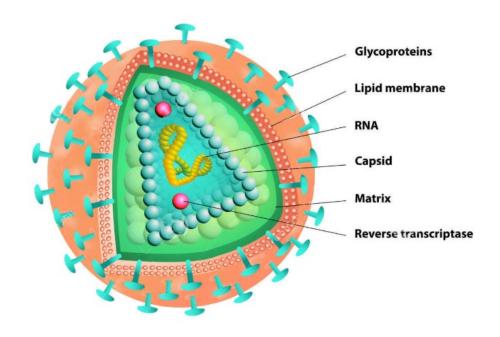


## **Global HIV**

# Structure of the Human Immunodeficiency Virus (HIV)



37.9



Million people Globally living with HIV 1.7



Million people became newly infected

770,000



People died from AIDs-related illness in 2018

74.9



Million people have become infected with HIV since the start of the epidemic

**32** 



Million people have died from AIDs-related illness since the start of the epidemic



## **Confronting an Epidemic**



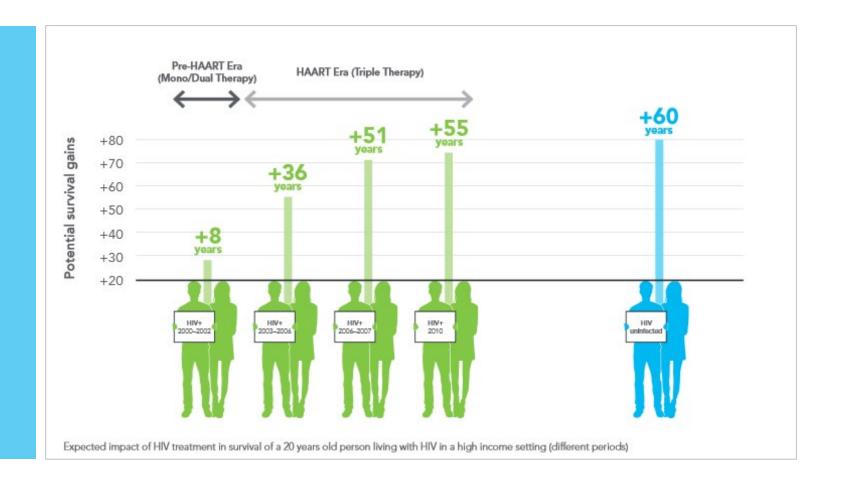
## **Expected Lifespan Increase**



Life expectancy for people with HIV is now near-normal, but only for those accessing treatment



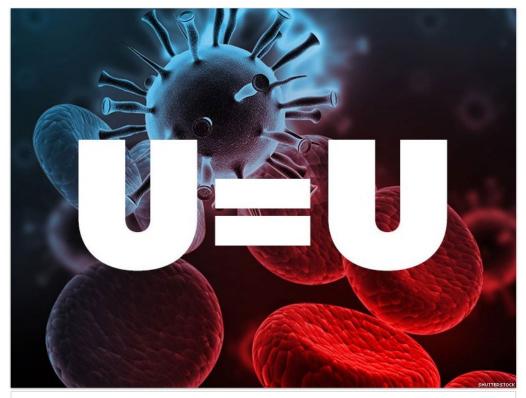
A 20 year old person living with HIV who started treatment after 2008, can now expect to live to 78



## Undetectable=Untransmittable

#### TREATMENT > TREATMENT

# CDC Officially Admits People With HIV Who Are Undetectable Can't Transmit HIV

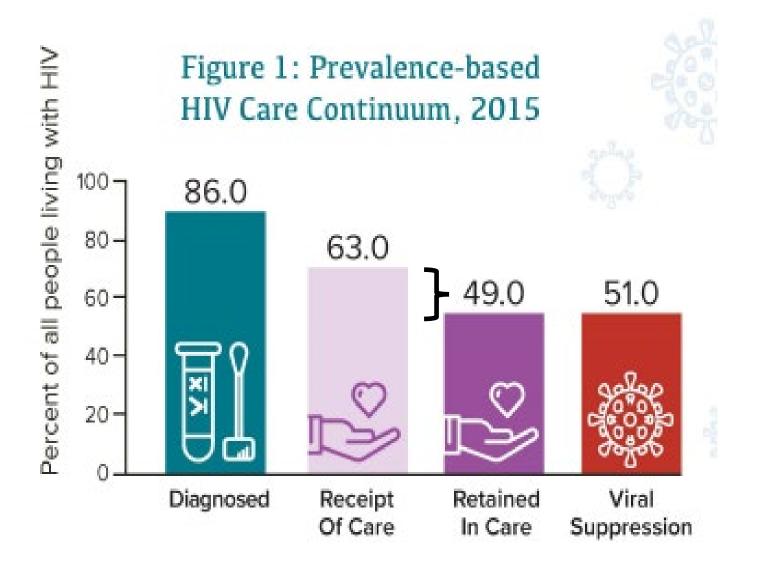


In a historic letter, the Centers for Disease Control and Prevention support the science behind "Undetectable Equals Untransmittable."

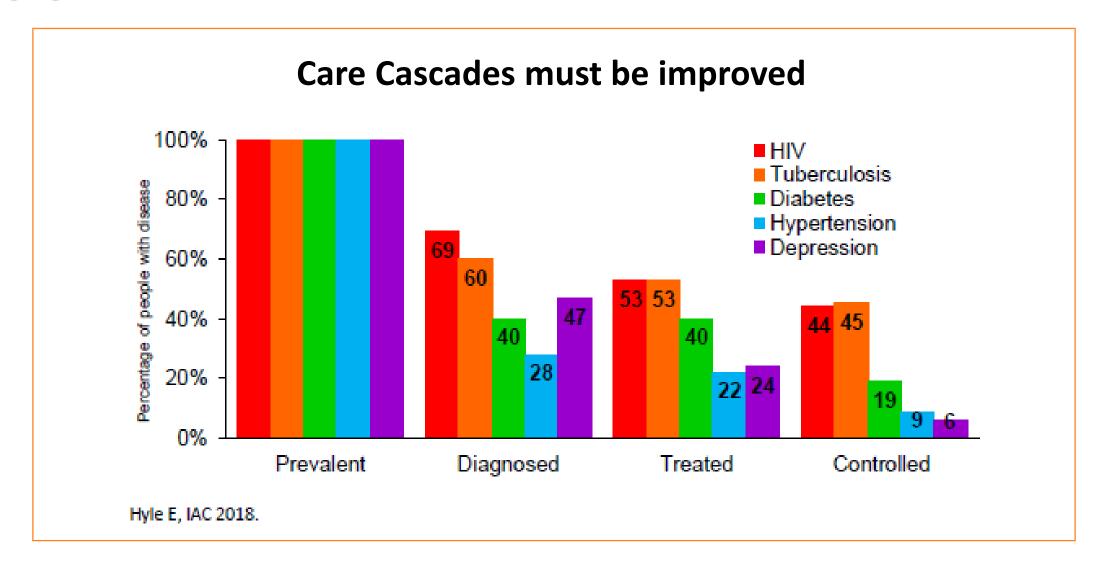
By Savas Abadsidis OCTOBER 22 2017 3:25 PM EDT



## **HIV Care Continuum**



## **Engagement in Care**

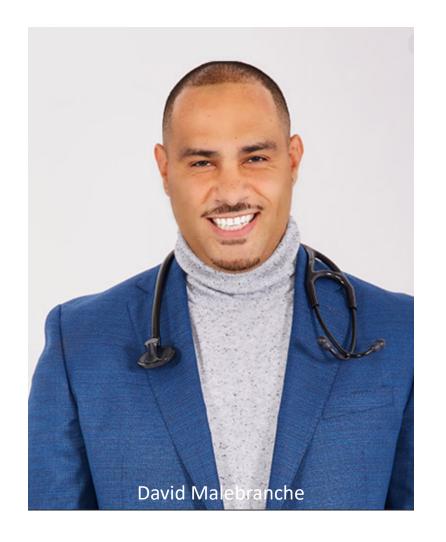




## How do we Improve Care Engagement?

"If customers stop coming to the restaurant, the chef doesn't ask "What's wrong with the customers?" It's time to improve the restaurant!"

