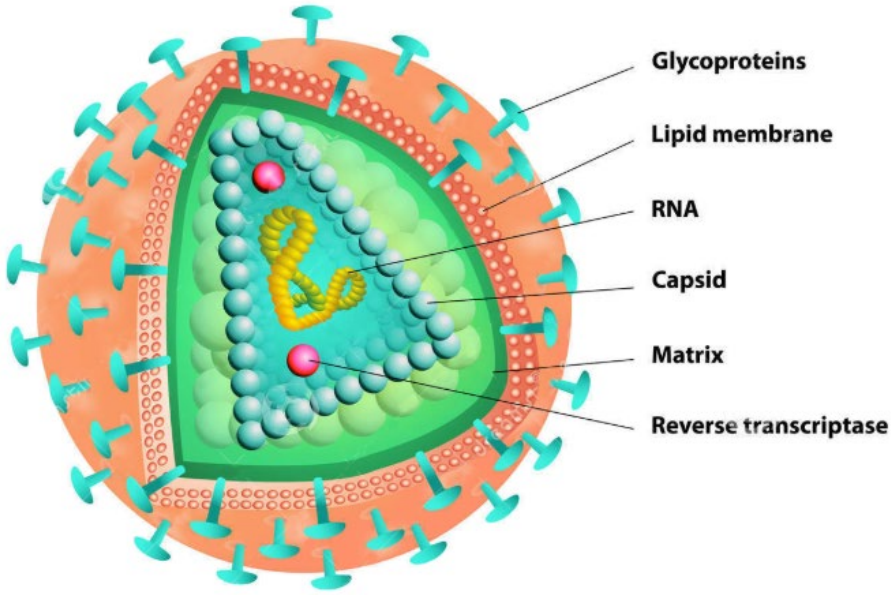
Edlich-Henderson Innovator Award Public Address

Rebecca Dillingham
Karen Ingersoll

February 18, 2020

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

Global HIV & AIDS statistics – 2019 fact sheet, UNAIDS. Unaids.org/en/resources/fact-sheet. Accessed 2/16/2020. HIV illustration courtesy Dreamstime.com

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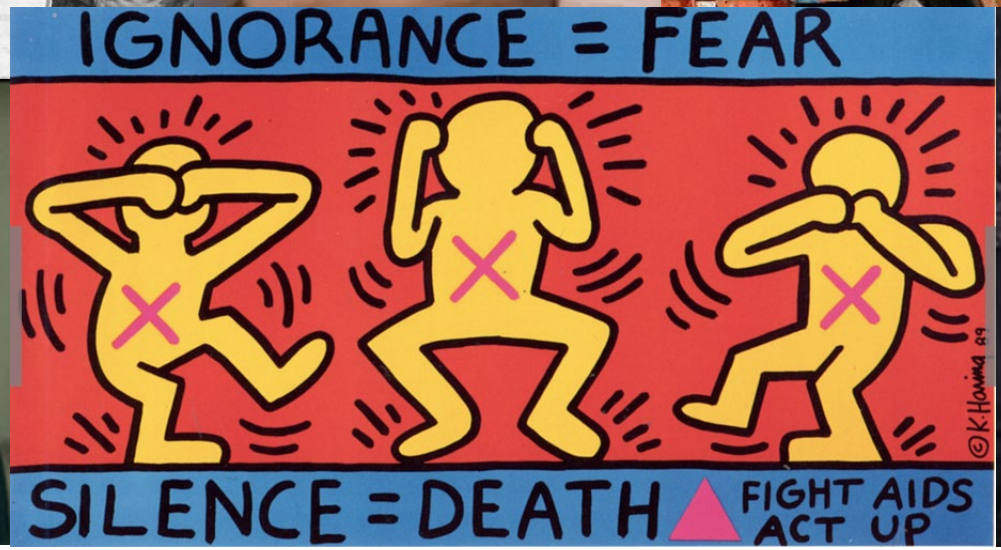
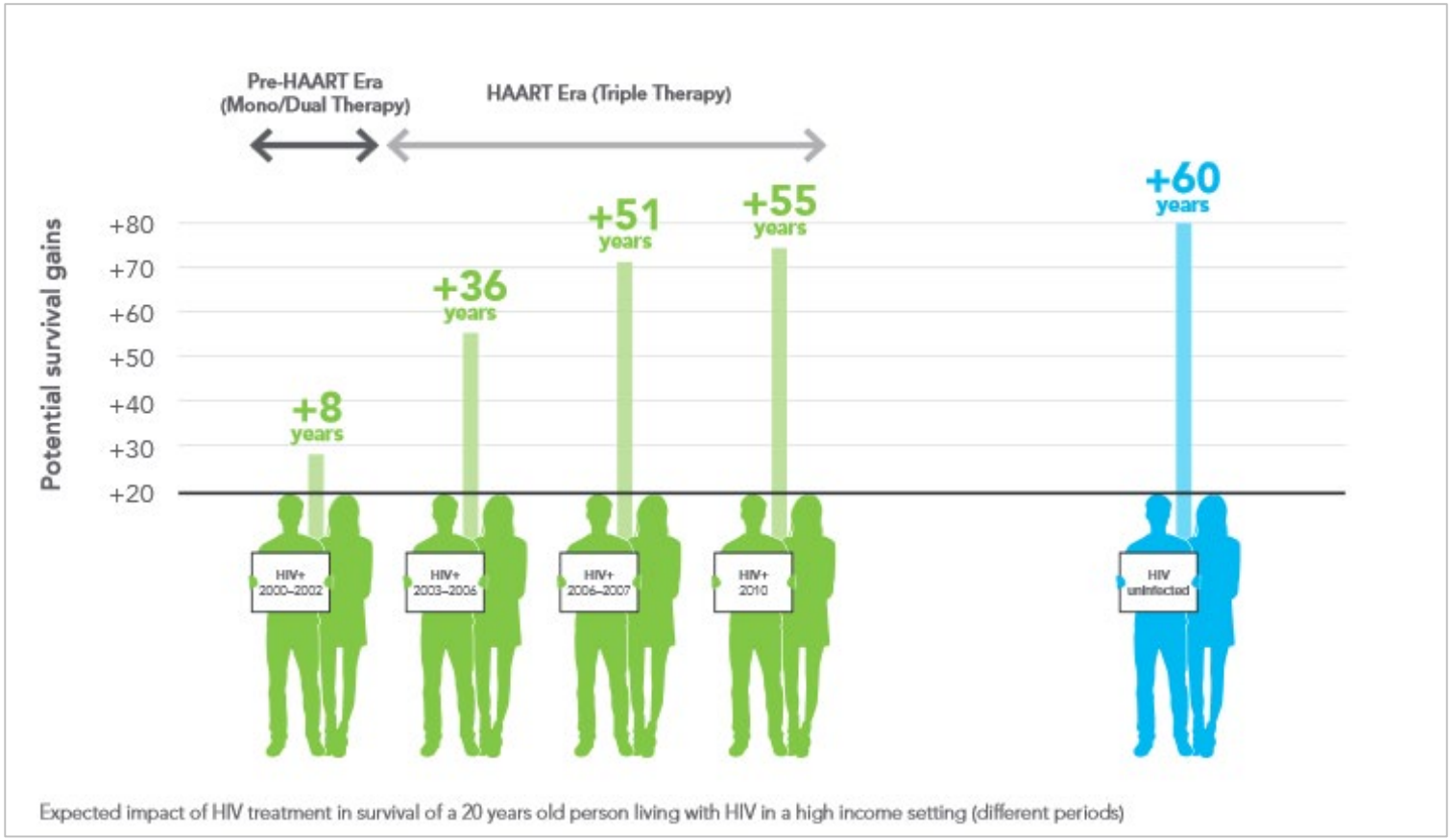
Confronting an Epidemic



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**



Expected impact of HIV treatment in survival of a 20 years old person living with HIV in a high income setting (different periods)

Source: Samji H et al, PLoS ONE, 2013. https://www.avert.org/news/life-expectancy-people-hiv-now-near-normal accessed 2/15/2020

