

From concept to implementation: the story of PositiveLinks mhealth intervention for HIV Karen Ingersoll Ph.D., ABPP,

Professor of Psychiatry & Neurobehavioral Sciences, University of Virginia

Adherence 2023 · June 11-13 · Puerto Rico



The challenge in HIV care

- Inadequate retention in HIV Care is common and must be improved to meet revised EHE targets:
 - 95% of people know they have HIV
 - 95% of those remain in care
 - 95% achieve viral suppression
- Our clinic served over 50 counties, mostly rural, in Central and Northwest Virginia
 - Many patients said they knew nobody else with HIV

2010-12: addressing medication adherence: STEM

- Cellular phones had very basic functionality
- STEM was partially automated; required staff actions

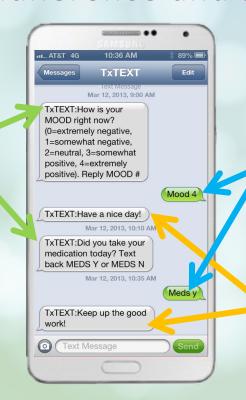


 "Yeah, it did everything leading up to my decision to get back involved in my life. Take my meds on time, stop drinking, stop using drugs, be more accountable. It did everything because I'm like, 'that #\$%^%\$# phone gonna blow up (ring)' 'cause I know it's getting ready to, you know?"

2012-14 Automated text messaging for HIV medication adherence and substance use: TxText

- Web interface allowed staff to set timing for med reminders/ queries and input patient-designed messages
- Fully automated system queried mood, substance use, med adherence daily using a code for SU: How were the skies? Clear, rainy, cloudy, snowy, other

Step 1: System sends automatic EMA queries for mood twice/day and medications at time of dosing



Step 2: Patient responds with keyword and answer

Step 3: Patientdesigned responses automatically sent by system System sent patientdesigned personalized messages based on responses:

- Keep your head up
- God loves you
- Don't forget your grandchildren
- Great job!
- You need to clear it up
- Stay smiling
- Be more responsible
- Keep up the good work
- Yay!

#ADHERENCE2023

TxText Pilot Outcomes/Participant reactions

STRONG USAGE:

Patients responded to 68% of Medication, 64% of Mood, and 66% of Substance Use queries over 12 weeks. **IMPACT ON ADHERENCE:** Controlling for baseline, Pharmacy Refill Adherence improved by 12.2% from baseline to 3M in TxText vs. control (p=.04)

Minor improvements on RIC or DRUG USE; ns

"It feels good that I can actually talk to someone every day about it. Even if it's a machine, its feels great to know that there's someone there to affirm to me that this is a good and right thing. "congratulations" sounds good, you know?"

"It gave me more positive feelings about myself that I've done something good that day for me. Having somebody at your back is a positive thing."

Ingersoll et al., JSAT. 2014; Ingersoll et al., Health Psychology, 2015.





 Consumer demand Better studied Rich media Phones are cheaper Community features possible Phone screens more durable Security & privacy features Cost per message on some plans Can send more messages without added cost Limited 1:1 communication

Theoretical bases of PositiveLinks

ARTAS model:

- 1. Linkage relationship
- 2. Focus on strengths
- 3. Facilitation of goals
- 4. Patient-driven

IMB model:

- 1. Care Information
- 2. Quizzes/prizes and HIV Education
- 3. Self monitoring over time

Social Action Theory:

- 1. Self-change processes
- 2. Contextual influences
- 3. Action States: Self control, problem solving



Platform Development Strategy

Boost connection to Clinic Team

Self-monitor mood, stress, medication as cues for action Shrink the distance for rural/distant patients