-David Malebranche, MD MPH Associate Professor Morehouse School of Medicine





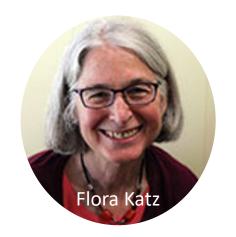
## Innovation?

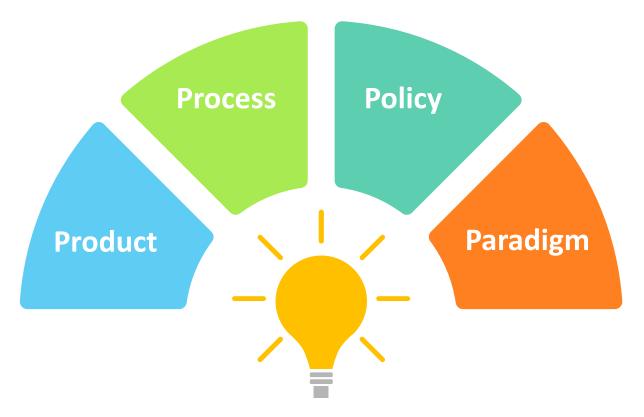


## **Definitions of Innovation**

## **Working Definition of Innovation:**

An implementation that is often disruptive of the prevailing product, process, policy, or paradigm and creates an outcome that is more effective, affordable, accessible, easier to use or deliver, and/or provides superior scalability





## **Innovation Effectiveness**

An innovation implies a successful implementation and, indeed, may take a known product or process and modify or adapt it to a new use, with greatly improved outcomes...



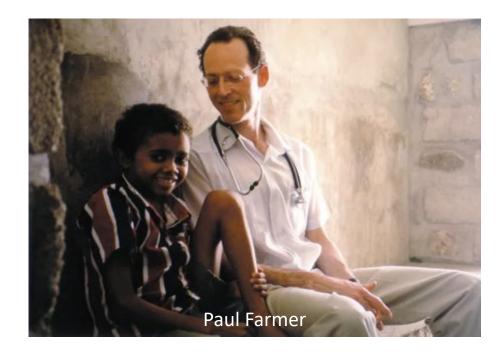
## Accompagnement

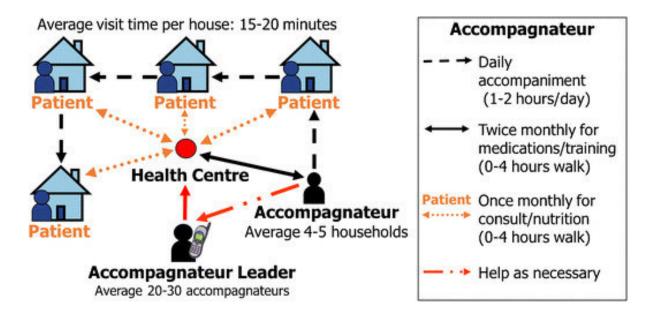
Curr HIV/AIDS Rep DOI 10.1007/s11904-016-0335-7

THE GLOBAL EPIDEMIC (SH VERMUND, SECTION EDITOR)

## Community-Based ART Programs: Sustaining Adherence and Follow-up

Joia S. Mukherjee  $^{1,2,3}$  · Danika Barry  $^{2,3}$  · Robert D. Weatherford  $^{2,3}$  · Ishaan K. Desai  $^{1,2}$  · Paul E. Farmer  $^{1,2,3}$ 





Books & Arts | Published: 29 June 2017

## **Medicine: Heroes of global health**

Amy Maxmen

Nature **546**, 598(2017) | Cite this article **332** Accesses | **110** Altmetric | Metrics

Amy Maxmen assesses a documentary on medical pioneer Paul Farmer and colleagues round the world.



## HIV Care Challenges Rural VA

- Stigma
- Transportation
- Poverty
- Isolation
- Alcohol/drug use
- Mental health challenges



## mHealth

"mHealth refers to the use of mobile communication technologies to promote health by supporting healthcare practices (e.g. health data collection, delivery of healthcare information, or patient observation and provision of care)."

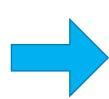
- Aranda-Jan et al. BMC Public Health. 2014.

mHealth can facilitate interventions addressing one or more challenges to living well with HIV when and where clients want and need it

# mHealth in rural Virginia?











## **STeM**

## Edit Text Messages

#### Schedule 1 -

Click to select or unselect the days messages are sent:

Mon	Tues	Wed	Thurs	Fri	Sat	Sun
$\checkmark$	<b>√</b>	/	/	$\checkmark$	<b>\</b>	/

Enter time and text message (160 characters or fewer):

11 : 00 AM 💌 Get your ass up and take your 5 meds.

09 : 00 PM 💌 Did you take your 2?

: AM 💌

Add another message

Clear Schedule



## **STeM Participant**

"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?"





## **TxText: Self-monitoring queries**

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:** Patient-designed responses automatically sent by system



## Perspectives on TeXT - Medication

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



## App vs Text

## Text

- Better studied
- Phones are cheaper
- Harder to crack phone screens when dropped

## App



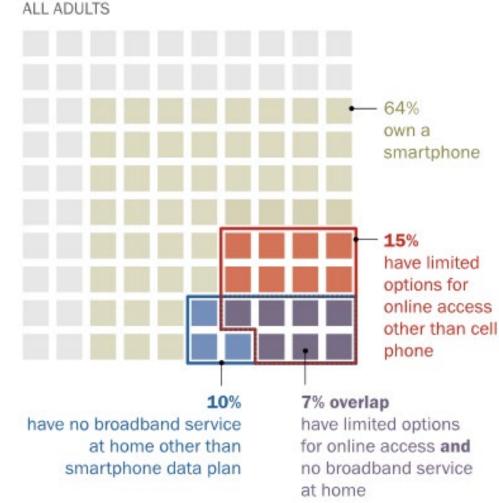
- Consumer demand
- Rich media views, videos and community functions
- More secure
- Can send more messages without added cost

## Digital divide

# The "Smartphone-Dependent" Population: 7% of Americans Rely Heavily on a Smartphone for Online Access

% of U.S. adults who have a smartphone, but lack other broadband internet service at home, and/or have limited options for going online other than their cell phone 13% of low income households (<\$30K) are smartphone dependent vs. 1% of households earning \$75K.