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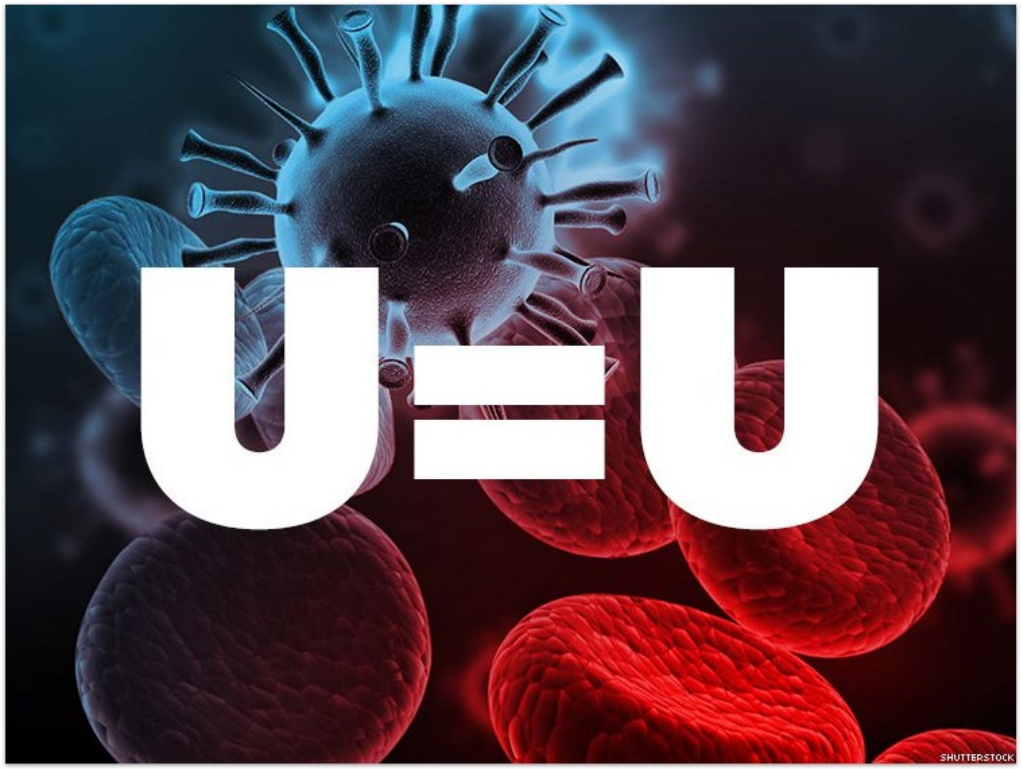
Undetectable=Untransmittable

TREATMENT ▶ TREATMENT

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



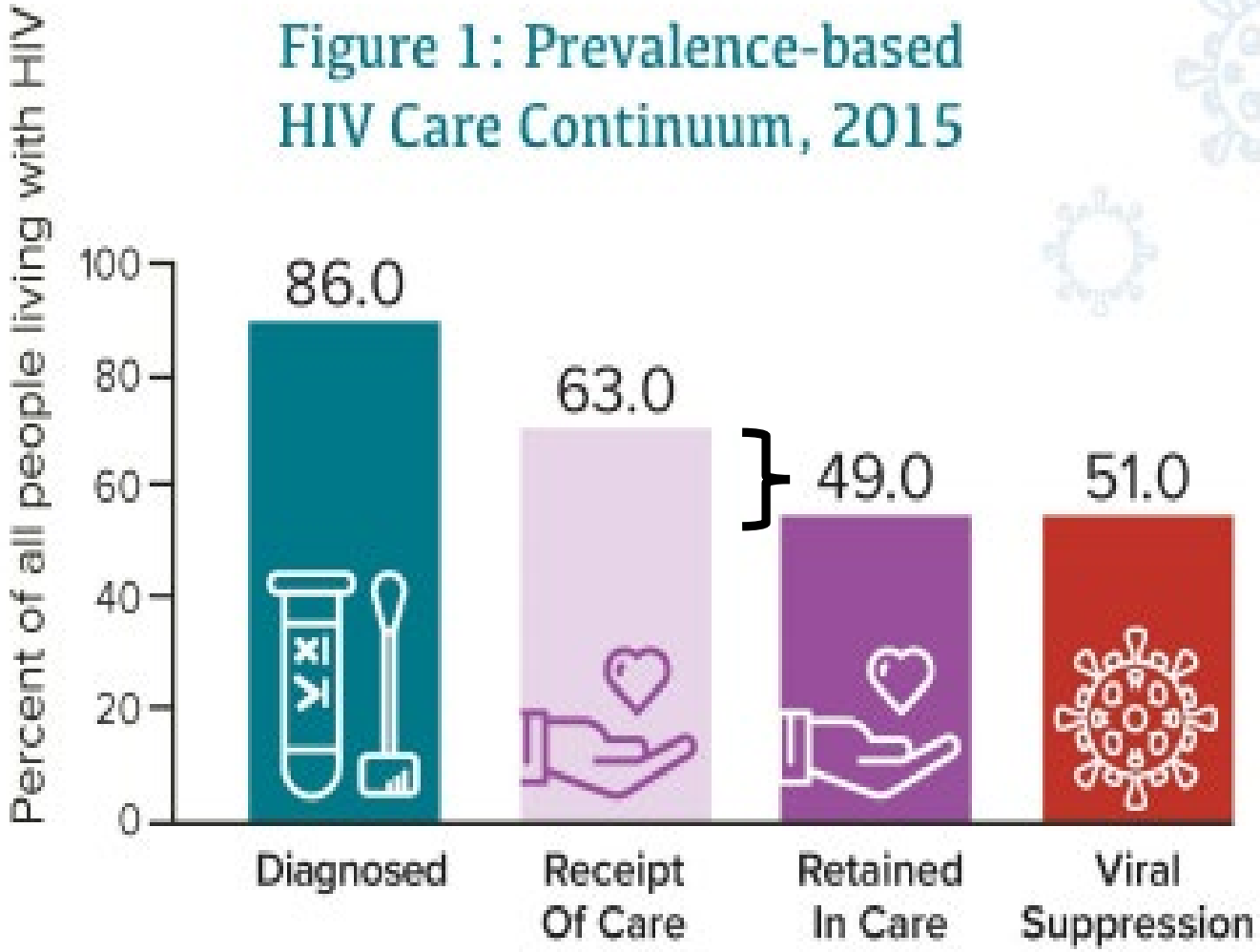
In a historic letter, the Centers for Disease Control and Prevention support the science behind "Undetectable Equals Untransmittable."

By Savas Abadsidis

OCTOBER 22 2017 3:25 PM EDT

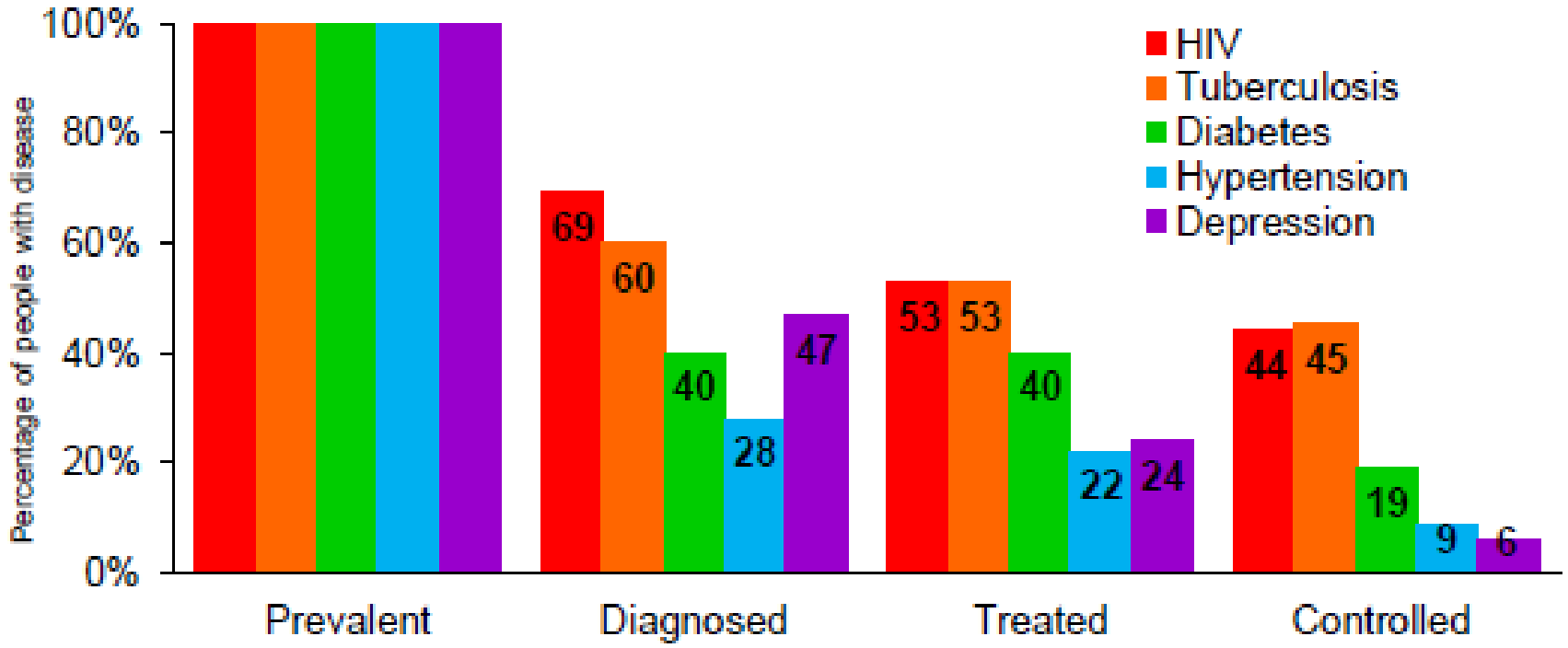
https://www.hivplusmag.com/undetectable/2017/9/27/breaking-cdc-officially-recognizes-undetectableuntransmittable-hiv-prevention

HIV Care Continuum



https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf

Engagement in Care



Hyle E, IAC 2018.

