Development of PositiveLinks:
A Smart Phone Application to Promote Linkage to Care for People with HIV

Colleen Laurence MD MPH¹, Erin Wispelwey MSC¹, Tabor E. Flickinger MD MPH¹,
Marika Grabowski MPH¹, Ava Lena Waldman MHS CHES CCRP¹, Erin Plews-Ogan
BA¹, Claire Debolt MD¹, George Reynolds BA², Wendy Cohn PhD³, Karen Ingersoll
PhD⁴, and Rebecca Dillingham MD MPH¹

University of Virginia School of Medicine Department of Medicine, Charlottesville VA¹
Health Decision Technologies, Oakland CA²
University of Virginia Department of Public Health Sciences, Charlottesville VA³
University of Virginia School of Medicine Department of Psychiatry and
Neurobehavioral Sciences, Charlottesville VA⁴

Corresponding Author: Dr. Dillingham

UVA Center for Global Health
P.O. Box 801379
Charlottesville, VA 22908
Phone: 434-982-0103
Fax: 434-924-0075
Email: rd8v@virginia.edu
Abstract

Background: Linkage to and retention in HIV care are challenging, especially in the Southeastern United States. The rise in smartphone application (app) use and the potential for an app to deliver ‘just in time’ messaging provides a new opportunity to improve linkage and retention among people living with HIV (PLWH).

Objective: We aimed to develop an app to engage, link and retain people in care. We evaluated the acceptability, feasibility, and impact of the app among users.

Methods: App development was informed by principles of chronic disease self-management and formative interviews with PLWH. Once developed, the app was distributed to participants, and usability feedback was incorporated in subsequent iterations. We interviewed app users after 3 weeks to identify usability issues, need for training on the phone or app, and to assess acceptability. We tracked and analyzed usage of app features for the cohort over 2 years.

Results: Seventy-seven participants used the app during the pilot study. Query response rate for the first 2 years was 47.7%. Query response declined at a rate of 0.67% per month. The community message board was the most popular feature, and 77.9% of users posted on the board at least once during the 2 years.

Conclusions: The PositiveLinks app was feasible and acceptable among non-urban PLWH. High participation on the community message board suggests that social support from peers is important for people recently diagnosed with or returning to care for HIV.

Key Words: mHealth, HIV treatment cascade, linkage to care, retention in care, adherence
Introduction

HIV treatment has markedly improved in the United States over the last 20 years, and morbidity and mortality have declined as a result. Although effective treatments are available, not everyone with HIV consistently accesses care. Estimates suggest that of the 1.1 million people living with HIV (PLWH) in the U.S., 85% are diagnosed, 62% are linked to medical care, and 49% maintain a non-detectable viral load [1]. These gaps in the cascade of HIV treatment are related to poorer clinical outcomes. Patients who “no-show” at visits within the first two years of initiating care fail to achieve virologic suppression as quickly as those who keep all appointments [2-4]. Delayed linkage to care, missed visits, and poor retention are associated with increased morbidity and mortality for PLWH and increase the risk of new infections [5-7]. Racial and ethnic disparities remain an issue in HIV care in the United States, where black and Latino patients have lower rates of retention in care and viral suppression than white patients [8, 9].

Interventions to improve linkage to and retention in HIV care use several strategies to help clients navigate health care systems. These include education, transportation, assistance in attending appointments, counseling services, co-located ancillary services, visual tools to convey welcoming and positive messages, peers as part of the health care team, and brief messages from health care providers to encourage engagement [1, 10-16]. High initial contact and enhanced personal contact improve visit constancy and adherence and reduce the likelihood of a substantial gap in HIV primary care during the first 12 months of follow-up [17, 18]. Frequent contact with new patients may help reduce the perceived stigma of HIV and structural barriers to health care [17-19]. Strengths-based case management can also aid patients in recognizing their own abilities to access resources and solve problems leading to decreased perceptions of
Unmet needs remain a barrier to care and impact regional health disparities. In the United States, the HIV epidemic has shifted away from concentrated urban centers to non-urban areas in the southeast [22, 23]. Factors prevalent in this region and disproportionately affecting HIV prevention efforts—as well as linkage and access to health care—including poor health infrastructure, lack of health insurance, unique demographic and racial characteristics, high rates of other sexually transmitted infections, poverty, and low access to affordable housing [24-26]. While people living in the U.S. South are harder to reach for engagement and linkage to care, they may be most in need of tailored linkage services. In addition, social support can be more difficult to access in rural areas. PLWH with perceived social support have improved physical and mental health and are more likely to achieve viral suppression than those without social support [27, 28].