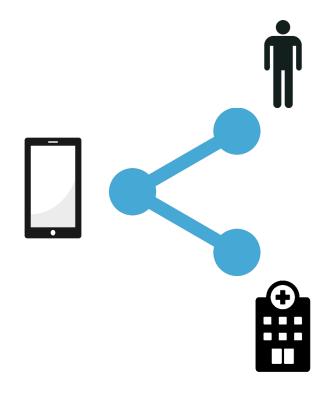
12% of
African
Americans vs
4% of Whites.





## Consistent Phone Access and Engagement in Care

- Recent literature underscores importance of access to consistent communication
- Those who experienced a change in phone number during the past year were significantly more likely to be not engaged in care

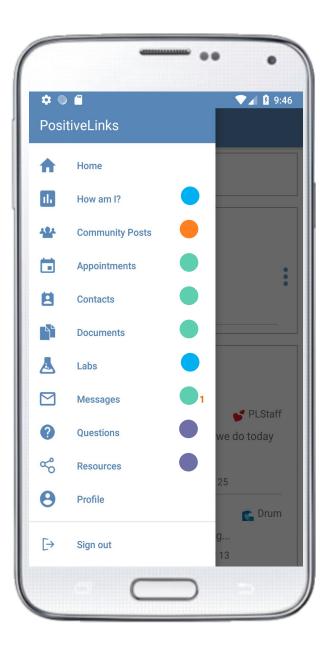




# **App Development Strategies**



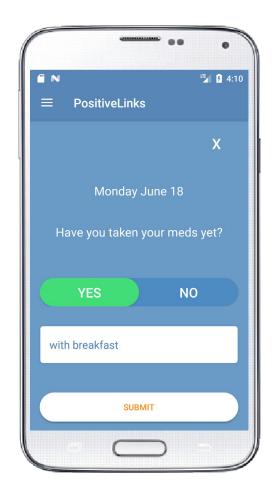
## PL App Components

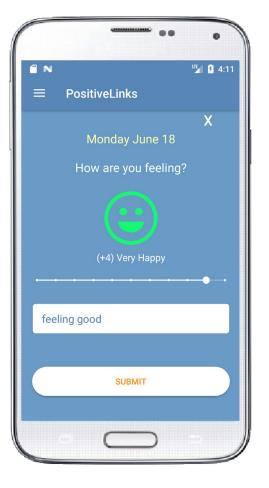


- Self-Monitoring and Management
- Care Coordination
- Educational Resources
- Social Support



## **Self-monitoring Check-Ins**





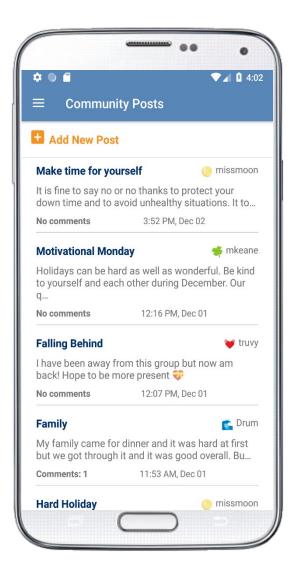


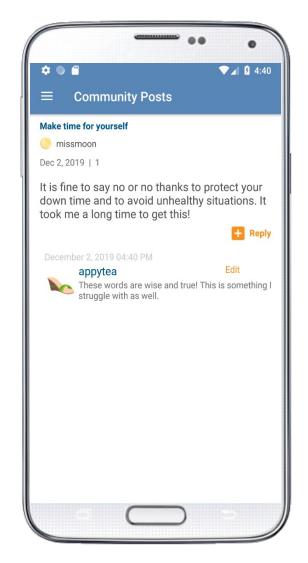
"The questions make me focus on my mood and my stress and makes me more in touch with myself you can say. When it pops up, it makes me stop and think. I usually don't think about that kind of thing."

- PL Participant



## **Community Posts**



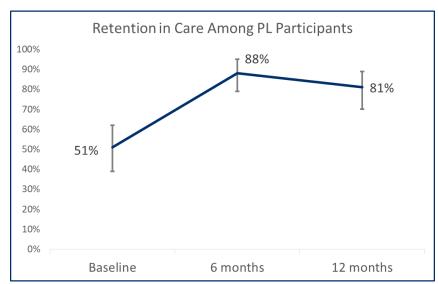


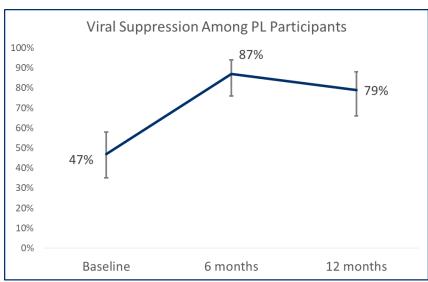
"You get to talk to people who are going through exactly what you are going through. When you are down somebody uplifts you, when somebody else is down you can uplift them, it's basically like one big family"

- PL Member



## PL V1.0 Outcomes





- Significant *increases* in engagement in care (top) and in HIV viral load suppression (bottom) over one year of follow-up (n=77)
- Stigma scores are improved with increased used of the community message board.\*
- Social support is sought and provided regularly. \*\*
- In app patient-provider messaging is a mechanism to build rapport.\*\*\*



## **CDC Compendium**

COMPENDIUM OF EVIDENCE-BASED INTERVENTIONS AND BEST PRACTICES FOR HIV PREVENTION

### **POSITIVELINKS**

**Evidence-Informed for Retention in Care** 

#### INTERVENTION DESCRIPTION

#### Goal of Intervention

- Improve retention in HIV care
- Improve HIV viral suppression
- Decrease HIV viral load

#### **Target Population**

Clinic patients

#### **Brief Description**

PositiveLinks (PL) is a clinic-based smartphone app that features tailored educational resources; daily queries of stress, mood and medication adherence; weekly quizzes; appointment reminders; and a community message board (CMB). The educational resources include an orientation to the clinic, information on HIV and health, and stress reduction techniques. For the CMB, participants select user names to protect anonymity and can start new conversations or respond to older conversations. The PL team intermittently introduces new conversation topics on HIV or general well-being, and the team can communicate with the participants privately to address technical issues and assist with care coordination on the CMB. Contact information for the clinic-affiliated PL team is also included in the app. Participants were given smartphones with the PositiveLinks app installed.

## Linkage to, Retention in, and Reengagement in HIV Care (LRC) Chapter

This chapter of the <u>Compendium</u> categorizes the best practices in promoting Linkage to, Retention in, and Re-engagement in HIV Care among people living with HIV, one of the priorities outlined in the U.S. National HIV/AIDS Strategy. Additional details about the LRC Chapter or the <u>Prevention Research Synthesis (PRS) Project</u> can be obtained by contacting PRS.