Slide from Dr. Melanie Thompson's Ryan White Clinical Conference Presentation, December 2018

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

David Malebranche

Slide from Dr. Melanie Thompson's Ryan White Clinical Conference Presentation, December 2018

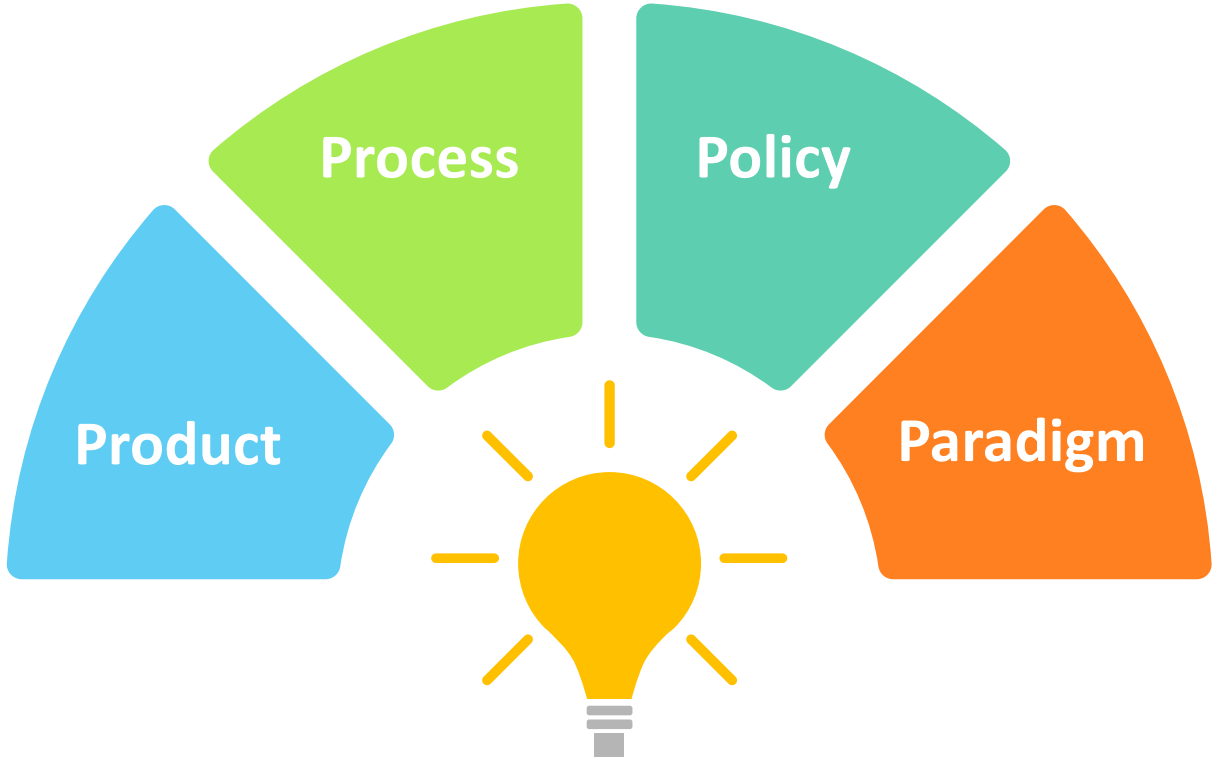
Innovation?

Malcolm Gladwell

Steve Jobs

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…

https://grants.nih.gov/grants/guide/pa-files/PAR-12-003.html

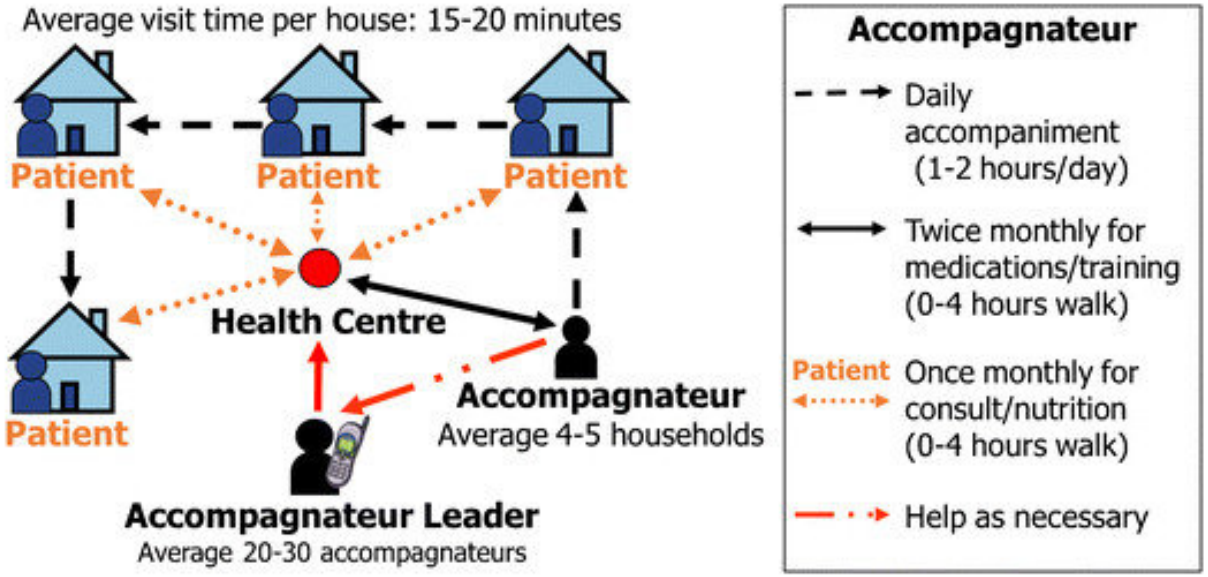
Accompagnement

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
✓	✓	✓	✓	✓	✓	✓

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

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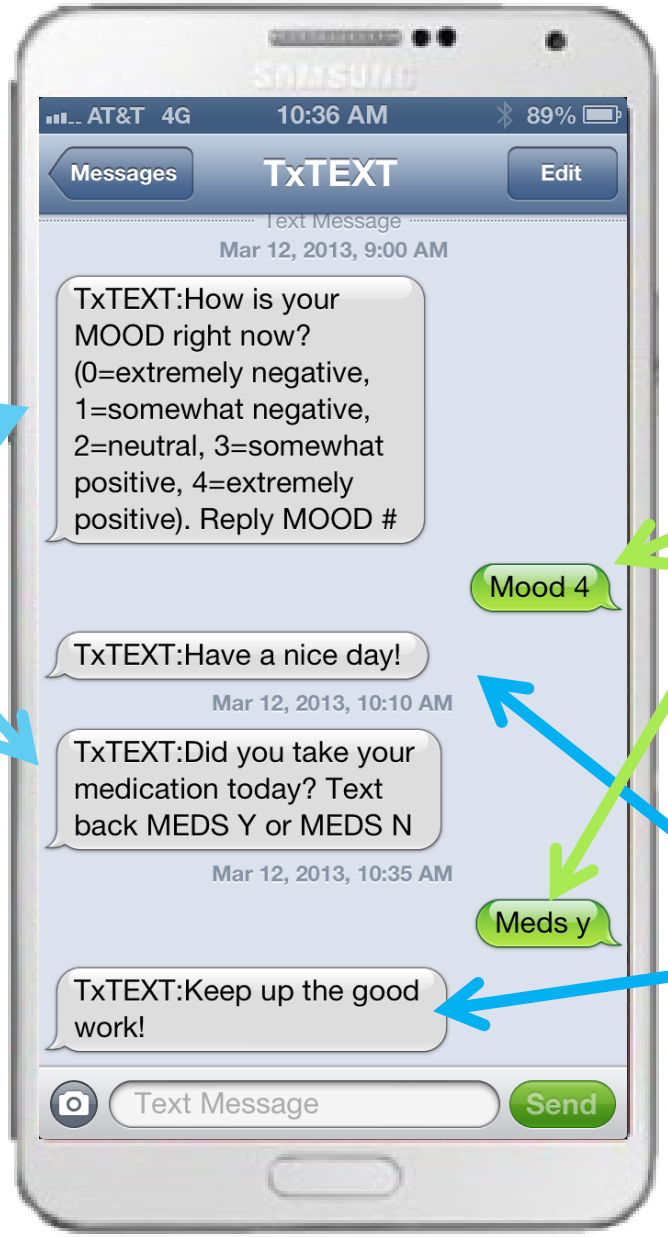
STeM Participant

"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

Ingersoll et al. JSAT. 2014.

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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."