Mobile health interventions (mHealth) provide a platform that can efficiently deliver evidence-based practices for linkage to and retention in care to harder-to-reach populations. With 75-77% of U.S. adults owning smartphones and African-American and Hispanic populations increasingly relying on smartphones for internet access, mHealth has the opportunity to reach diverse populations [29, 30]. Mobile technology is particularly well-suited to deliver Ecological Momentary Assessments (EMAs) and Interventions, which reach people in their everyday lives and natural settings, in "real time" [31]. Such interventions have been feasible, acceptable, and efficacious in a variety of chronic disease management and health promotion contexts, such as diabetes care and smoking cessation [32]. Text messaging interventions can promote health behavior change, treatment adherence, appointment attendance, and better patient outcomes in
many chronic diseases [33-35]. In HIV care, text messaging interventions have
demonstrated improved medication adherence and improved physiologic measures of
CD4 counts and viral loads [36-43].

mHealth interventions that are based on smartphone applications (apps) have
some advantages over texting, such as richer functionality and enhanced security.
However, many health apps currently available are not rigorously evidence-based [44],
including those targeting PLWH [45, 46]. Recent research on mHealth interventions
places emphasis on user-centered and theory-based design to tailor apps to users’
motivations and preferences and to understand device usability [47, 48]. Timing
messages to correspond to medication dose, individual tailoring of message content or
user-based personalization, and sending messages with content designed to evoke a reply
from recipients (bi-directional) may lead to better outcomes due to enhanced engagement
[38]. Formative work, related to mHealth and eHealth interventions, has shown that
PLWH seek reliable information about HIV and other health topics, connection with
other PLWH, assistance with medication and appointment reminders, and tools for self-
management [49-52]. Other desirable mHealth features include attractive, private, and
individualized design, goal setting, motivational messages, wording that would not
inadvertently reveal HIV status, password protection and other security measures,
interaction with other participants, and the ability to customize reminders [53]. In
addition, technology that can address mental health and emotional needs is particularly
important to PLWH [54]. Interventions that provide access to online peer-to-peer support
can improve psychological health and empowerment for PLWH and may help address
issues of loneliness and stigma [55-57].
Despite the growing evidence for mHealth interventions for PLWH, many gaps remain. In particular, there is a need for (1) more evidence-based and user-centered design; (2) interventions that target hard-to-reach and vulnerable populations; (3) attention to linkage and retention in care; and (4) provision of connection to others while being private and secure [47, 58-61]. To address these needs, our team has designed and piloted a mHealth intervention for PLWH called PositiveLinks. To our knowledge, PositiveLinks is unique in specifically targeting linkage and retention in care for PLWH and in reaching a non-urban population in the southern U.S. The purpose of this paper is to describe the development and initial testing phases of PositiveLinks with evaluation of usability, feasibility, and acceptability in a clinic population.

Methods

Expert Development Phase

The primary goal of PositiveLinks is to improve linkage and retention in HIV care. The intervention aims to accomplish this goal by encouraging self-monitoring of medication adherence, stress, and mood; by providing access to vetted medical information about HIV/AIDS; and by increasing social support. The development was informed by our team’s prior work on text-based mobile interventions, which demonstrated that PLWH respond to bidirectional queries and value tailored messaging to their responses [62, 63]. The team also used the emerging mHealth evidence base as well as commonly identified needs among our patient population to design the first version of the app. Key features were designed to promote chronic disease self-management through self-regulation and feedback, just-in-time assistance, and social support. EMAs of medication dosing, mood, and stress, and appointment reminders targeted possible behavioral and psychological barriers to care. With access to patient-reported
information, PositiveLinks staff members could respond in nearly real time to threats to medication adherence and retention in care. In order to motivate participants to use the app regularly, we included engaging features such as weekly quiz questions and a community message board. The latter also functions to reinforce social support by peers.

Formative Phase
Seventeen patients from the University of Virginia Ryan White Clinic provided feedback on the design, desirability, usability, usefulness, and fit in everyday life of app features for non-urban PLWH users. We sought the perspectives of both those recently diagnosed with HIV and those who had been living with HIV for many years to capture varying perceptions of the needs, barriers to engagement, and challenges to medication adherence. Interview questions covered three main themes—the story of their HIV diagnosis, initial linkage to medical care, and current phone and Internet use (including any experiences with multi-media or community groups developed for PLWH and use of apps or social media not directly related to HIV). Participants also provided input on app features that might help someone newly diagnosed with HIV.
Feedback was elicited with open-ended questions first, followed by a review of preliminary app screenshots. Interviewers explained the features to the participants who commented on design, content, usability, and desirability or need of each feature.

Interviews with participants were audiotaped and transcribed. The transcriptions were summarized in notes by three reviewers and key themes were identified. Technical feedback and insights from open-ended questions were sorted by feature and
disseminated to the app developer to integrate user input about features and content. After developing the app prototype following the analysis of patient input, we finalized the initial app to be deployed and tested. It included daily queries, a dashboard that displayed self-reported query data, a community message board, and various resources such as HIV-related information and stress management tools (Figure 1).