## **In-house Development**

Nimble

Responsive

Embedded with clinical staff

# **Patient-Centered Design**



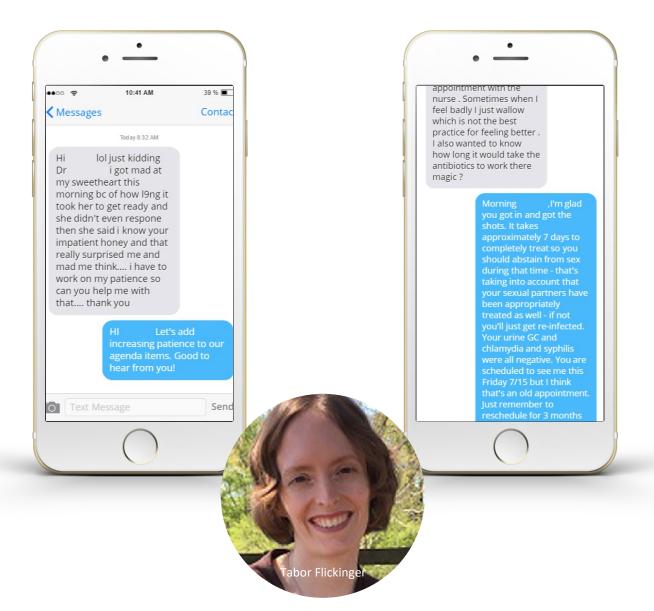






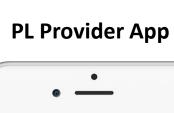
## **ELECTRONIC COMMUNICATION**

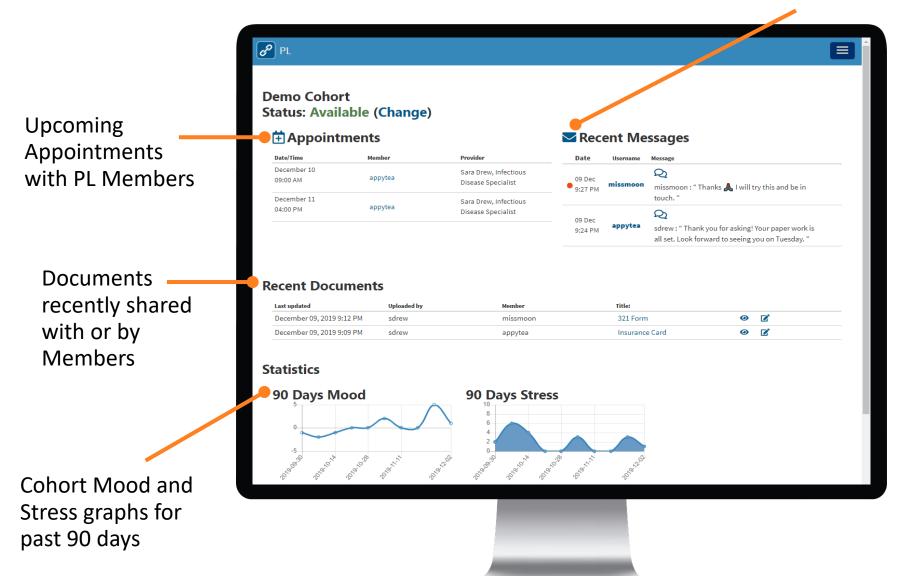




## PL Provider Portal Summary

Recent Messages from or to Members



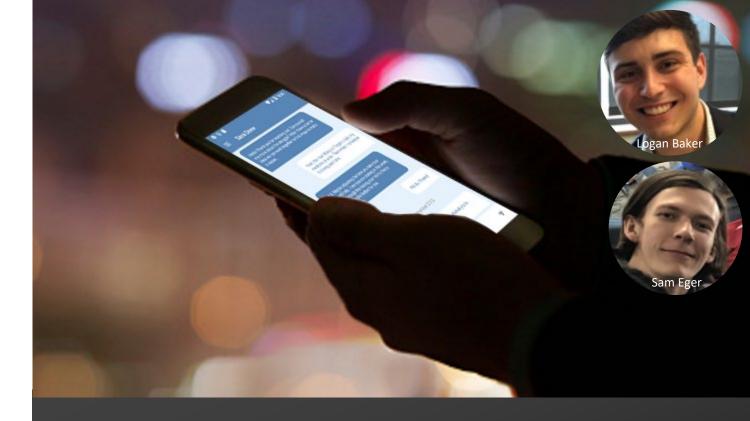






"I can contact
[my provider]
more frequently
now. I like to
have that
option."

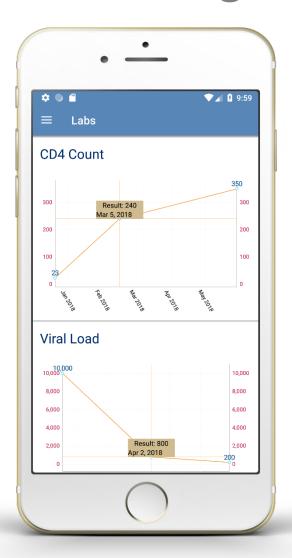
"It's convenient to be able to talk with doctors and nurses... it's kind of made me care more about wanting to continue in care."



What do our most at-risk users say about messaging?

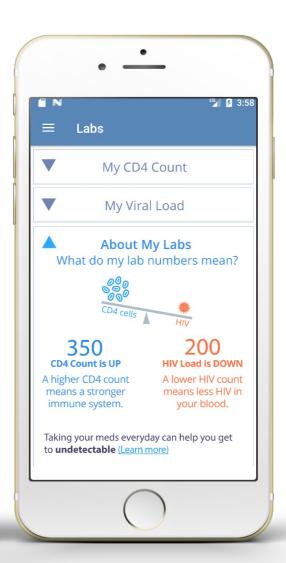
These users find messaging to be one of the most useful features of the app—more useful than medication tracking!

## Labs Redesign









Before

After

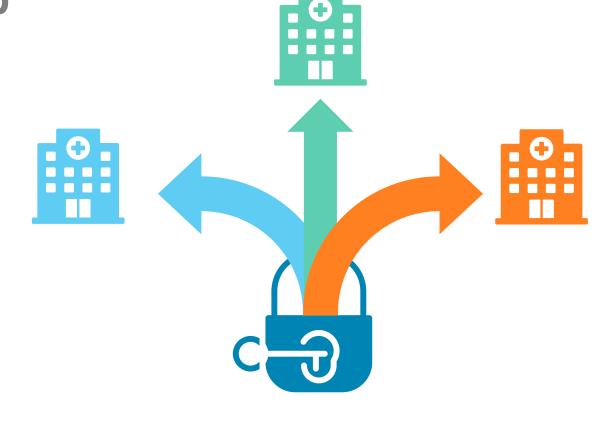


## **Community of Practice**



# Public – Academic Partnership



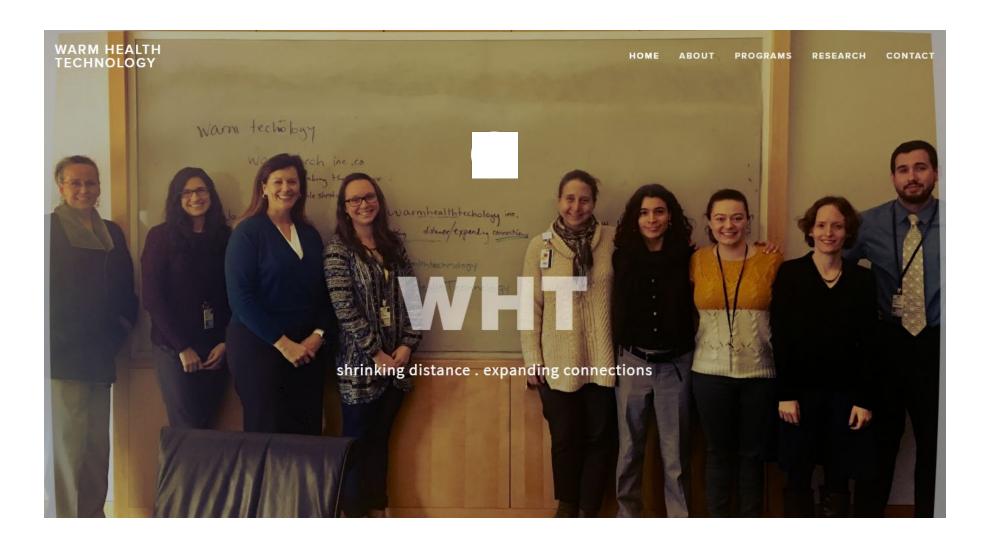


Scaling PL to other clinics with a turn key system





# Warm Health Technology



## **Ethics of Data Safety and Equity of Access**

Informatics for Health: Connected Citizen-Led Wellness and Population Health R. Randell et al. (Eds.)
© 2017 European Federation for Medical Informatics (EFMI) and IOS Press.