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

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

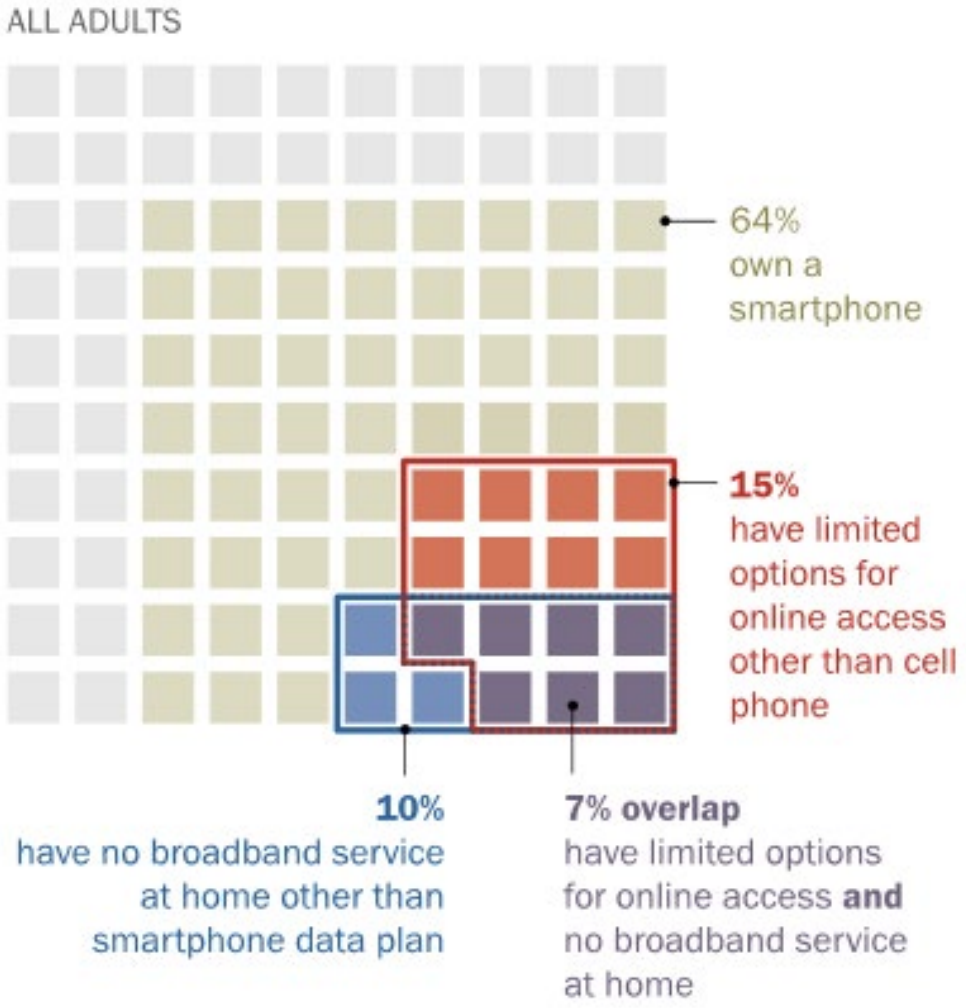
Digital divide

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.

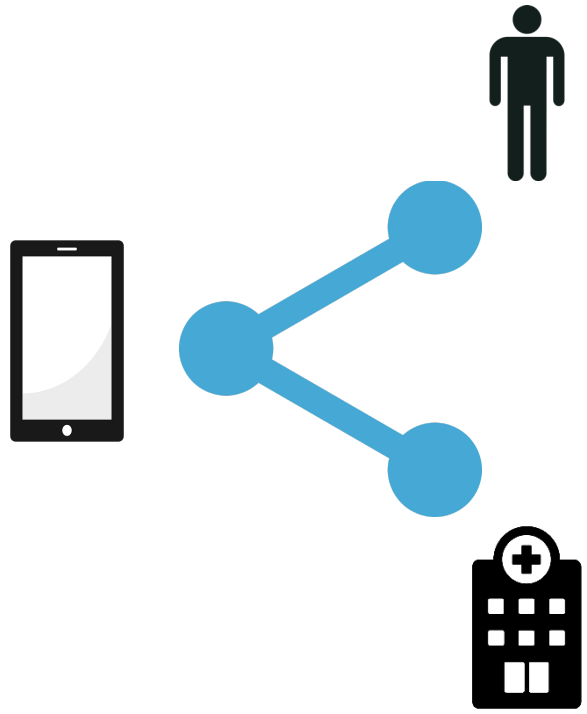
12% of African Americans vs **4%** of Whites.



Pew Research Center, April, 2015, "The Smartphone Difference. Available at: http://www.pewinternet.org/2015/04/01/us-smartphone-use-in -2015

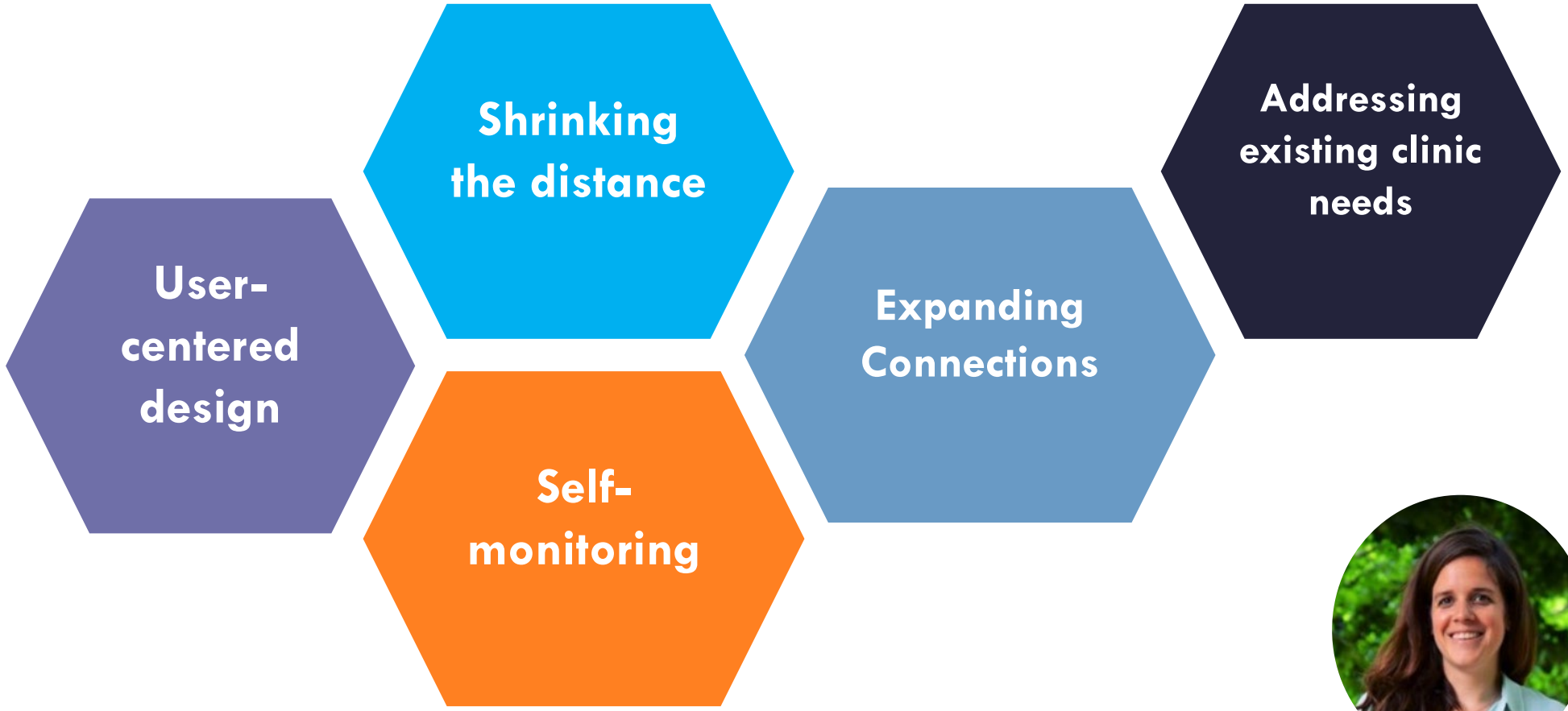
Consistent Phone Access and Engagement in Care

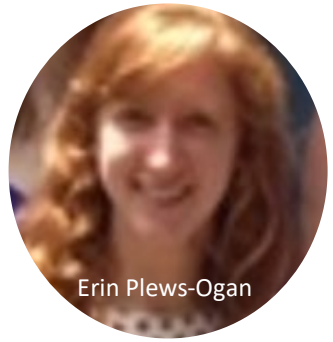
- Recent literature underscores importance of access to consistent communication
- Those who experienced a **change in phone number** during the past year were **significantly more likely to be not engaged in care**



Colasanti J, Stahl N, et al. J Acquir Immune Defic Syndr. 2017;74 Suppl 2(Suppl 2):S113-S120.