**App Features: Queries and Dashboard**

The medication query offered a simple yes-no option, while the mood and stress queries used sliding scales with numbers and different images to facilitate accurate, consistent reporting. Participants recorded their mood using a sliding scale from -5 to +5, with -5 representing a negative mood and +5, a positive mood. The stress query used a scale of 1-10, with 1 representing a low stress level and 10, a high stress level. The mood and stress queries, designed as EMAs, were sent at random times during patient identified waking hours and asked participants to report their feelings in the moment. In contrast, participants scheduled when they wished to receive medication reminders to match their own dosing schedule. Participants received weekly quizzes in addition to the medication and mental health queries. The weekly quizzes were structured so that some questions had correct answers, some were survey based, and others offered participants the opportunity to reflect their thoughts or feelings.

After responding to a query, users received an automatic response. PositiveLinks uses an algorithm to determine this tailored message based on participants’ reported stress, mood, or medication adherence. For example, if a participant logged an especially high stress level, they might receive the message, “Remember to breathe deeply.” Participants could modify this message text to better suit their interests and motivations.

The dashboard section of the app synthesized participant responses to medication,
Participants received weekly summary reports each Wednesday, which were developed in response to user feedback to help with interpretation of the graphs. These reports detailed participants’ medication adherence, average mood, and average stress level for the previous week, their individual change from the prior week’s averages, and their query response rates. Each summary invited participants to reflect on their adherence, mood, and stress and to reach out to the PositiveLinks team if they would like to discuss their health and wellness goals. Collectively, the mood and stress EMAs, medication reminder, and dashboard features sought to encourage healthy self-monitoring.
and care management.

**App Features: Community Message Board**

The community message board allowed users to share and interact with other PositiveLinks app users in a private and anonymized social network. Each participant chose a community handle to protect their anonymity. Participants could start new conversations with each other on the board or respond to older conversations in a thread. The PositiveLinks study team monitored the board for incorrect information or concerning comments. Concerning comments could include suicidal or homicidal ideation and sharing of personal identifying information. The PositiveLinks coordinators followed up individually with participants if there was an indication on the community message board that additional support was needed. The PositiveLinks team also introduced new conversation topics on HIV or general wellbeing every Monday (Messaging Mondays) and posted funny videos every Friday (Funny Friday).

**Pilot Phase**

Enrollment for the pilot phase began in September 2013 and ended in May 2015. Participants were recruited through provider referrals at our local university-based Ryan White Clinic, from area AIDS service organizations, and through an emergency department HIV testing program at the local university hospital. Participants were either newly diagnosed with HIV (within 90 days of enrollment) or were at risk of falling out of care, as determined by their care provider. Participation was limited to those who achieved a score of 40 or above on the Wide Range Achievement Test (WRAT-4) [64] or passed a subsequent reading test corresponding to an approximately fourth grade level. 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
PositiveLinks app. Participants received either a Samsung Galaxy 2 or Galaxy 3 phone with unlimited minutes, texts, and data for the study year. Before distributing to participants, the PositiveLinks team encrypted and password-protected the phones and installed a remote locate-and-wipe functionality. The app was also password protected.

This analysis draws from several complementary data sources to assess the usability and acceptability of the app. Quantitative data were gathered from tracking app usage and participant questionnaires. Qualitative data were gathered from the community message board posts and participant interviews. Data collection occurred concurrently with app implementation and allowed for ongoing user-driven iterative design of the app. Analyses presented here were completed after the pilot study ended.

**Participant Characteristics**

At enrollment, participants completed baseline assessments of self-reported demographic information (age, sex, race/ethnicity), socio-economic data (employment, education, insurance status), distance from clinic, and prior cellphone ownership. HIV-specific information included treatment with antiretroviral therapy and self-reported adherence. Mental health measures included substance use, perceived stress [65], HIV-related stigma [66], and social support [67]. The study team collected viral load from the electronic medical records at baseline for each participant.

**App Usage**

Response rates and values for the three daily query types—medication, mood, and stress—were calculated monthly for the whole cohort from September 29, 2013 to September 26, 2015. Response rates for the weekly quizzes were also analyzed. Posts per month to the community message board during this time period was also assessed. These monthly data were then used to calculate the percent of posters to the board, average
number of posts per enrolled participant, and average number of posts per poster. We
determined average participation on the board each month using the number of posts each
month divided by the average number of participants enrolled in PositiveLinks at that
time.

In addition to queries and community message board measures, the PositiveLinks
team tracked cohort usage of individual app pages. Google Analytics allowed us to assess
the number of screen views for each app feature each month. Screen views data helps us
to understand which features are most popular with the participants. Looking specifically
at the community message board, this data also provided an indication of the degree of
“lurking” on the board (participants who visited the board without posting). We
summarized screen views data by month and divided by the average number of enrolled
participants in that month.