© 2017 European Federation for Medical Informatics (EFMI) and IOS Press.

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Mobile Medical Apps and mHealth Devices: A Framework to Build Medical Apps and mHealth Devices in an Ethical Manner to Promote Safer Use – A Literature Review

Mary SHARP<sup>a1</sup> and Declan O'SULLIVAN<sup>a</sup>

<sup>a</sup> School of Computer Science and Statistics, Trinity College, Dublin 2

EXPERT REVIEW OF ANTI-INFECTIVE THERAPY https://doi.org/10.1080/14787210.2019.1578649



363





Bridging the digital health divide: toward equitable global access to mobile health interventions for people living with HIV

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

<sup>a</sup>Department of Medicine, University of Virginia School of Medicine, Charlottesville, VA, USA; <sup>b</sup>Department of Psychiatry and Neurobehavioral Sciences, University of Virginia School of Medicine, Charlottesville, VA, USA

ARTICLE HISTORY Received 17 October 2018; Accepted 1 February 2019

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





PL Research

ahlatse Modipane

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

Tabor E. Flickinger<sup>1</sup> \* Claire DeBob<sup>1</sup> \* Ava Lona Waldman<sup>1</sup> \* George Reynolds<sup>2</sup> \* Wendy F. Cohn<sup>1</sup> · Mary Catherine Beach<sup>1</sup> · Karen Ingersoll<sup>4</sup> · Rebecca Dillingham<sup>1,8</sup>

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. Rickinger, MD, MPH,

Secure Messaging Through PositiveLi Communication in a Clinic-Affiliated Living with HIV

Tabor E. Hickinger, MD, MHI, Tiaren Ingeradi, PhD, Sebrina Swager, BS. Marika Grabowski, MPH,

Descripents of 'Medicine and 'Psychistry and Neurobehovi Sciences, Chiamothy of Wiginia Sci and (12 Aux Co) Charlottneville, Virginia.

University of Virginia School of Medicine, Cherlettesville,

#### Abstract

Purpose: Server increaging between patients and their ked cure trum cun facilitate chrunic cure management. Puniti Hubs (PL) is a clinic-offliated mantphone application is stoned for patients living with HIV that includes a need mennaging feature for patients, FL staff, and clinic provide to communicate. Our olin was to examine the contratfunction of managing within FL.

Methodology: We enumined messages exchanged through from November 2017 through January 2018. Occident analysis included categorization of topics as: related to b app, medical care, or social needs. Messaging functions as categorized as information exchange or support building. Results: Of the 1,474 PL messages analyted, 44% were so by FL staff, 1996 by patients, and 1996 by providers, when 61% were received by patients, 22% by providers, and 2. y FL staff. Message topics included app-related (\$7.69 medical care (14.1%), and notici converse (12.4%). Ap related messages addressed technical difficulties, soften updates, or coordinating phone payments. Medical mema included medical information, medications, appointment outrack, and care coordination for physical and more Angith. Social parenogra related to insurance, transporter bearing, food, utilities, disability, finances, and work a eraces. Message function coding showed that 47.3% menages cantained information exchange and 33.8% or

D Tabor E. Flickinger et al 2019; Published by Mary Ann Liebert. Commons License [http://creativecommons.org/licenses/bg/4.0 medium, provided the original work is properly ched.

Background HIV treatment to the last 20 years a result. Altho

Introductio

ne corptability. W

Results: A tot Query response (90/77) of users

Conclusion: 7

DIER FORMATIVE RESEARCH

Original Paper

Development of Posit Linkage and Retention

College Laure Ava Lesa Wa Wendy Colin<sup>3</sup> Depotament of M See in Decision. Department of Po

Department of Po Corresponding University of V PO Bus 201379 Charlettesville, United States Phone: 1 434 91 Frant: Result1

Abstract and revention at Wise, Wise, VA, USA Objective: '71 Seathiller, and Methods: Ap PLWH, Once d frontions, Web

Obe this as: 78W 2019;0 doi:10.1093/tbm/bz180 @ The Authority 2019, Published b

based Ryan White clinic enrolled in PL from June 2016 to March 2017 and were followed for up to 12 months. A subset (N = 49) completed interviews after 3 weeks of

enrollment to explore their experiences with and opinions of PL. We differentiated PL members based on 6-month of St. We differential of III, markets based on 6 months wages of gos basers using based case solving like exclusion of the state of the state of the state of somewhat from the case of the state of the state of 68 St. members fell into four classes. "Maximizer' used all purchased procured (CSPS). "Order baser" and "It-leaded Commerciators" interaction with the pur-minimal (CSPS). "Or smooted for manifest find the among all cases as that of months of "T remainful flight. It mostly, states are based on the commerciators" interaction 5-54(S), Chacke in Users (CSPS, 100M), and Moderate All-fames Users (CSPS, 40M), and moderate All-der of the commerciators and the commerciators of the commerciators of destricts of the commerciators and commerciators of destricts of the commerciators and critical commerciators stated to the commerciators and commerciators stated to the commerciators of stated on the commerciators and stated on the commerciato distinct in characteristics and clinical outcomes. Identifying and characterizing mHealth user classes offers opportun to tailor interventions appropriately based on patient needs

PLWH, Mobile health, Viral suppression, Latent

and preferences as well as to provide targeted alternative

support to arbigue clinical enals

Addressing Stigma Through a Virtual Community for People Living

George Reynolds<sup>4</sup> · Mark Conaway<sup>5</sup> · Wendy F. Cohn<sup>5</sup> · Karen Ingersoll<sup>6</sup> · Rebecca Dillingham<sup>1,7</sup>G

accessed through a clinic-affiliated smartphone app, can help people living with HIV to address stigma.

with HIV: A Mixed Methods Study of the PositiveLinks Mobile Health

Tabor E. Flickinger<sup>1</sup> · Claire DeBolt<sup>2</sup> · Alice Xie<sup>3</sup> · Alison Kosmacki<sup>2</sup> · Marika Grabowski<sup>1</sup> · Ava Lena Waldman<sup>1</sup> ·

Stigma has negative consequences for quality of life and HIV care outcomes. PositiveLinks is a mobile health intervention

that includes a secure amony mous community message board (CMB). We investigated discussion of stigma and changes in