App Development Strategies

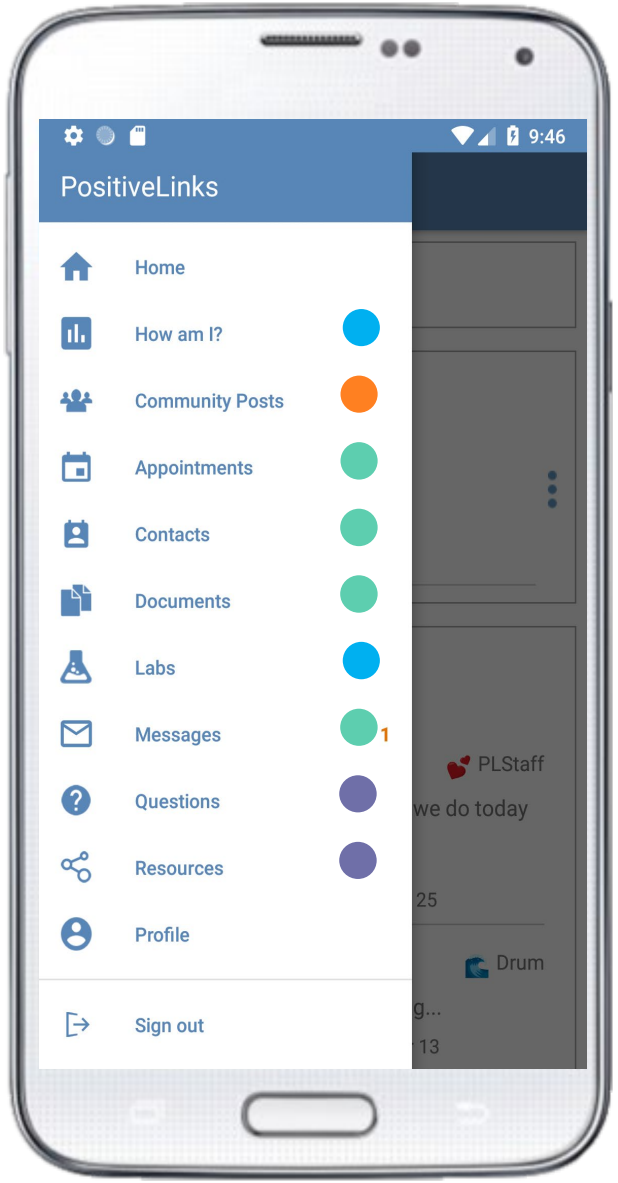



Erin Plews-Ogan

Erin Wispelwey

Colleen Laurence

PL App Components



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

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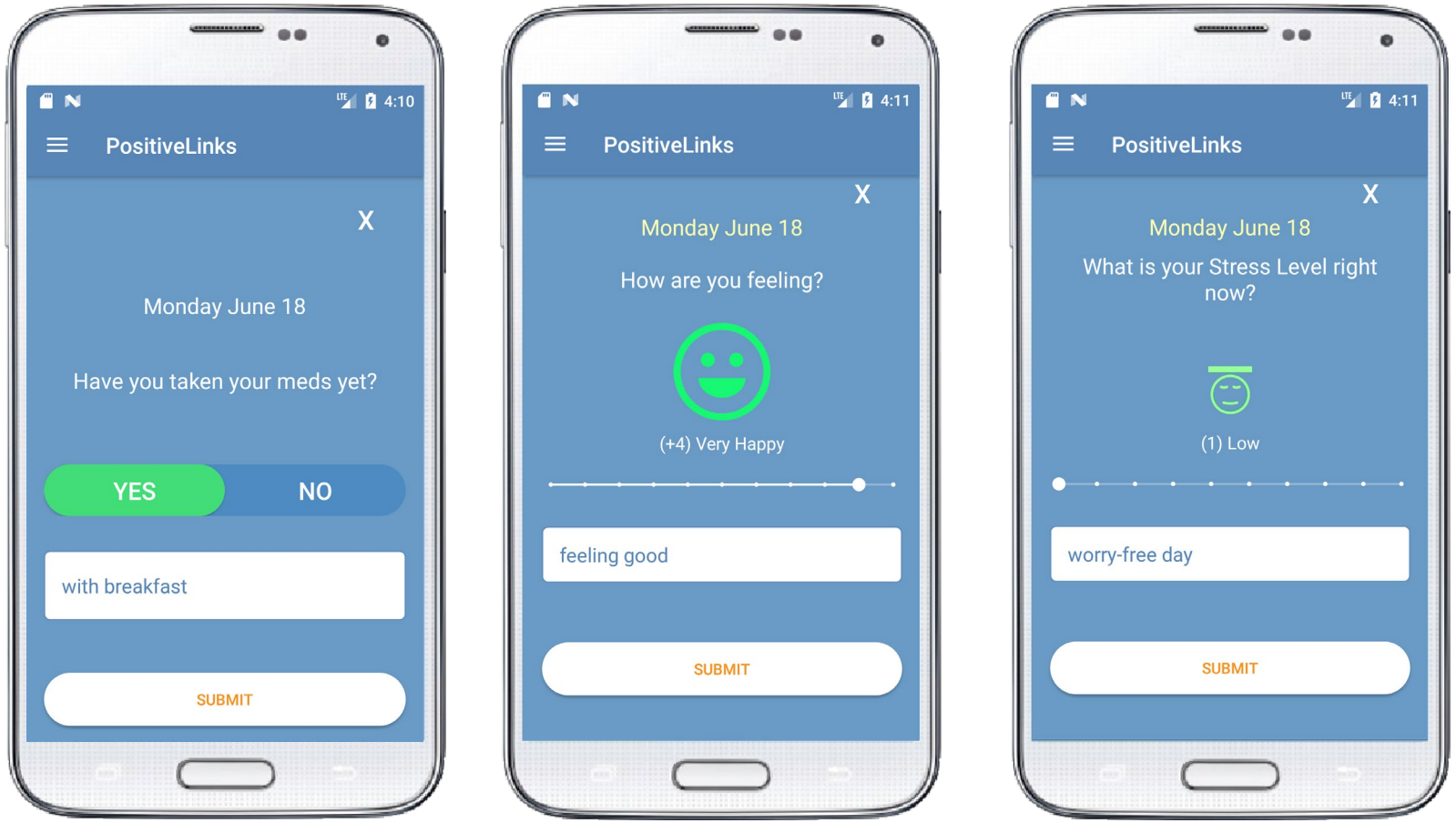
Self-monitoring Check-Ins



"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

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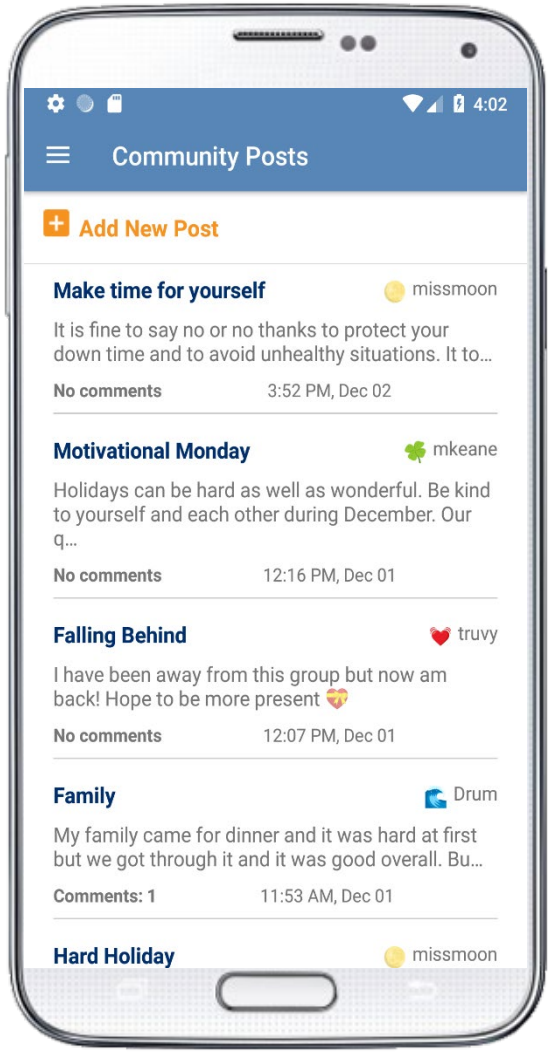
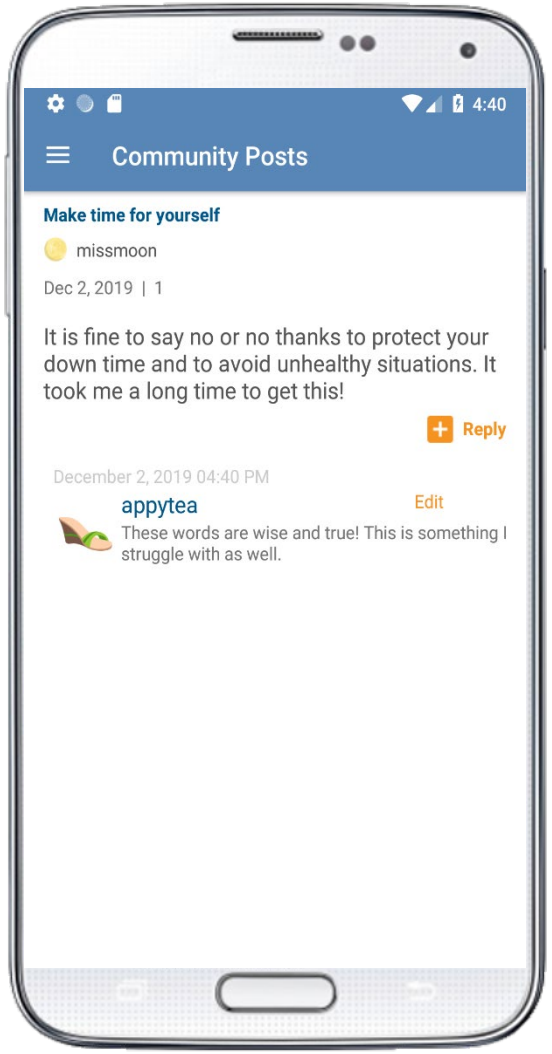
Community Posts