Participatory humancentered design Improve engagement in care

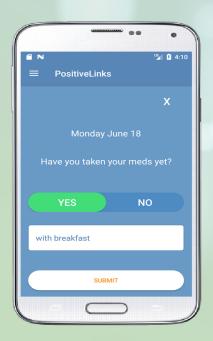
PL App Components

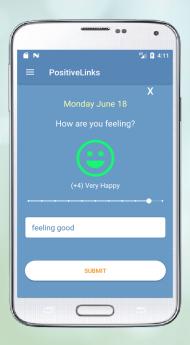
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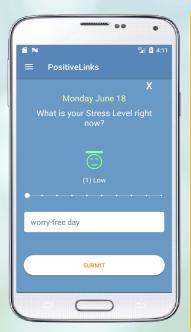
- Self monitoring for self management
- Care coordination/easy connection
- Social support with peers with HIV
- Educational resources
- Platform Security:
 - Access via app stores is "invitation code only"
 - Password protection with Biometric sign-in option
 - Automatic Log-out with disuse
 - Requires anonymity on secure community board
 - No personally identifying information stored



Self-monitoring Check-Ins







"The questions make me focus on my mood and my stress and makes me more in touch with myself you can say. When it pops up, it makes me stop and think. I usually don't think about that kind of thing."

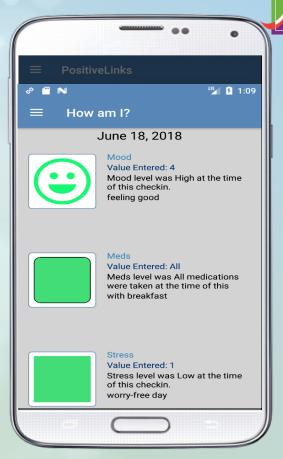
- PL Participant

PositiveLinks ଟ ଟ ଟ 🖱 N ITE 5 12:39 How am I? June, 2018 \odot **(** \odot 13 15 16 **((** (E) 21 22 23 17 19 20 \odot \odot \odot 24 25 26 27 28 29 <u>(</u> **(** Stress Mood Meds

How am I?

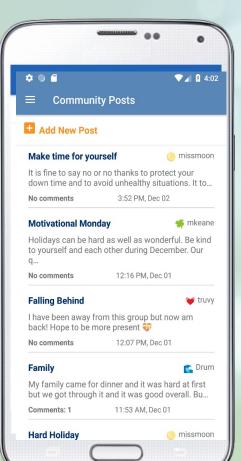


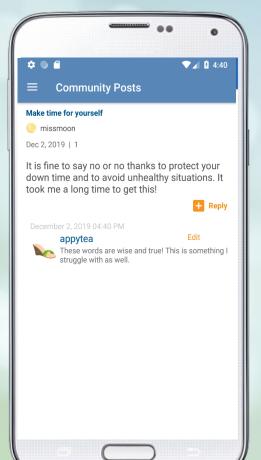
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Community Board





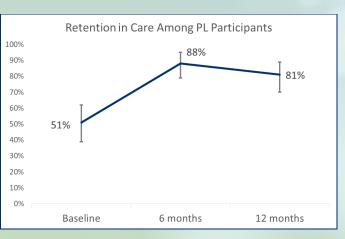


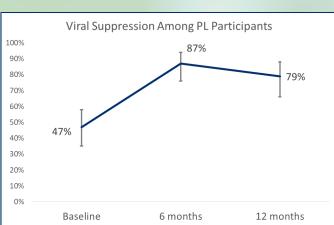
"You get to talk to people who are going through exactly what you are going through. When you are down somebody uplifts you, when somebody else is down you can uplift them, it's basically like one big family"

- PL Member

PL V1.0 Outcomes







A 12-month prospective trial of the *PositiveLinks v1.0* app with nonurban PWH found significant improvements in RIC (top) and viral suppression (bottom) over one year of follow-up (n=77).

AIDS PATIENT CARE and STDs Volume 32, Number 6, 2018 Mary Ann Liebert, Inc. DOI: 10.1089/apc.2017.0303

BEHAVIORAL AND PSYCHOSOCIAL RESEARCH

PositiveLinks:

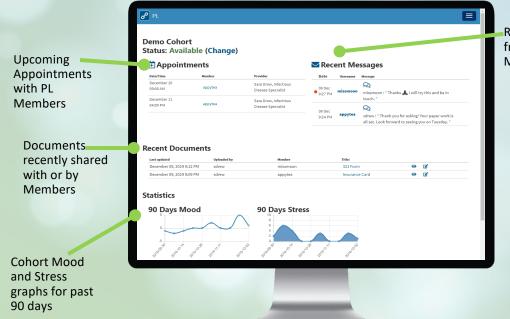
A Mobile Health Intervention for Retention in HIV Care and Clinical Outcomes with 12-Month Follow-Up