User Perceptions of the App

To capture participants’ initial impressions of the phone and PositiveLinks app,
study coordinators contacted participants three weeks after enrollment to conduct
usability interviews. In these interviews, the team assessed ease, utility, and attractiveness
of the app and elicited feedback on what the participant would change. Coordinators
conducted these semi-structured interviews on the phone and in-person. Audio files of the
interviews were loaded into a database and summary notes shared with the team. These
interviews also provided coordinators with the opportunity to answer any questions that
participants might have or troubleshoot technical issues early in their participation.
Coordinators also interviewed participants six months after enrollment to re-assess a
subset of the baseline questions and to ask about user perceptions of the community
message board.
**Results**

**Formative Phase**

Seventeen participants completed formative interviews. Some participants were familiar with smartphones and apps while others were more technologically naïve. The demographic characteristics of participants were similar to the demographics of the clinic’s patient population. Participants had mean age of 43.7 years (SD 15.3). Fifty-nine percent were male, 35% female, and 6% transgender male to female. Fifty-three percent identified as African-American, 35% as white, and 6% as Hispanic.

In their interviews, formative participants offered feedback on the dashboard and daily queries and noted their desire to annotate query responses, so that they could document triggers, aids, or explanations for entries. For example, one stated that he “would probably leave notes if my mood was low, especially if they’re retrievable so that I could bring them in to talk to my provider.” Other participants appreciated the opportunity to add notes to their medication reminders for the same reason, “you can explain why you didn’t [take] or forgot to log your medication.” Formative participants also welcomed the idea of the community message board and emphasized the importance of the anonymity as well as the accessibility of the support in a phone. Others wanted the message board to discuss and interpret recent news or research about HIV.

**Pilot Phase**

**Participant Characteristics**

Seventy-seven participants enrolled in the PositiveLinks pilot study between September 25, 2013 and May 28, 2015 (Table 1). Participants were predominantly male (64%, 49) with a median age of 33 (Range 18-57). Forty-nine percent of participants identified as black, non-Hispanic, and 34% identified as white, non-Hispanic. A majority of participants (65%, 50) had a high school equivalent education or lower, and 30%
attended some college, community college or more. At baseline, 44% (34) of participants were unemployed and only 25% (19) were employed full time. Forty-three percent (33) had public insurance, and 30% (23) had no insurance. At enrollment, 73% (56) owned a cell phone, and 66% (37) of those currently owning cellphones had smartphones.

Participants had been diagnosed with HIV for an average of 60 months at the time of enrollment (Median: 1.7 years, SD: 6.3 years), and 47% (36) were virally suppressed (<200 copies/ml). Of the 55 participants on antiretroviral medication at baseline, 16% (9) reported missing a dose that past weekend. Half of participants reported using non-injection drugs in the past 12 months (38), but very few reported injection drug use in the last 12 months (6.5%, 5). Nearly half, 47% (36), reported binge drinking in the past 12 months (4 drinks in a sitting for women and 5 drinks for men). Most participants (87%, 67) reported experiencing moderate or high stress and HIV-related stigma and moderate levels of social support.

Table 1. Participant characteristics for the pilot phase

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean in years (SD)</td>
<td>36 (11.7)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>49 (63.6)</td>
</tr>
<tr>
<td>Female</td>
<td>26 (33.8)</td>
</tr>
<tr>
<td>Transgender Male-to-Female</td>
<td>2 (2.6)</td>
</tr>
<tr>
<td>Race/Ethnicity, n (%)</td>
<td></td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>38 (49.4)</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>26 (33.8)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6 (7.8)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (7.8)</td>
</tr>
<tr>
<td>Refused</td>
<td>1 (1.3)</td>
</tr>
<tr>
<td>Education Completed, n (%)</td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>15 (19.5)</td>
</tr>
<tr>
<td>GED or High School Graduate</td>
<td>35 (45.5)</td>
</tr>
<tr>
<td>Trade/Technical Training or Community College</td>
<td>6 (7.8)</td>
</tr>
<tr>
<td>Some College</td>
<td>15 (19.5)</td>
</tr>
<tr>
<td>College Graduate</td>
<td>6 (7.8)</td>
</tr>
<tr>
<td>Employment, n (%)</td>
<td></td>
</tr>
<tr>
<td>Employment Status</td>
<td>Count (Percentage)</td>
</tr>
<tr>
<td>------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Full time</td>
<td>19 (24.7)</td>
</tr>
<tr>
<td>Part time</td>
<td>10 (13.0)</td>
</tr>
<tr>
<td>Disabled</td>
<td>9 (11.7)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>34 (44.2)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (6.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insurance</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public (Medicare or Medicaid)</td>
<td>33 (42.9)</td>
</tr>
<tr>
<td>Private</td>
<td>16 (20.8)</td>
</tr>
<tr>
<td>None</td>
<td>23 (29.8)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (6.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Percentage of Federal Poverty Level</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>34 (44.2)</td>
</tr>
<tr>
<td>1-100</td>
<td>23 (29.9)</td>
</tr>
<tr>
<td>101-200</td>
<td>16 (20.8)</td>
</tr>
<tr>
<td>201-300</td>
<td>3 (3.9)</td>
</tr>
<tr>
<td>Over 300</td>
<td>1 (1.3)</td>
</tr>
</tbody>
</table>