"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

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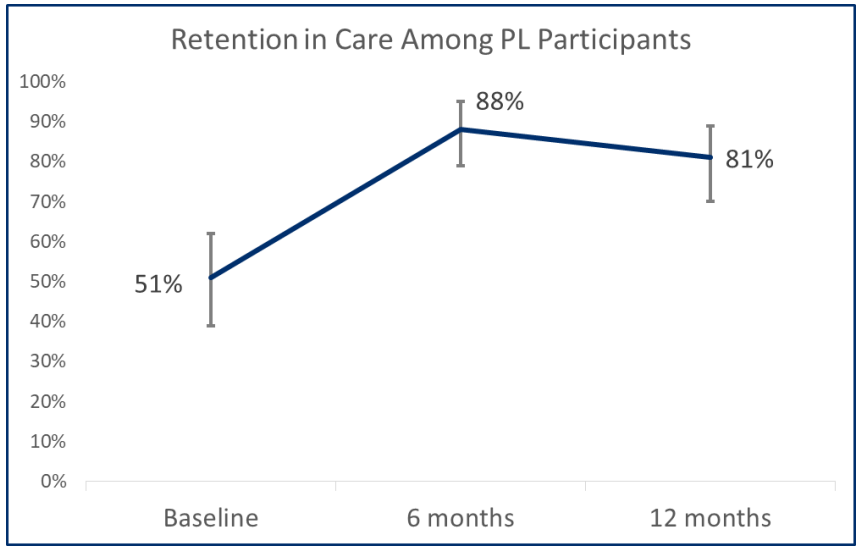
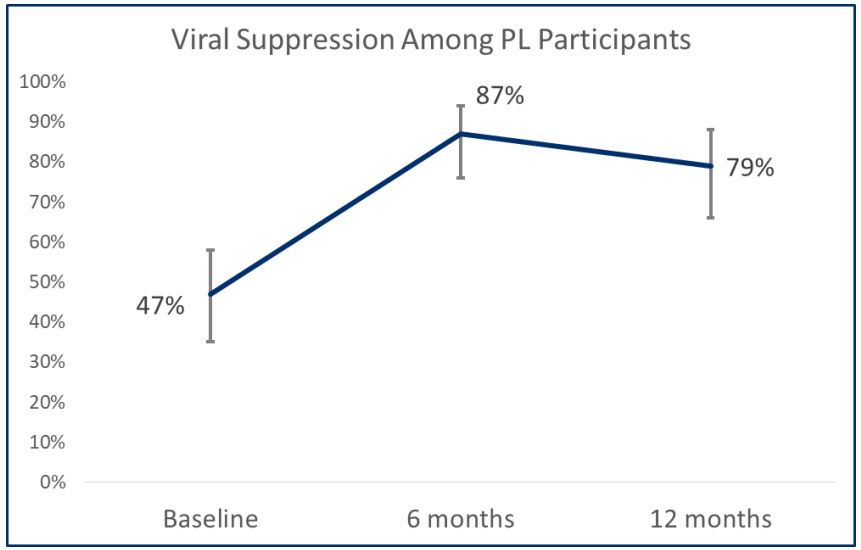
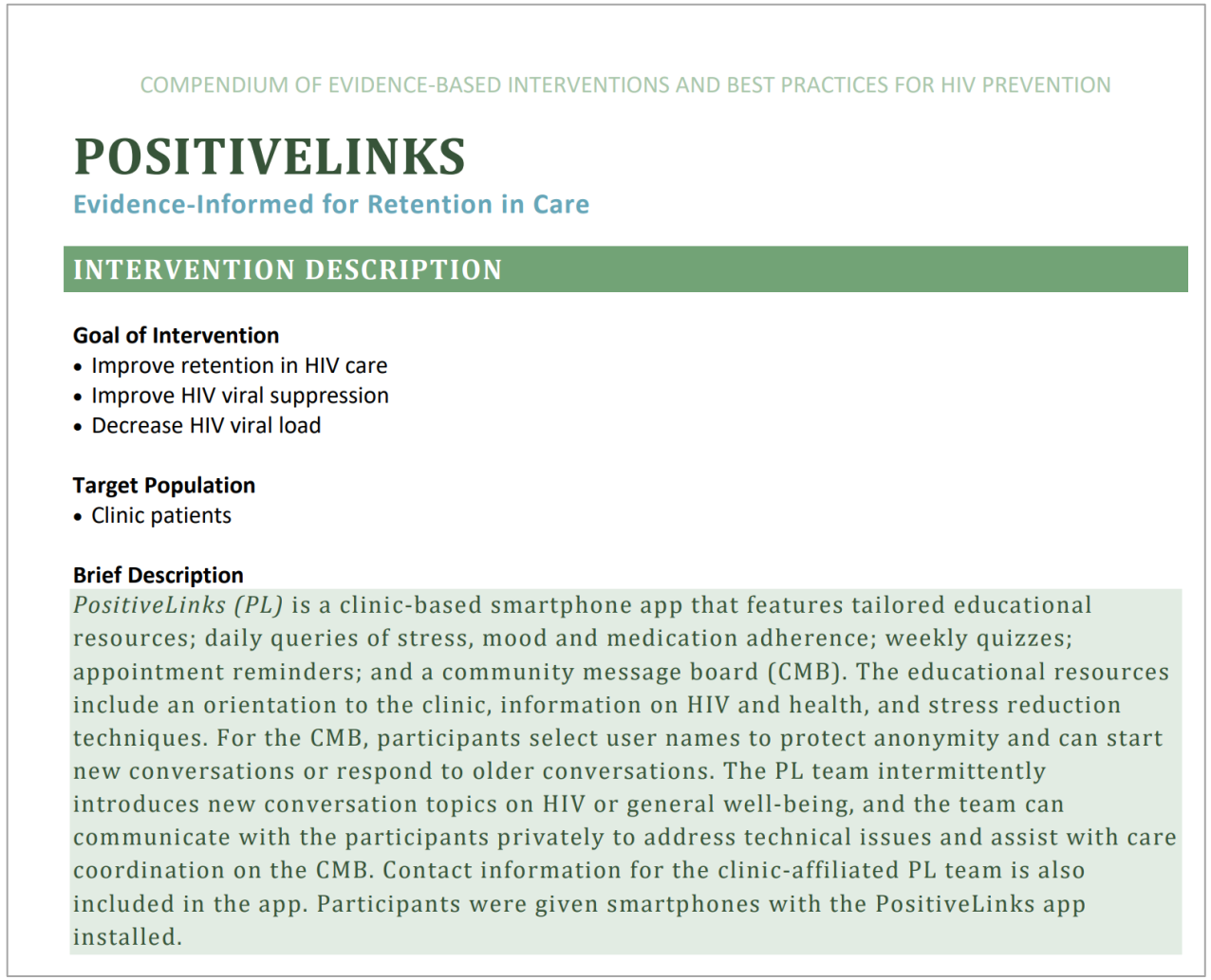
PL V1.0 Outcomes





- 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 Re-engagement in HIV Care (LRC) Chapter

This chapter of the *Compendium* 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 Prevention Research Synthesis (PRS) Project can be obtained by contacting PRS.