Rebecca Dillingham, MD, MPH, Karen Ingersoll, PhD, Tabor E. Flickinger, MD, MPH, Ava Lena Waldman, MHS, CHES, CCRP, Marika Grabowski, MPH, Colleen Laurence, MPH, Erin Wispelwey, MSC, George Reynolds, BA, Mark Conaway, PhD, and Wendy F. Cohn, PhD

PL Provider Portal/ PL 2.0 added Provider App







Recent Messages from or to Members

MENU Members Messages **Appointments** Resources **Ouestions?** Logout

DEPARTMENT OF HEALTH Protecting You and Your Environment

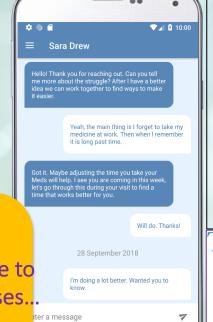
Scaling to other clinics with a turn key system

We distributed the app to Virginia HIV clinics statewide

PL 2.0: Longer term Outcomes,

Secure messaging, Internal Design/Dev team





Usage Impact:

Patients with high PL use were 2.09 (95% CI 0.64–6.88) times more likely to achieve viral suppression and 1.52 (95% CI 0.89–2.57) times more likely to become engaged in care compared to patients with low PL use.

Toward understanding the impact of mHealth features for people with HIV: a latent class analysis of PositiveLinks usage

Chelse E. Canari, To Tabor E. Flickinger, Marika Waselewski, Alexa Tabachman, Logan Baker, Samuel Eser, And Lena D. Waldman, Karen Ingersoll, Rebecca Dillingham,

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Long term impact of *PositiveLinks*: Clinic-deployed mobile technology to improve engagement with HIV care PLOS One,

Chelsea E. Canan 1, Marika E. Waselewski 1, Ava Lena D. Waldman 1, George Reynolds 2, Tabor E. Flickinger 1, Wendy F. Cohn 3, Karen Ingersoll 4, Rebecca Dillingham 1 *

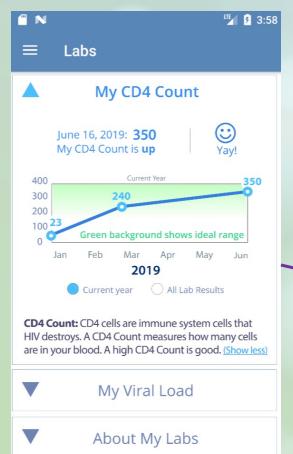
"It's convenient to be able to talk with doctors and nurses... it's kind of made me care more about wanting to continue in care."

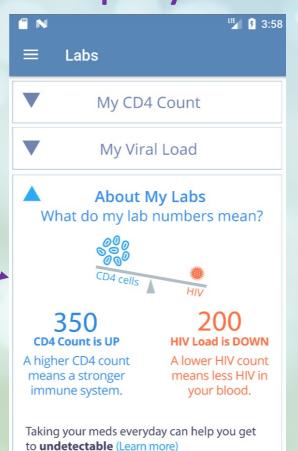
Flickinger, et al, 2020. Secure Messaging Through PositiveLinks: Examination of Electronic Communication in a Clinic-Affiliated Smartphone App for Patients Living with HIV.

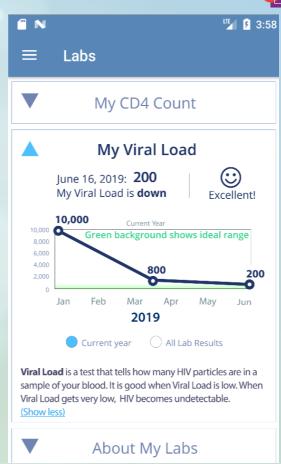
• VOL. 26 NO. 3 • MARCH 2020 TELEMEDICINE and e-HEALTH

Labs display revised











PositiveLinks Spanish: Prospera Libre









Technology Use Among Patients in a Nonurban Southern U.S. HIV Clinic in 2015

Living with HIV

Tabor E. Histinger, MD, AMPI, ¹ Sover Impressit, PhD: ² Solicine Swager, BD, ² Mariko Grabovski, APPI, ² and Pelecon Oldinghon, MD, AMPI.