WRAT Literacy Score, mean (SD): 55 (9.1)

**Mobile Phone Exposure**

<table>
<thead>
<tr>
<th>Ownership Status</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own a cellphone at Baseline</td>
<td>56 (72.7)</td>
</tr>
</tbody>
</table>
| If yes, is it a smartphone?  
  Android          | 27 (73.0) |
| iPhone           | 9 (24.3) |

**HIV Health**

<table>
<thead>
<tr>
<th>Medication Status</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently taking antiretroviral medication</td>
<td>55 (71.4)</td>
</tr>
<tr>
<td>If yes, missed doses past weekend?</td>
<td>9 (16.4)</td>
</tr>
</tbody>
</table>

Viral Load Suppression (<200 copies/ml), n (%): 36 (46.8)

**Substance Use**

<table>
<thead>
<tr>
<th>Substance Use</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Past 12 months – Non Injection Drug Use</td>
<td>38 (49.4)</td>
</tr>
<tr>
<td>Past 12 months- Injection Drug use</td>
<td>5 (6.5)</td>
</tr>
<tr>
<td>Smoke Cigarettes at present</td>
<td>42 (54.5)</td>
</tr>
<tr>
<td>Last time you binge drank</td>
<td>17 (22.1)</td>
</tr>
<tr>
<td>Never</td>
<td>36 (46.8)</td>
</tr>
<tr>
<td>In the past year</td>
<td>24 (31.2)</td>
</tr>
</tbody>
</table>

**Mental Health**

Perceived Stress Score, mean (SD) (PSS10, range 0-40): 30 (8.8)

Berger Stigma Scale, n (%)

<table>
<thead>
<tr>
<th>Stigma Level</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Stigma (41-80)</td>
<td>10 (13.0)</td>
</tr>
<tr>
<td>Moderate Stigma (81-120)</td>
<td>56 (72.7)</td>
</tr>
<tr>
<td>High Stigma (121-160)</td>
<td>11 (14.3)</td>
</tr>
</tbody>
</table>

Social Support Appraisal, mean (SD) (SS-A, range 23-71): 48 (29.2)

**App Usage**

In the first 2 years of the pilot study 101,609 queries were sent to participants
through the PositiveLinks app. Participants responded to 48% (48,454) of all queries sent. Response rates for the individual query types were all within 1% of each other (Table 2).

Medication adherence, excluding non-responses, was reported as 94% (14,837 affirmative responses) during this 2 year pilot. Average participant mood was 1.49 (SD: 2.95) and average stress was 2.95 (SD: 2.36).

Table 2. Descriptive statistics of app usage over the first 2 years of the pilot study

<table>
<thead>
<tr>
<th>App Usage by Feature</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Total queries:</strong> 101,609</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total query responses, n (%)</td>
<td>48,454 (47.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Medication queries:</strong> 32,701</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication responses, n (%)</td>
<td>15,825 (58.4)</td>
<td></td>
</tr>
<tr>
<td>Medication responses w/notes, n (%)</td>
<td>503 (3.2)</td>
<td></td>
</tr>
<tr>
<td>Affirmative responses, n (%)</td>
<td>14,837 (93.8)</td>
<td></td>
</tr>
<tr>
<td>Negative responses, n (%)</td>
<td>988 (6.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Mood queries:</strong> 32,304</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood responses, n (%)</td>
<td>15,346 (47.5)</td>
<td></td>
</tr>
<tr>
<td>Mood responses w/notes, n (%)</td>
<td>578 (3.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Stress queries:</strong> 32,193</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress responses, n (%)</td>
<td>15,286 (47.5)</td>
<td></td>
</tr>
<tr>
<td>Stress responses w/notes, n (%)</td>
<td>562 (3.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Quizzes:</strong> 4,411</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quiz responses, n (%)</td>
<td>1,997 (45.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Total community message board posts:</strong> 2,073</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unique posters, n (%)</td>
<td>60 (77.9)</td>
<td></td>
</tr>
<tr>
<td>Monthly posts per enrolled member, mean (SD)</td>
<td>2.2 (1.7)</td>
<td></td>
</tr>
<tr>
<td>Monthly posts per poster, mean (SD)</td>
<td>5.0 (2.7)</td>
<td></td>
</tr>
</tbody>
</table>

