aspects. Participants could mention more than one category, which were not mutually exclusive, so frequencies may add up to more than 100 %.

In their interviews, 64 % of participants cited connecting with others and 42 % cited support as a benefit of the app. Connection was defined as expressions of user's ability to connect with others going through a similar experience or increased feelings of universality. Support was defined as expressions of giving, receiving, and observing others give or receive support.

In discussing the perception of connection, one participant said: "Like if I need someone to talk to, I can talk to someone, like someone is there, right there". Another said: "getting to see other people's perspective on life, let me know that I'm not going through this by myself, there is other people out there like me, it's good". One participant described difficulty in communicating with counselors, stating that "I don't feel connected to them only because they can guess at the situation but without them actually living the situation it's hard for them to really understand what's going on", whereas other users of the app could directly share the experience of living with HIV. This participant also reported that "I have a hard time expressing myself vocally anyway so it's always better that I can type out something have them type back". Making connections with others electronically appeared to be particularly important for those who had trouble doing so in person.

When asked what they liked most about the app, one participant said: "If I'm having a bad day, I can get on there and vent or whatever and then like it's real people that actually reply to my post and stuff and reply to how I'm feeling making me feel better...it's good to have somebody to talk to, even if it's just a text it's good to have



**Table 3** Types of impact reported by participants, with definitions and frequencies

Categories of impact	Definition	Number of people (n, %)
<b>Benefits</b>		
Self-monitoring	Describes benefit from ability to monitor mood and stress; describes increased self-awareness after monitoring	41 (74.55)
Keeping track of meds	Describes being more capable of keeping track of meds daily, finds that app supports adherence that was already good, or feels improved adherence to treatment regimen as a result of the app	39 (70.91)
Privacy	Feels that app is very secure and private and safe to have on a phone	35 (63.64)
Connecting with others	Likes ability to connect with others going through a similar experience; user has experienced increased feelings of universality	35 (63.64)
Connecting to the clinic	Benefits from appointment reminders, has improved engagement in HIV care, feels more connected to the clinic, benefits from the phone numbers for clinic being readily available	34 (61.82)
Easy to use	Reports that the application and/or the phone is easy to use	32 (58.18)
Benefits of phone	Reports using the phone for a variety of purposes in addition to the app	32 (58.18)
Resources	Reports learning from posted resources on the app, including resources on the CMB	26 (47.27)
Support	Benefits in giving, receiving, and seeing others give/receive support	23 (41.82)
Positive outlook	Develops more positive outlook as a result of the program	16 (29.09)
Experiences	Reports learning from the experience of other participants	9 (16.36)
Improved outside interactions	Describes that the application helps them better interact with people that do not have HIV, their partners, or people outside of the app	7 (12.73)
Fun	Describes that app can be entertaining, mentally stimulating, and/or fun	6 (10.91)
Goals	Reports liking the goal setting feature or having more success because goal-setting feature	3 (5.45)
Improved self-care	Reports improved self-care, outside of medication adherence; for example, user reports eating better or exercising more	2 (3.64)
Writing	Reports they find it easier to express self through writing or texting than they do vocally, and the app enables them to do so	2 (3.64)
<b>Negative aspects</b>		
Feelings of obligation	Describes feeling “forced” or obligated to use the app	10 (18.18)
Complaining	Discusses how CMB posts can seem to have a lot of complaining	9 (16.36)
Suicidal posts	Describes negative impacts of suicidal posts	5 (9.09)
Outsider	Describes disappointment with not receiving responses to posts	5 (9.09)
Vulgarity	Describes discomfort with vulgarity, poor language, or taboo topics on CMB	1 (1.81)
Too personal	Describes feeling uncomfortable with amount of personal information posted	1 (1.81)
Religiosity	Describes feeling uncomfortable with the level of religiosity on the CMB	1 (1.81)
<b>Barriers</b>		
Technical problems with application	Describes problems with application, such as difficulty navigating between screens, difficulty following conversations on CMB, having to scroll through screens, clearing notifications, appearance of newsfeed vs substance of message. They might also describe lack of awareness, such as not knowing about particular features	36 (65.45)
Phone problems	Describes difficulty with things related to the actual phone, like battery life or texting	24 (43.64)
Privacy concerns	Describes user concerns about privacy	12 (21.82)
Time constraints	Describes that user doesn’t have time to participate or review features of the app	10 (18.18)
Personal readiness	Describes a feeling of having no limitations except themselves, for example not feeling personally ready to discuss their HIV, not yet ready to interact on the application, or that they are in the process of “getting comfortable”	7 (12.73)
Communication rules	Describes limitations in participation on the CMB due to defined “cliques” within the CMB or unclear communication etiquette	7 (12.73)
No immediate feedback	Expresses frustration with lack of immediacy in feedback	3 (5.45)
Own phone	Describes that having two phones makes the Positive Links phone seem redundant	3 (5.45)
Other users	Describes knowing another user personally and feeling uncomfortable interacting with them	2 (3.64)
Participation	Describes being frustrated with lower levels of participation of other users	2 (3.64)