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BEHAVIORAL AND PSYCHOSOCIAL RESEARCH

A Mobile Health Intervention for Retention in HIV Care and Clinical Outcomes with 12-Month Follow-Lin

Matthew Mark States and States an

Development of PositiveLinks: A Mobile Phone App to Promote Linkage and Retention in Care for People With HIV

Ava Lena Waldman¹, MRS, CHES, CCRP, Esia Plews Ogas¹, BA, Claire Deboh¹, MD, George Reynolds², BA; Weath Colm², PaD, Karen Internell², PhD: Ketheco Dilinetani², MD, MPS

University of Virginia School of Medicine PO Res 801370 Charletteville, Vit. 22908 United States Phone: 1 454 PEZ 0105 Exted: Riffer/Unional reconstrain edu

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EXPERT REVIEW OF ANTI-INFECTIVE THERAPY Objective. This study sized to develop as app to expect, link, and sense. https://doi.org/10.1080/14787210.2019.1578649

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Secure Messaging Through PositiveLinks: Examination of Electronic Communication in a Clinic-Affiliated Smartphone App for Patients

Teher E. Fledinger, MD, MFH, Claire DeBolt, EA,¹
Irin Wilgelberg, MFE, Colleen Leurence, MFH,²
Irin Fine-Depon, EA, An Lene DeBoltere, MFE, CHEY,²
George Reynolds Wilest, F. Cole, Mid., Pal.³
Hary Cattledon Reach, Pal.³ Force Ingernal, Phl.²
and Reboton Diffusions, MFH, MD²

Department of Medicine, University of Virginia School of Medicine, Cheriottendile, Virginia. Department of Medicine, Vinite Format School of Medicine, Ministra Solent, North Certilins.

Flantin Derhale Technologier, Beldend, California.

*Department of Medicine, Johns Hapkins University School of Medicine, Bullimore, Maryland,

Parkground: Although there is growing introvet in mobile

applications and enline support groups to enhance chronic Alexand and management, little is became about their potential impact for propie living with BIV PLNH). Introduction: We developed on innovative online support group delivered through a community memoer based (CMB) within a clinicoffiliated smortphene application Pusitive Links (FL). We are-lyed characteristics of posters and unspecters to the CMB and evaluated control point is the CAS. Materials and Methods: and the sensitivity of disclosure. At the same time, stigma-For this study, 3f 1774-injected patients contributed oil places: with the PL opplication that included the opportunity to in-FAMB, as a means of accessing support while maintaining many with other section of aCMB. Logistic representation inser-ment with other section of aCMB. Logistic representation inserdissing associations between sorticipant observatoristics and instirely. Results: 24 perticipants period to the CMS; 14 did vertice smartphone application (Positive Links [PL] designed to not, Participants had buser adds of meeting if they never white promote littings and retention in HV care. The app was denot, remanqueme not usual quiente familia y divergative ment promote tating and internation in the carbon single-(p. 6.0.00) and had private familiar private familiar private tables by the study team and it satisfable only posts and higherwaits of private private familiar surrougherment and participates referred by project partners. In addition to the closely \$6.0.000, Of the 400 CARB meanages even it works. 62% had psychosotial control, followed by community char (20%), and bloomfall control (10%). Discussion: Psychoecial contents in maniproceiotes this CMS, in content to connecting and anistance. The CMS within the PL app provides tier seller former deminstral by informational counter. In unique data set for context analysis of an online summer

Support Group for People Living with HIV

Constantions: This CMII on a clinic-efficient mobile applica tion may reach values able populations, including racing otheric entworther and those of lawer socioecessenic status, and pro-

Keywoods: HIV/AIDS, qualitative analysis, online support groups, mehlie app., m-health, behavioral medicine