Participants used the notes feature on their medication, mood, and stress queries only 3.4% of the times they responded to questions (1,643 notes). Notes included in their medication responses included explanations like “Almost missed it because of meetings” or encouragement, “Every morning like washing my face!” or “Always!!! They r my lifeline.” For stress query notes, participants referenced certain stressors like rent, landlords, disclosure of status, and taking their meds. Notes included in mood responses covered a broad spectrum of emotion and depth - from short, celebratory notes (“Getting
my GED,” “My hubby is coming home”) to more reflective comments. A week after learning of his HIV diagnosis, a newly-diagnosed participant wrote, “Feeling normal. At least for the meantime. Still a worried about so much but having a new phone is making the blow a little lighter ¶”.

The PositiveLinks community message board was a widely-used app feature (2,073 posts in 2 years), though participation varied over time and by user. Sixty participants (78%) posted on the board at least once and many participants noted in usability interviews that they followed the message board even if they never posted

![Graph 3a](image)

**Figure 3.** Graphs of cohort engagement over the first 2 years of the pilot study: a. monthly query response rates; b. community board usage per enrolled member.
themselves. Average community message board posts per enrolled member was 2.2 per month (SD: 1.7) while average posts per poster was 5 per month (SD: 2.7).

Participants’ app engagement declined slightly over time during the first 2 years of the pilot study. Query response rates declined at an average rate of 0.67% each month. For the first 6 months of the pilot study, the cohort response rate was 55.7% (SD: 14.1); however, this rate decreased to 41% (SD: 6.6) in the last 6 months. We also analyzed the number of community message board posts per enrolled member each month and noted large variation over time. Community message board usage peaked at 6.9 posts per enrolled member per month during month 4 of the pilot study and decreased at an average rate of 0.15 posts per enrolled member per month (Figure 3). Graphs are summarized in 4 week intervals (28 days) rather than traditional months.

Google Analytics was used to show the frequency with which participants visit different parts of the app. Screen views data, assessed for the first 2 years of the pilot, are listed in Table 3. After logging into the app, which accounted for 53.4% of screen views (36,952), the community message board and its related screens were the most frequently viewed screens, accounting for 12,534 screen views (18.1%). The dashboard and its related screens that allowed participants to look at their medication adherence, mood, and stress over time garnered 7,347 (10.6%) hits (Figure 4). Total screen views per enrolled member declined at a rate of 7.9 views per month in the first 2 years.

Table 3: Total cohort screen views for the first 2 years of the pilot study

<table>
<thead>
<tr>
<th>Screen Name</th>
<th>2 year screen views, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logins</td>
<td>36,952 (53.4)</td>
</tr>
<tr>
<td>Community message board</td>
<td>12,534 (18.1)</td>
</tr>
<tr>
<td>Dashboard</td>
<td>7,347 (10.6)</td>
</tr>
<tr>
<td>Appointments</td>
<td>3,934 (5.7)</td>
</tr>
<tr>
<td>Resources</td>
<td>3,630 (5.2)</td>
</tr>
<tr>
<td>Contacts</td>
<td>2,404 (3.5)</td>
</tr>
</tbody>
</table>
Queries and Dashboard

In the usability interviews, participants shared their perceptions of the EMA queries. Participants reported that tracking mood and stress provided an opportunity to reflect on sources of variability (either positive or negative) and, potentially, to modify them. The dashboard, in particular, allowed participants to visualize trends over time and consider possible explanations for these trends. As one participant observed, “when I
have high stress levels I can go back and look and reflect on what I coulda done different that day and you know what was I dealing with at that moment.” Many participants used the app’s medication query as a reminder and as motivation to take medications. One participant stated, “after a while you get tired of taking pills and stuff but it just like a nice reminder…it's been encouraging me to or reminding me that I need to take better care of myself.”

*Community Message Board*

The community message board fostered lively discussions. Conversational topics and themes on the board range from seeking medical advice, seeking support, giving support, and chit chat [68, 69]. Although most of the messages on the community message board were positive, there were rare times when participants posted suicidal ideations or had negative interactions with other participants. These adverse events were mitigated through responses by the PositiveLinks coordinators and clinic staff; however, they did influence the experiences of other posters and app users not involved in the events. In usability interviews, participants shared that the community message board connected them to people going through similar situations and provided a sense of not being alone. For example, “You know 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.”

The community message board has also encouraged participants to believe that relationships remain a possibility for PLWH. After reading others’ posts about their relationships on the community message board, one participant said “I’ve sort of thrown that out the window since I’ve been positive but it’s opened my eyes a little bit.” Even those who did not post but only read others’ posts reported benefiting from the
community message board. For example: “I was reading it yesterday when someone new had joined and I was thinking I should introduce myself and get out there … I don’t think I’ve felt comfortable doing it yet, I read it every time. I still have the alert on when someone posts and I still read it.”