Table 3 continued

Categories of impact	Definition	Number of people (n, %)
Forced anonymity	Describes wishing being able to talk directly with others or in person	2 (3.64)
Potential loss	Describes the potential of lost relationships once the study has been completed	1 (1.81)

somebody there that supports you.” Others expressed similar sentiments, such as: “You get to talk to people who are going through exactly what you are going through. When you are down somebody uplifts you, when somebody else is down you can uplift them, it’s basically like one big family.” In addition to receiving support, participants appreciated the opportunity of providing support for others. One expressed this concept by saying: “Yeah it’s very beneficial to everybody and me personally what helps me is helping others so if I can help somebody that helps me 10 times.” Another said: “you try and uplift someone else cuz they might be having a down day so I really look for all the positive things”.

Reading other users’ posts also provided a sense of support. One participant said: “I mean I may not post like all the time but most of the time I see what everybody is saying and I can relate”. Another expressed that “reading some of the things that the other people post really has opened my eyes that I’m not alone when there have been times when I have felt that I’m sort of in this darker box and alone”. Observing other participants helping each other was “very uplifting to see other people reach out to people they don’t know and literally lift them up and that shows that we are like all in this together”.

Participants were also asked about possible negative aspects of the app during their interviews. Some users felt that by participating in the study, they felt obligated to use the app, making it feel like a job (18 %). Although interactions on the CMB were predominantly positive, some participants did have concerns about posts perceived as too negative or “complaining” (16 %). The study team monitoring the CMB reached out to participants privately regarding posts that reflected mental health concerns, including suicidal content. Some users cited suicidal posts as having negative impacts on themselves, as participants reading the posts (9 %). Participants sometimes perceived some posts as “attacking” other users (9 %) or “too personal” in the content that was shared (2 %). Others felt like “outsiders” in the community (9 %) or felt excluded by the religious content on the CMB (2 %).

Some participants encountered barriers to using the app. The most commonly cited were technical problems with the app (65 %) and technical problems with the phone itself (44 %). Other concerns included privacy (21 %) and personal time constraints (18 %). Some participants

reported they did not feel personally ready to discuss topics on the CMB, even though it would be anonymously (13 %). Some participants reported not using the CMB due to concerns about communication etiquette within the community (13 %). Another potential barrier was the avoidance of forming connections due to concern of future loss of the community at the study’s conclusion (2 %). One participant said: “Well since I really haven’t posted yet, it really hasn’t affected me but I have thought you if you start posting if you start to build a friendship with some of these people, there is no way of knowing who they are even after the program is over”. The anonymity of the CMB was perceived as a benefit in ensuring privacy, but some users desired to meet in person and expressed frustration that this was not possible.

## Discussion

People living with HIV sought social support from and provided social support to their peers through a clinic-affiliated smartphone app with a community message board. Our findings suggest that online support groups on a smartphone can reach PLWH and help them engage in self-management and community building beyond their clinic visits. Strengths of this study include the use of 2 independent coders to enhance reliability of the qualitative analysis and complementing the content analysis with participant interviews, which have not been possible in prior studies of online social support for PLWH [27, 33]. In addition, our intervention targeted PLWH in the rural southern U.S., predominantly of racial/ethnic minorities and socioeconomic disadvantage, who bear a disproportionate burden of HIV and barriers to favorable clinical outcomes [36–38]. Positive Links shows promise in helping to address many of these barriers, including geographic and social isolation, and fostering social support as a means to improve mental and physical health for PLWH.

In our study, emotional support was the most commonly requested and provided form of social support observed. In contrast, a publicly accessible online support group for PLWH was dominated by information support [27]. On a private Facebook group affiliated with an HIV clinic’s young adult program, the most commonly requested type of support was emotional, while the most commonly given

was esteem support [33]. The relatively low proportion of information support exchanged on our CMB may indicate that participants relied on other sources besides their peers for information. Although the sharing of misinformation is a potential risk of online support groups, this was not observed. The involvement of the Positive Links study team may also mitigate this risk, as the team routinely monitored board content and could answer questions or clarify biomedical information.

Some subcategories of social support seen in other studies were not found on our CMB, such as posts seeking instrumental support [33] or posts providing teaching or relief of blame [27]. Subcategories were added to our coding scheme, which were prominent on our CMB but not in prior studies. In particular, community companionship and prayer were surprisingly important to many of our participants. On the CMB, participants appeared to value the community as a group united by shared experiences and referred to the group as the “Positive Links family” or “Positive Links Posse”. Although prayer was not universal to all participants, those who did seek and provide spiritual encouragement were able to support each other. In our sample, most patients identified themselves as religious or spiritual. This likely reflects the demographics and culture of our clinic population in the rural southern United States, which differs from the predominantly urban populations of prior studies of social support among PLWH. Many African-American PLWH in the southern United States report unmet needs for social support from faith communities [39] and may seek this support from more informal connections with peers who are also PLWH. However, it should be noted that religious content on the CMB was perceived as a barrier to some users, who felt excluded rather than supported by it.