Introduction

Content Analysis and User Characteristics of a Smartphone-Based Online

explicitiving with HIV (PLWH) face many challenges, including unmer needs for support and information from pown. Online support groups have the potential to overcome hunters to meeting these needs. Prior studies of ordine support groups for a variety of districtle diseases have shown that the online support group content generally focuses on informational support and direct experience." Online support groups can promote patient empowerment.⁶⁻⁸ but may also present disks.⁶⁻¹³ Lack of neaverhal ones can lead to mitundereandings, while lack of quality control may allow misinformation to diversinate. Regative portings or imppropriate interactions may undermine norm terms of support. FLWH may be particularly subsemble to the risks of ordine support groups, due to the origina normanding this lines

Our shally examines an online support droup delivered through a community message board (CMB) within an innotion adherence, appainment reminders, tailored educational resources, and access to the study team for indistinglish there assume present assumes any approximation content, a tempte care and no content integrals of an entire support for each other, group for PDMC. In addition to useful out on our participants and chiral for the community, and a preception that the haddendersongraphic and chiral data on our participants not no plant a positive rate in their IIIV adi-management. gradulate in prior studies in IIIV, which used online regulations

200 management and

TBM

ORIGINAL RESEARCH

Toward understanding the impact of mHealth features for people with HIV: a latent class analysis of PositiveLinks usage

Taylor & Francis



Breanna R. Campbell 60°, Karen S. Ingersoll 60°, Tabor E. Flickinger 60° and Rebecca Dillingham 60°

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interventions for people living with HIV

Sciences, University of Virginia School of Medicine, Charlottesville, VA, USA

KEYWORDS Mhealth; mobile applications; text messaging; HIV; smartphone; internet; digital divide; telemedicine

toland exprove building. Messages next by providers were near their to contain repport building at 54-89s. Conclusions: Pl. nessaging was said to lander medical and social meth units premittal depart on patients' leadle and affers an opportunity in strengtion particular-position rela-

care memasiae formula e chia-affiliated successors and

Addressing Stigma Through a Virtual Community for People Living with HIV: A Mixed Methods Study of the PositiveLinks Mobile Health

Tabor E. Flickinger¹ - Claire DeBok² - Alice Xia³ - Alicen Kosmacki² - Marka Grabowski¹ - Ava Lena Waldn George Reynolds⁴ - Mark Conway³ - Wendy F. Cohr³ - Karen Ingersolf⁶ - Rebecca Dillingham^{1,7} © Stigma has negative consequences for quality of life and HIV care outcomes. PositiveLinks is a mobile health

stigma scores, Of 77 participants in our pilot, 63% were male, 49% Black, and 72% had incomes below the fe

level. Twenty-one percent of CMB posts (394/834) contained stigms seland centert including negative stigms) and positive (secrecoming stigms) posts addressing intrapersonal and interpersonal stigms. Higher by one positive to contained with stress and negative increased with IEV case self-efficiency. 12-months data at beautiful to the improved stigmts account for posters on the CMB versus non-posters (-4.5 vs - 0.63) and for post related context versus other context (-5.1 vs - 3.3). Parliaminary evidence suggests that a supportive virsus nonerous of through to clinic william of unsurphore uses, can belo nonerole below with PMV to address with

ORIGINAL DADER

Intervention

Dissemination

- #ADHERENCE2023
- PL v3.0 became usual care In 2017 in the originating clinic and in other Virginia HIV clinics (with Health Dept support)
- Clinics outside Virginia wanted PL; University of Virginia established a company, Warm Health Technology, LLC, to disseminate a commercial version (PLCares). https://www.wht.care/
- PL/PL Cares: 22 implementations in 7 U.S. states and 4 countries





What drove success? #ADHERENCE2023



- PositiveLinks is a clinic-based HIV care app that promotes connection between patients and clinic teams
- Community Board promotes Social support
- Clinic-based innovation (in COVID, had early telehealth)
- In-house design/dev team: responsive, nimble
- Research to establish evidence of PositiveLinks' impact, mechanisms
- Visionary support for PL as part of standard HIV care from State Health Department
- National awards/recognition as Evidence-based practice in HIV care
- University-commercial partnership to distribute the app outside Virginia



Thank you!

Karen Ingersoll: kes7a@uvahealth.org

https://www.positivelinks4ric.com/

https://www.wht.care/