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

level. Twenty-one percent of CMB posts (394/1834) contained stigma-related content including negative (experiencing stigma) and positive (overcoming stigma) posts addressing intrapersonal and interpersonal stigma. Higher baseline stigma

was positively correlated with stress and negatively correlated with HIV care self-efficacy. 12-month data showed a trend

toward more improved stigma scores for posters on the CMB versus non-posters (-4.5 vs - 0.63) and for posters of stigma-

related content versus other content (-5.1 vs -3.3). Preliminary evidence suggests that a supportive virtual community,

ORIGINAL RESEARCH

Mahlatse B. Mo Ava Lena Walds AIDS and Behavior (2018) 22:3395-3406 Rebecca Dilling and Karen S. In https://doi.org/10.1007/s10461-018-2174-6

Technology Use Among Patients in a Nonurban Southern

School of Media ORIGINAL PAPER

U.S. HIV Clinic in 2015

#### Abstract Background:

still have inad Methods: We re natients receivi Clinic serving Virginia, Our ai and smartphon delivery of a s technology. Res patients used co tablets. The res access. Of thos reported weekly Internet use. Co Internet access

tions. It is time Keywords: Inte er Characteristics of a Smartphone-Based Online e Living with HIV

la atención del VIH. PositiveLinks es

anónimo seguro (CMB por sus siglas

le estigma. De los 77 participantes en

ingresos por debajo del nivel federaj

relacionado con el estigma, incluidas

que abordaban el estigma intrapersonal

s y se correlacionó negativamente con

hacia puntajes de estigma mejorados

y para quienes publicaban contenido

iminar sugiere que una comunidad vir-

afiliada a la clínica, puede ayudar a las

nces in HIV care, stigma against per-

ct on quality of life and overall health

d States, HIV-related stigma is par-

in rural areas and in the South [3-8].

can be complicated by other sources

H also experience based on gender,

Springer

e psychosocial support to PLNH.

incrities and those of layer socioeconomic status, and proyeards: HIV/AIDS, qualitative analysis, colline support sps. mebile ann, m-health, behavioral medicine

Conclusions: This CMB on a clinic-offliated mobile applicafor may reach value while populations, including racial/ethnic

copic living with HIV (PLWH) face many challenges, including unmet needs for support and information from poem. Online support groups have the potential to overcome hunters to meeting these needs. Prior dies of online support groups for a variety of dumnic diseases. ne shown that the online support group content generally times on informational support and illness experience." taker support gioups can promote patient empowerment.<sup>6–6</sup> at may also present risks.<sup>6–1</sup> Lack of nonverbal coes can lead misunderstandings, while lack of quality control may allow sinformation to diversinate. Regative postings or impopriate interactions may undermine users' sense of support. Will may be porticularly vulnerable to the risks of online pport groups, due to the stigms commanding this illness the sensitivity of disclosure. At the same time, stigma make online support groups particularly valuable for IWH, as a means of accessing support while maintaining

Our study examines an online appoint droup delivered rough a community message board (CMB) within an innotive seartphone application (Positive Links [PL]) designed to more linkage and retention in HIV care. The anniwas delioped in-house by the study team and it available only to articipants referred by project partners. In addition to the MR, the PL app includes daily queries of stress and medican adherence, appointment reminders, tailored educational trees, and access to the study team for individualized speling and anistance. The CMB within the PL app provides nique data set for context analysis of an online support roup for PLWIL in addition to users' posts, our ago study fudes demographic and clinical data on our participants not Natio prior studies in HIV, which used on line recruitment

20th manufacturing and a

Wendy Cohn

### $\Gamma \mathrm{BM}$

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

Chelsea E. Canan, <sup>50</sup> Tabor E. Flickinger, <sup>5</sup> Marika Waselewski, <sup>5</sup> Alexa Tabackman, <sup>2</sup> Logan Baker, <sup>3</sup> Samuel Eger, <sup>3</sup> Ava Lena D. Waldman, <sup>5</sup> Karen Ingersoll, <sup>6</sup> Rebecca Dillingham <sup>5</sup>

Correspondence to: R Dillingham, RDSV gihs. mcc.virginia.edu

message board. HIV. (IMIR Form R KEYWORDS milienith: HIV:

Abstract
PositiveLinks (PL) is a multi-feature smartphone-based
platform to improve engagement-in-care and viral
suppression (VS) among clinic patients living with HIV. Practice: Mobile health interventions support self-care for people living with HIV through a var-iety of mechanisms; these mechanisms should be targeted based on user needs and preferences to provide maximal benefit. ins, a community board, and secure provider messaging. Our goal was to examine how PL users interact with the app and determine whether usage patterns correlate with clinical outcomes. Patients (N = 83) at a university

> Policy: Effective use of mobile health should in corporate an understanding that multi-featured interventions impact users differently and should incentivize use of technology in ways that best fit with individuals' needs and preferences.

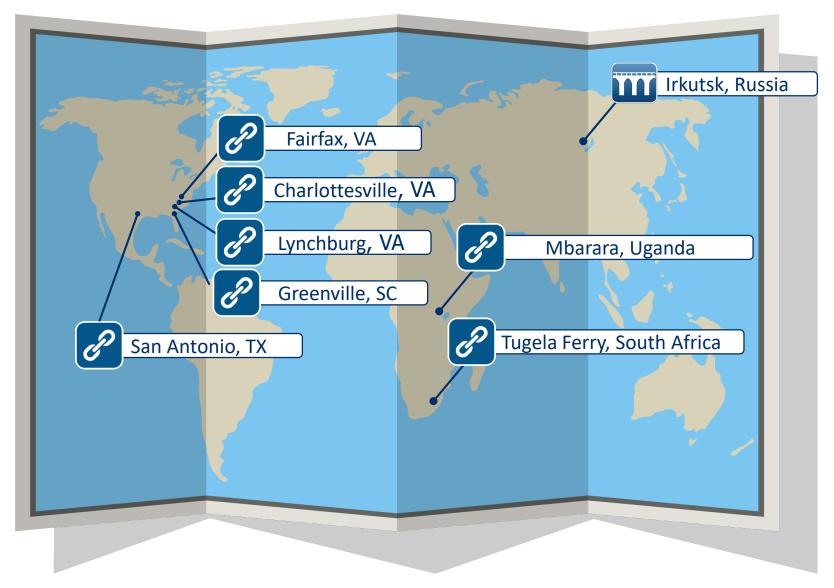
tesearch: Researchers should consider that the nechanism of action for multi-featured interventions may vary across participants and future research should consider examining patterns of engagement with interventions to better under-stand their impact.