Participants perceived connection and support as important benefits of the app. In particular, the CMB allowed people who previously felt alone to find others who could share their experiences. Participants’ comments about support primarily focused on emotional support, expressing appreciation for the empathy, sympathy, encouragement, and care communicated on the CMB. Network support was also perceived by participants, especially the importance of community companionship. The community felt like a “family” who cared about each other and were present to help. Even those who did not post on the CMB perceived benefit from observing others giving and receiving support in the community. This aspect of the CMB was not visible in the posts themselves but became clear in the usability interviews. Similarly, the value of providing support to others emerged from the interviews, as participants expressed a sense of fulfillment and more positive outlook from their ability to help others in the community.

However, negative interactions on the CMB also occurred and may undermine the potential benefits. Most interactions were positive, but some posts were perceived as complaining too much, attacking others, sharing too much information, or excluding those who did not feel like a part of the group. Barriers to participation were also reported, which may prevent full utilization of the CMB. Technical issues were the majority of barriers discussed, but personal barriers were perceived as well. In particular, some participants may be reluctant to form connections through the CMB, without the ability to meet in person or maintain the community beyond the study period.

This study has several limitations to consider. The project is in a pilot phase with a relatively small sample size. Also, the project remains ongoing, with rolling enrollment since the CMB and interview data were captured for this analysis. The app continues its iterative development process with changes made based on participant feedback in order to optimize its function and usability. With rolling enrollment and changing features of the board, not all users had equivalent amounts of time as a participant in the study. Additionally, various features to improve usability were added as a result of the ongoing development process, making comparison between users challenging. Some participants did not use the board and some within the board posted more frequently than others. Further analysis of patterns of use is planned, for the board and other app features, to delineate how participants interact with the app and with the community over time and to determine if certain patterns of use are more beneficial than others. Finally, the app is affiliated with the clinic and monitored by the study team, which may limit generalizability to other populations or contexts. Generalizability may also be limited by the fact that the phones and data plans were provided to participants with the cost supported by grant funding. Next steps for this project include development of plans for adapting the app for installation on users’ own phones (if they already possess one) and subsidies for phones and service (if needed) in order to make the app accessible to more users. A full cost-effectiveness analysis is also planned at the conclusion of follow-up. This paper presents an interim analysis, for which detailed cost data and longitudinal clinical outcomes are not yet available. These analyses are pending and expected to provide further information on the efficacy of the program and considerations for implementation and dissemination at other sites.

The Positive Links app offers an innovative way to address needs for social support among PLWH. Patients with barriers to accessing in-person support may particularly benefit from the ability to form virtual communities, in which they can seek and provide support to others with shared experiences. Next steps include further longitudinal

follow-up to assess clinical outcomes in participants and implementation of the app in other populations for reproducibility and optimization. Ultimately, the use of technology to connect people and offer social support may be a valuable tool in improving quality of life and outcomes for PLWH.

**Funding** This project was supported by the M.A.C.AIDS Fund and AIDS United. These sponsors had no role in study design; in the collection, analysis and interpretation of data; in the writing of the report; or in the decision to submit the article for publication. There is no associated grant number.

#### Compliance with Ethical Standards

**Conflicts of interest** None of the authors declare any conflicts of interest.

**Ethical approval** All procedures performed in this study that involved human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All participants in this study provided informed consent prior to entering the study.

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PositiveLinks Data Elements

Report Type	Member Activity	Provider Activity	System Activity	Member Achievements	Appointment Data	Clinical Data
Data Elements	PositiveLinks Webportal	PositiveLinks Webportal	PositiveLinks Webportal	PositiveLinks Webportal	EMR: Chart Review	EMR: Chart Review
	Overall Response Rate	Number of Dashboards Viewed	Number of Member Users	Days as a PL Member	Appointment Adherence Rate	CD4 values
	Medication Adherence Rate	System Logins	Number of Sessions	Number of App Logins	Missed Appointments	Viral Load values
	Average Mood	Messages Sent	Number of Screen Views by App Feature	Number of Quizzes Answered	Visit Constancy	
	Average Stress	Number of Messages Received		100% reported Medication Adherence Rate for four consecutive weeks	HRSA-1	
	Number of Community Message Board Posts			Number of Community Message Board Posts		
	Number of App Launches					
	Number of Quiz Responses					
	Number of Messages Sent					