Some participants expressed frustration about not being able to meet other members in person while others appreciated the anonymity. As one participant said, “I have a hard time expressing myself vocally anyway so it’s always better that I can type out something have them type back.” There was a reciprocal relationship on the community message board between giving and receiving support. For many participants, the community felt like having a family who understood them, “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.”

Connection to Care

Participants reported that using the app made them feel more connected to HIV care and more motivated to be consistently in care. One stated, “I feel closer, I feel like I’m more involved.” Those who were new to care or returning after a lapse could use the app to overcome barriers to care, such as social isolation and lack of knowledge about HIV care. For example, “It makes me more aware and…has opened my eyes that I’m not alone” and “I know more I guess…just know what to expect.” The app also provided practical assistance in setting reminders about appointments. For example, “I like going into the app, it helps me make sure that I’m doing what I need to do and keeping track of my medications and I actually used it to remind myself that I had the appointment today because I would have totally forgotten.”
User-driven Iteration of App Development

Participant usability interviews and feedback, as well as app data, helped the research team further develop and iterate the app throughout the pilot study. The queries and dashboard remained mostly in their initial format. However, weekly summary reports and monthly response raffles were added in response to usage and feedback patterns. The weekly reports sought to prompt reflection about adherence while the raffle incentivized consistent self-monitoring. The monthly raffle included participants with 100% response rates across medication, mood, and stress queries, and a randomly selected qualifying participant was awarded a $50 gift certificate. The winner and all participants included in the raffle were acknowledged (by their anonymous handle) on the community message board.

The community message board also evolved in its design and content in response to user feedback. Initially, participants received a push notification with part of the newly-posted message any time there was a new post on the community message board. Later, as more users enrolled and community message board participation increased, the notifications screen became crowded with messages and participants had to scroll down to see their own medication, mood, and stress queries. In response to this, the notifications screen was split so that queries and weekly summaries appeared at the top, and community message board posts were in a separate feed at the bottom (Figure 5) and users were given the option to turn off push messages from the community message board.
Conversations and questions on the community message board also allowed...
PositiveLinks team members to begin relevant discussion topics. In usability interviews, participants expressed a desire for more conversation on what was going on with HIV in the news. In responding to these needs, the team introduced conversations such as how the Affordable Care Act may change insurance for HIV care and other current events relevant to HIV. When participants expressed confusion about the biology of HIV in community message board posts and in response to quiz questions, the PositiveLinks team posted information to help address these issues. The team also addressed participants’ expressed needs with general health posts such as how to deal with stress or how to respond to others with empathy. The app allowed us to deliver these messages with links to short videos or articles on the internet in a way that lower-tech options do not. The resources feature of the app was updated throughout the study based on topics of interest to the participants. This further highlights the ability to offer a “just in time” dynamic intervention to participants through this mHealth platform.

Discussion

Sustained usage of the many PositiveLinks features over 2 years and positive feedback in usability interviews indicate that this type of application is both feasible and acceptable. Its evidence-based design was informed by self-management principles of: self-regulation and feedback, just-in-time assistance, and social support. Furthermore, its development process has been iterative and enriched by the input of the users themselves, in order to create an app customized to their preferences. This app may fill an important need in a non-urban community in the Southern U.S., where PLWH are at risk for poor clinical outcomes due to a disproportionate burden of low health literacy, low socio-economic status, and social and geographic isolation, affecting their ability to attend appointments and access medications [22-26]. PositiveLinks capitalizes on smartphones’
increasing popularity and accessibility by using a mobile platform to reach our
globally dispersed population of PLWH.
PositiveLinks builds on prior work supporting the use of mHealth interventions to
encourage self-monitoring and medication adherence for PLWH [70-74]. Our
development process drew from formative work exploring needs and preferences for app
design in other populations of PLWH [50-53], while also seeking our target users’ input
to customize PositiveLinks for them. Drawing on previous studies that demonstrated
improved HIV medication adherence with messaging matched to dosage time [38], the
PositiveLinks app allowed participants to customize their medication query timing so that
it could function as a reminder to take their medications. By contrast, the mood and stress
queries were EMAs, sent at random times each day [31]. For each query type, users could
customize the push messages that they received in response to their replies.
The most popular feature of the PositiveLinks app, as measured by screen views,
was the community message board. The usability interviews and prior analysis of
community message board content [68, 69] indicated the board fulfilled a desire to
receive information and social support. In contrast to publicly available online support
groups [56, 57], the community message board was accessible only through the private
secure app and was monitored by the PositiveLinks study team. This approach may
mitigate potential disadvantages of online interaction, such as misinformation.
Some features of the app were not used as consistently as expected. While
formative participants requested granular, customizable control into the PositiveLinks
app, such features as goal-setting and note-taking were not widely used. For participants’
query responses, only 3.4% included notes. Other mHealth interventions for PLWH have
also found low uptake of data summary and feedback features even though participants
understood their value [53]. In contrast, the dashboard display of query responses was the
second most visited feature on the app after the community message board, accounting for 11% of total screen views. Routinely recording medication adherence, mood, and stress is one mechanism for reinforcing behavior change and reflection, though it is difficult to assess in this study whether the effect of recording these data was further reinforced by subsequent review. Some participants did report perceived benefit from the dashboards. Further evaluation and adaptation is planned for future iterations of the PositiveLinks app, incorporating more formal use of design science and usability measures that have been validated since PositiveLinks’ initial development was conducted [75, 76].