of one's health, connecting patients to social net-works of peers with similar conditions, facilitating cation with healthcare providers, and providing accessible, targeted, and easily digestible in-formation related to a condition [1-3]. Multi-feature mHealth interventions are typically bundled as single nterventions, with all of their features offered to re cipients in their entirety, mHealth users may achieve imal benefit if they use all features; however they have the option to choose which features they want to use. Bundled features in mHealth tools make it difficult to identify the mechanism(s) of action be-hind multi-featured interventions. Therefore, it may be useful to tease apart the various aspects of a multimission (solid) in emerging as a been before the control of the co

self-management tools to allow personal monitoring

Published online: 9 December 2019

## Where we are

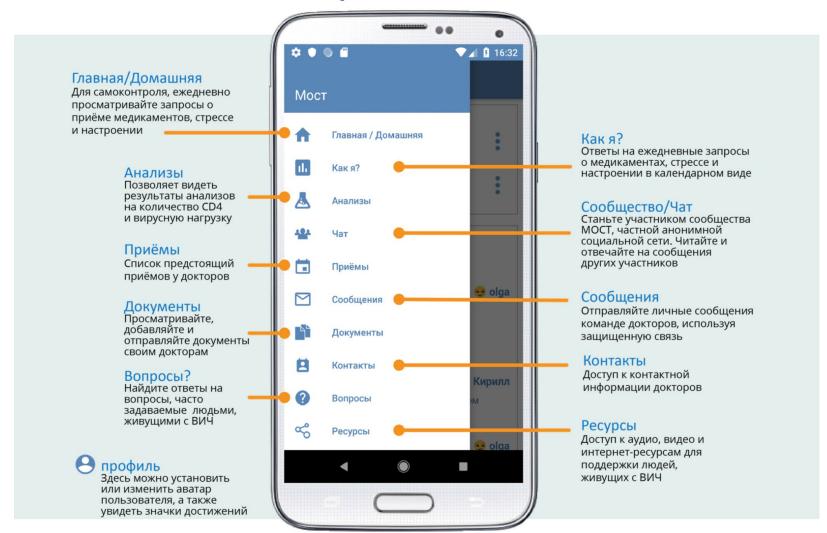






### PositiveLinks Irkutsk

### Открыть и Главная











# PositiveLinks Spanish







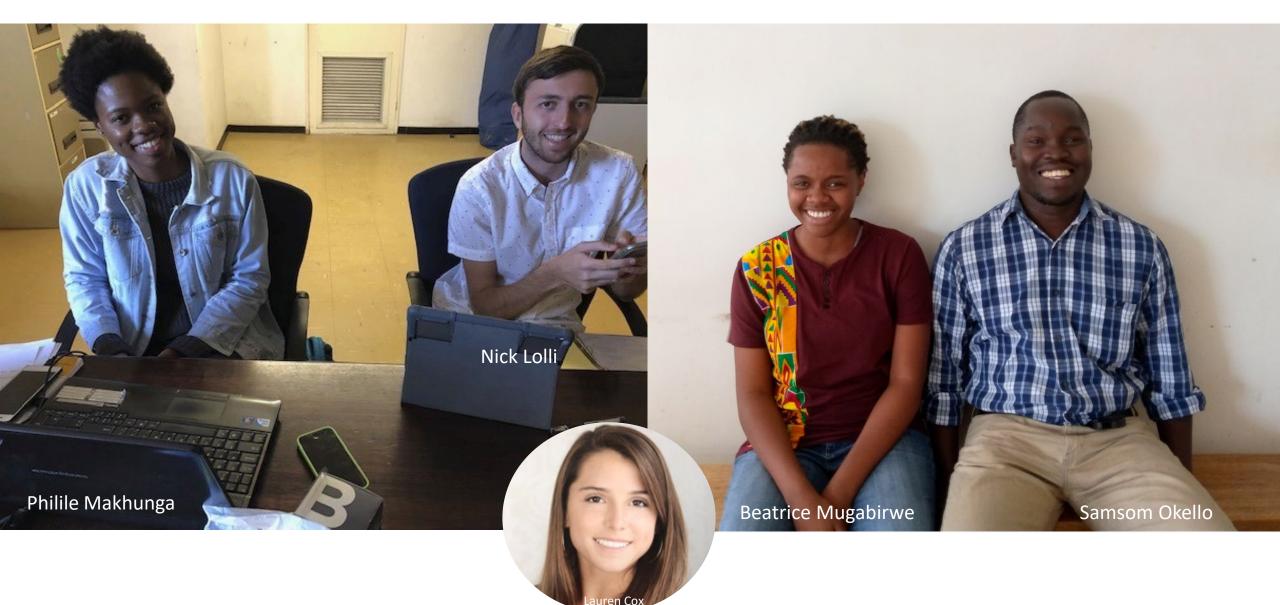




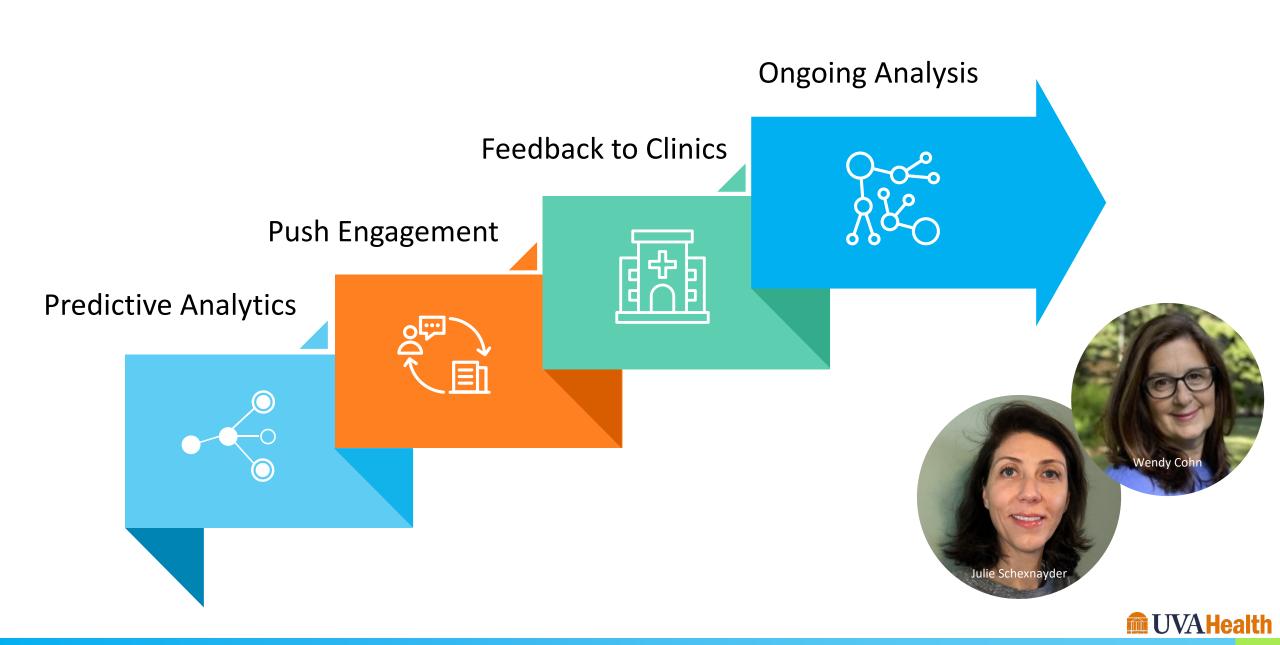




# Tugela Ferry, South Africa | Mbarara, Uganda



# **Next Steps**



# Adaptations



### **Pre-exposure prophylaxis (PrEP)**





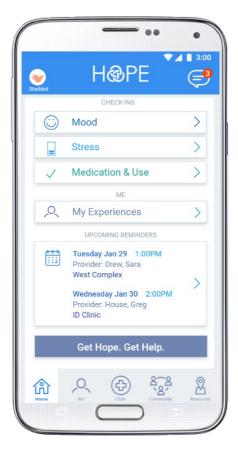
- PrEP uptake and adherence are essential for HIV prevention, and often remain low.
- Prep'd is designed with and by users to support PrEP clients and candidates in uptake and maintenance of PrEP.
- The app is currently being piloted, examining acceptability and feasibility and initial effects of the app.