https://www.cdc.gov/hiv/research/interventionresearch/compendium/lrc/index.html

In-house Development

Nimble

Responsive

Embedded with clinical staff

Patient-Centered Design

Freddie Jin

Jason Schwendinger

Pravalika Donthineni

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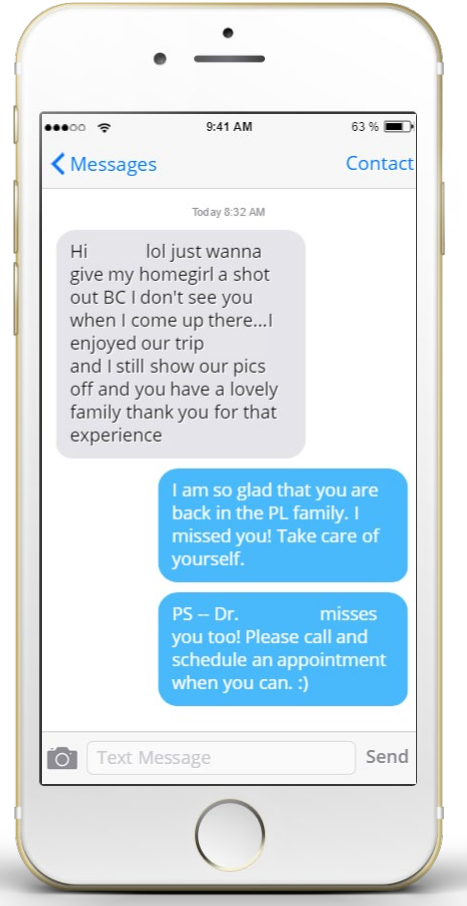
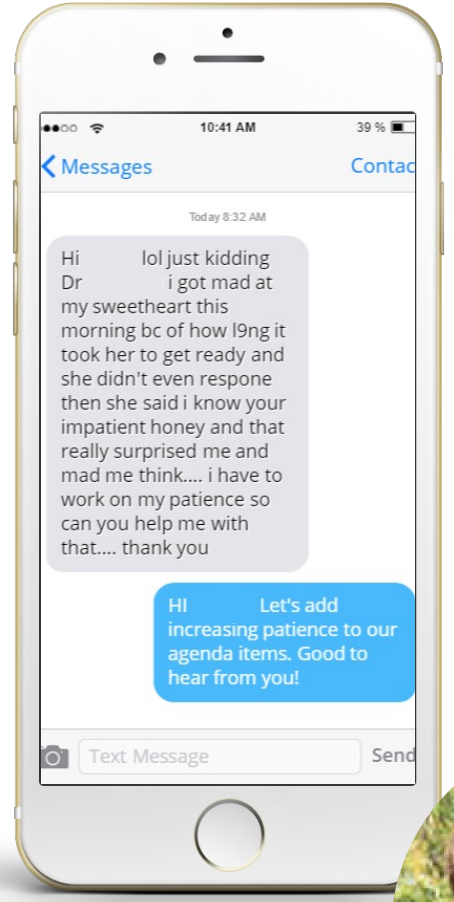
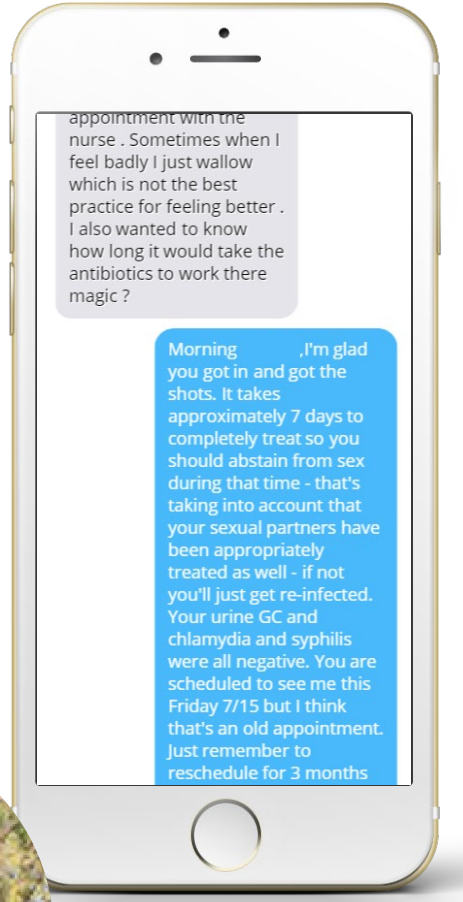
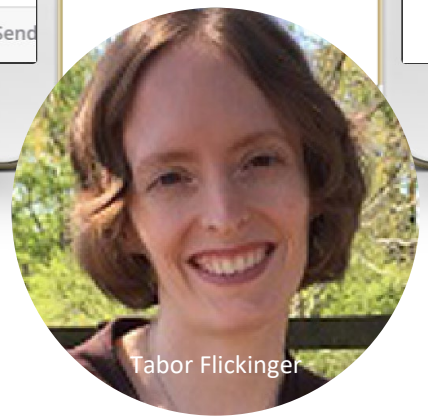
ELECTRONIC COMMUNICATION









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

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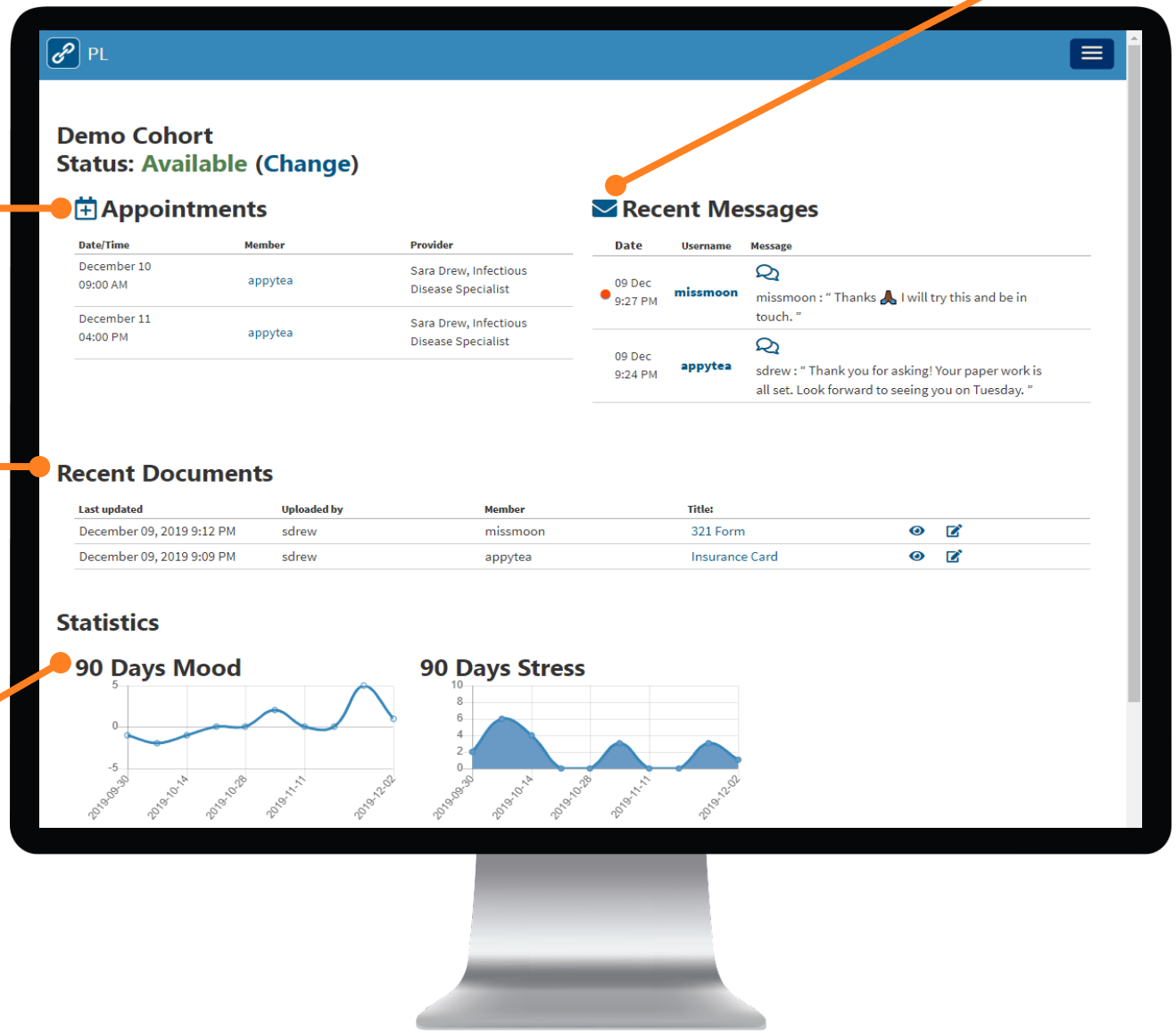
PL Provider Portal Summary