The PositiveLinks study was unusual among mHealth interventions by following participants for an extended period of time allowing for more accurate assessment of user fatigue [33]. We noted a gradual decline in app usage over time, however 45% of participants to at least one daily query during the last month of the 2 year pilot. For those participants’ whose usage declined, possible reasons include habituation or fatigue from daily queries, as has been observed in text-based interventions [38]. It is also possible that the app serves different functions for users over time, with more frequent feedback being more helpful early on or during a time of crisis. The optimal “dosage” of mHealth interventions to achieve effective self-management remains to be established. The monthly raffle provided some incentive for query responses. Financial reward for reporting can reinforce desired behaviors and be acceptable to PLWH [59], but too much reliance on incentives may not be feasible in scaling up mHealth interventions in the future.

In addition to encouraging self-monitoring, the queries also helped identify users having difficulty with medication adherence, mood, or stress. The EMAs offered an
opportunity for study team members to reach out to participants with “just-in-time”
assistance when they were struggling with medication adherence or coping with stressors.
Previous studies have noted that patients are interested in this kind of data sharing,
although they also express reservations about the security of the information and
concerns about negative reactions from providers to data [53]. In formative and usability
interviews conducted with our participants, individuals did not share the same concerns
and, in general, appreciated the role of the EMAs as a potential safety net. The
community message board also identifies users who may need just-in-time help (such as
a mental health crisis), with opportunities for the team to reach out to them. Next steps in
PositiveLinks app development include sharing participants’ query data with their HIV
clinicians and mental health providers to facilitate care in between clinic visits.

The iterative, user-driven approach to development has enhanced PositiveLinks’
usability and acceptability by allowing improvements in response to users' perceptions
and experiences. It is not possible to respond to all user feedback, but efforts were made
by the study team to accommodate suggestions that were feasible and consistent with the
goals of the PositiveLinks project. From a research standpoint, it can be challenging to
analyze app usage data when the app changes along the way, with further refinement of
features and functions. However, study participants reported that having a voice in the
app development was empowering and helped them to identify with the app, as part of
the "PositiveLinks Family".

This study has several limitations to consider. Technical difficulties including
cracked screens, service interruption, and slow connections interfered with use of the app.
Security and concern for participants' privacy required incorporation of mandatory
password protection, encryption, and remote wipe capabilities for lost phones. Additional
staff efforts were made to preserve anonymity on the community message board, particularly when participants expressed interest in meeting in person or sharing more personal information. For some participants, these additional security features to access the app created a barrier to use. Even with these measures, the risk of compromised identity and HIV status may not be entirely eliminated.

The observed differences in app use (with some participants not using the app or not using certain features) suggest that the app does not meet the needs of all participants equally. Individuals who owned a phone at enrollment were less likely to use the app, as it was only accessible on a secondary device, the study phone. Investigation into improving the app's accessibility on participants’ phones is needed. While analysis of screen views allows for increased understanding of preferred app features, this data does include screen views by the PositiveLinks study team, and those views cannot be removed.

Potential challenges in scaling up the app will also need to be considered. This deployment of PositiveLinks required funding to procure and maintain phones, data plans, and staff time. A determination of whether provision of smartphones and data plans is essential to usability and acceptability is also needed. It must also be noted that this pilot was conducted at a single HIV care site and may not be generalizable to other settings.

In conclusion, this report on the development of PositiveLinks demonstrates that patient-centered iterative design and testing yielded an appealing mHealth intervention for an at-risk group of PLWH. Participants used the app, contributed to its design, and perceived it as beneficial in their coping with HIV. In the pilot phase, the PositiveLinks app features permitted self-monitoring and personalized feedback, provided just-in-time assistance, and facilitated access to social support, all of which are important elements of
chronic disease management. Further investigation is needed to delineate which features of this multi-component mHealth intervention are most effective. The next iteration of PositiveLinks will incorporate additional features desired by participants, including sharing query responses and messaging with their care providers in the clinic. Expansion to other sites and populations is also planned.
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Conflicts of Interest
The authors have no conflicts of interest to declare.

Abbreviations
EMA: Ecological momentary assessment
PLWH: People living with HIV
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