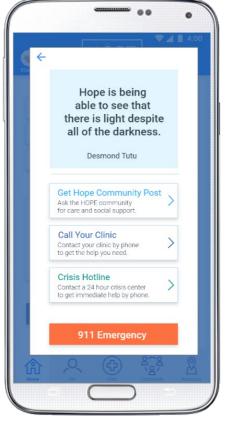




# Adaptations

### **Opioid Use Disorder**





- Opioid use disorder is an urgent public health concern. Avoiding relapse is essential to successful recovery.
- HOPE is designed to support individuals in recovery through self-monitoring tools, social support "get hope, get help", and informational resources.
- The app is under development with a pilot planned for up to three sites in Virginia.











# **Components of Success**

impact

usage

#### **PL SUCCESS USAGE EVIDENCE IMPACT WARMTH ENTHUSIASM PROCESS** High and Clinically **Impact** Users **User-centered** From users, Significant design Long term Related to Feel research to team, and

usage

supported

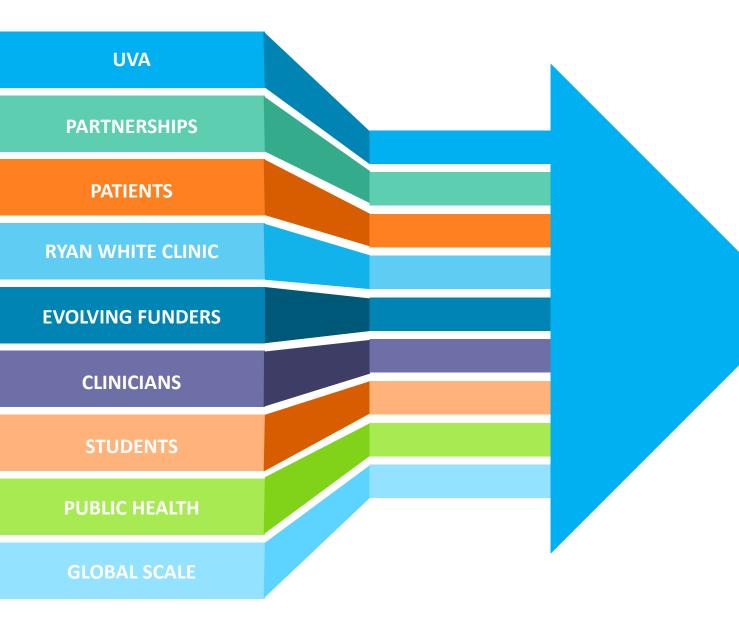
collaborators

R&D

Ongoing

improve

## **Facilitators**



#### **UVA Collaborative Environment**

Across schools, departments, areas of expertise

### **Public – Private Partnerships**

Expand reach

#### **Involvement of Patients**

Patient 'users' involved in every step

### **Ryan White Clinic**

Unique care environment, improve practice

### **Evolving Funders**

UVA-SON, NIH, AIDS United, M.A.C. AIDS, VDH, WHT

#### **Clinicians**

Inform clinical improvements, provide warmth

#### **Students**

Train next generation; science, clinic, public health

### **Public Health-Academic Partnerships**

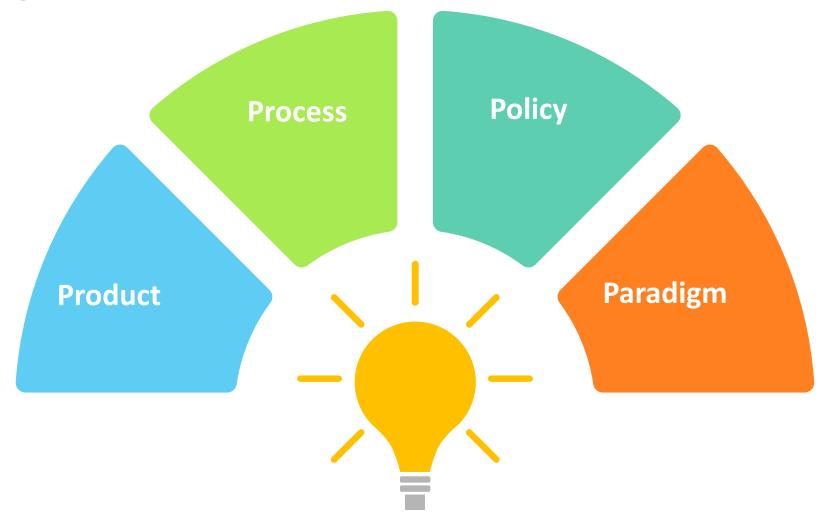
Substantial UVA-VDH partnerships

#### **Global Scale**

Expansion in Russian, Spanish, IsiZulu languages



# Innovations



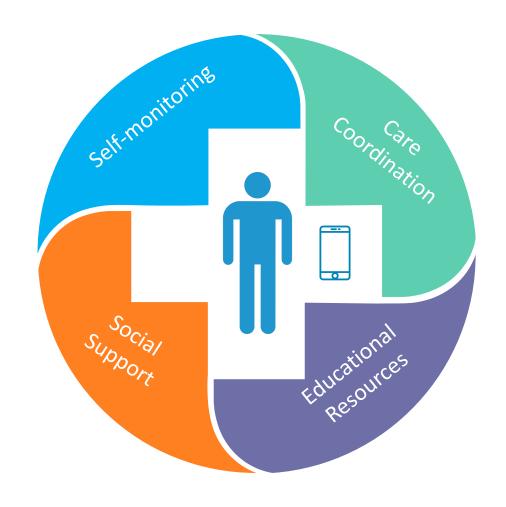
**Innovation Effectiveness** 



# A New Paradigm of Care



Trying to Engage in Care



**Facilitated Care** 



# Benefits of a new paradigm of care



"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 one day, one app, and one click at a time."

- PL Participant



## With Thanks

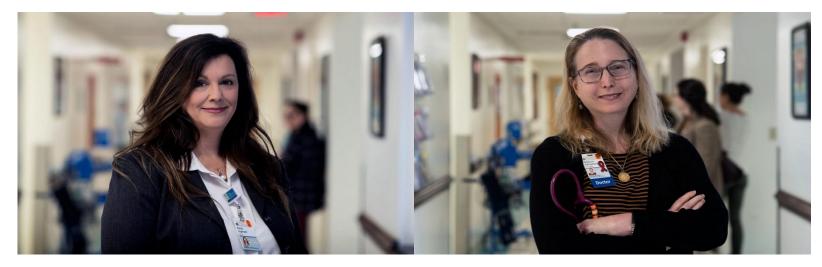


Photo Credit: Dan Addison, University Communications, UVA Today

To the patients, staff, and providers at the UVa Ryan White Clinic for inspiring and supporting this work.







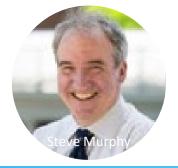


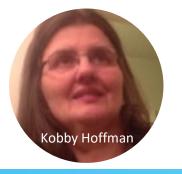


















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