Recent Messages from or to Members

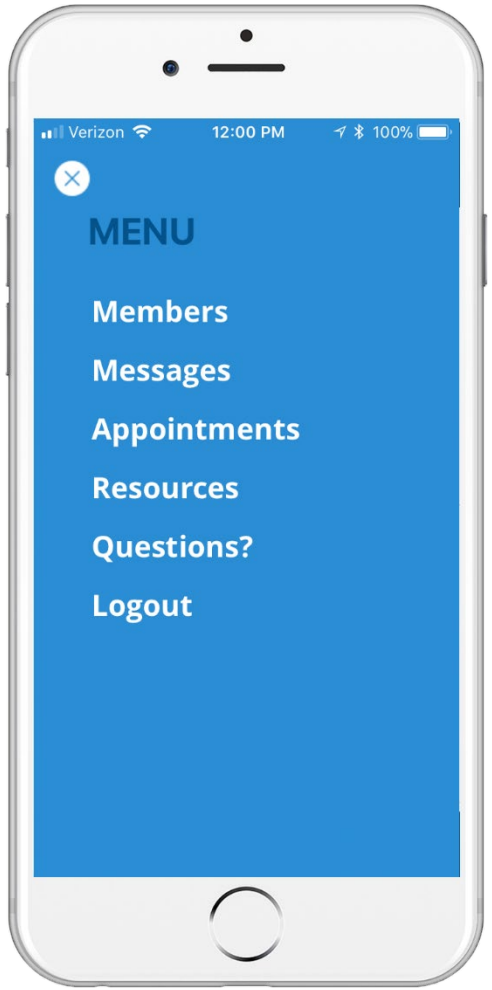
Upcoming Appointments with PL Members

Documents recently shared with or by Members

Cohort Mood and Stress graphs for past 90 days



PL Provider App



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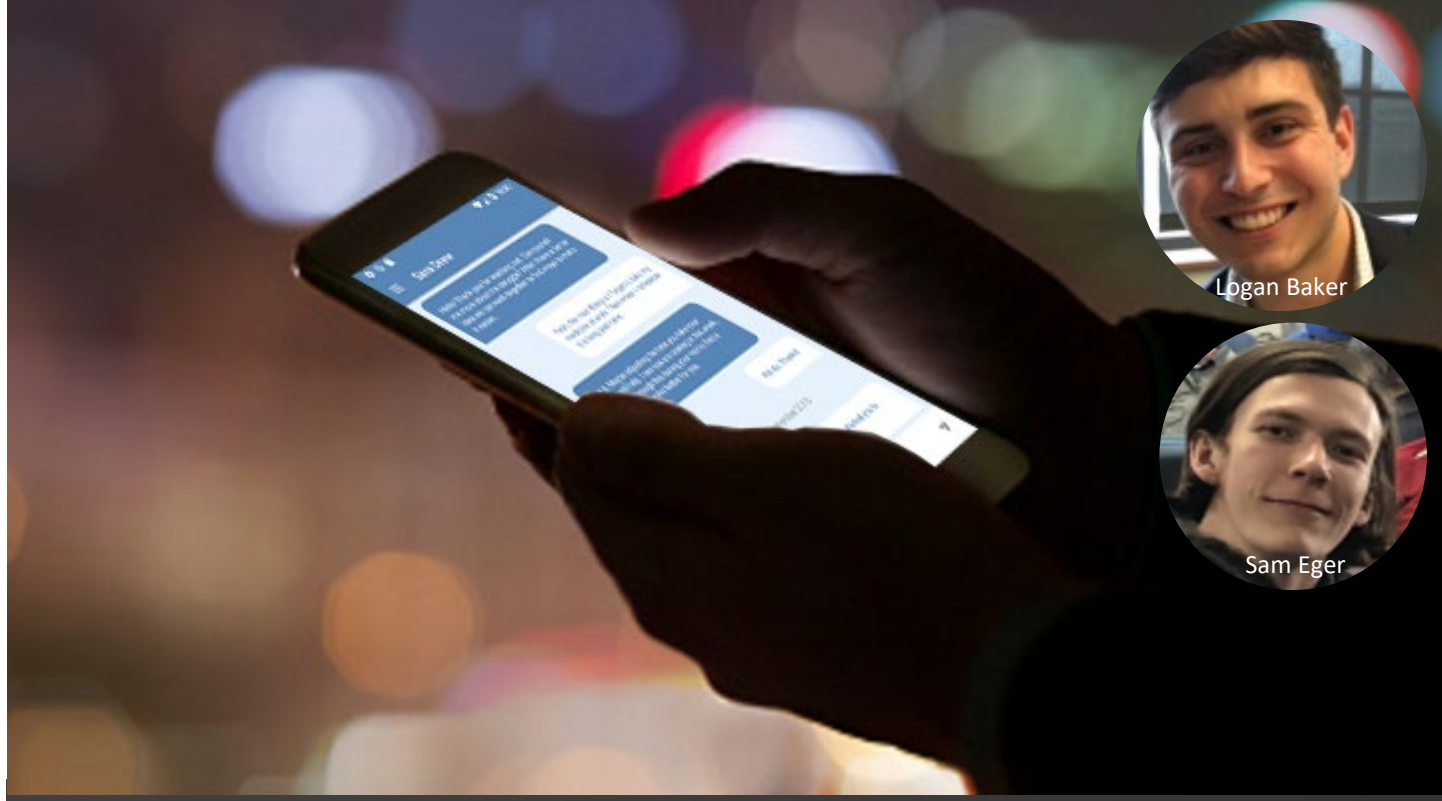
"I can contact [my provider] more frequently now. I like to have that option."

"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."

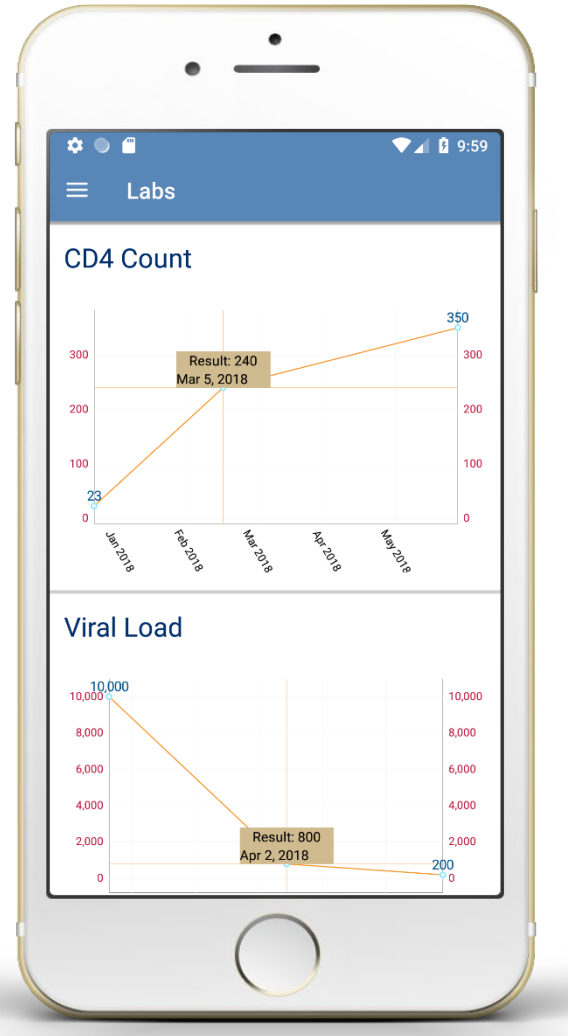


What do our most at-risk users say about messaging?

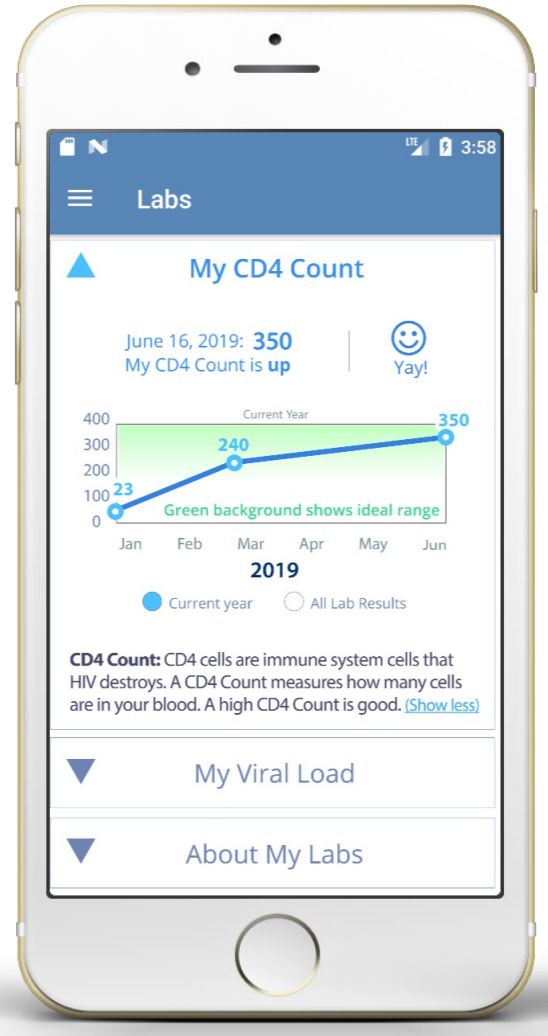
These users find messaging to be one of the most useful features of the app– more useful than medication tracking!

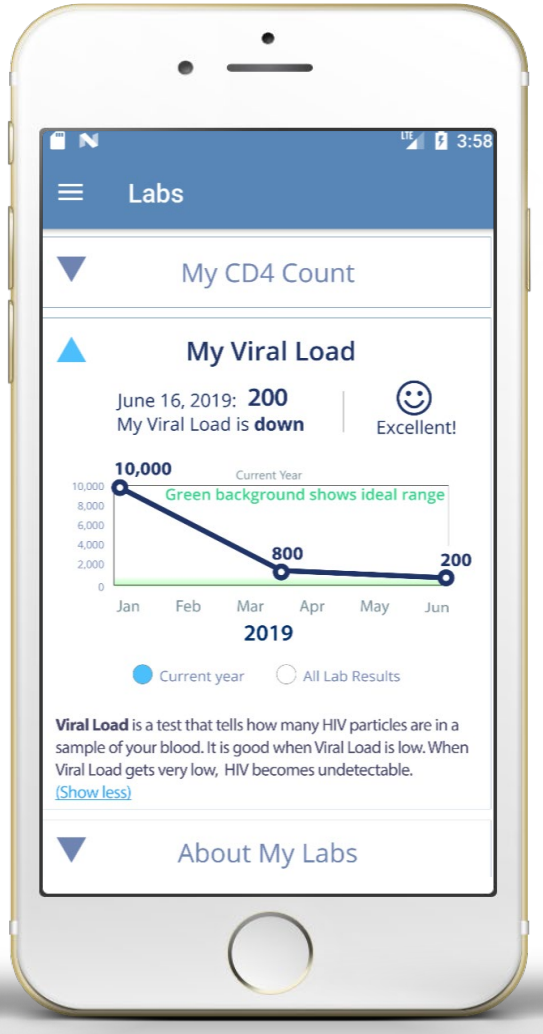
Canan C, Flickinger T, Grabowski M et al. Toward understanding the impact of mHealth features for people with HIV: a latent class analysis of PositiveLinks Usage. Transl Behav Med 2019 Dec 9

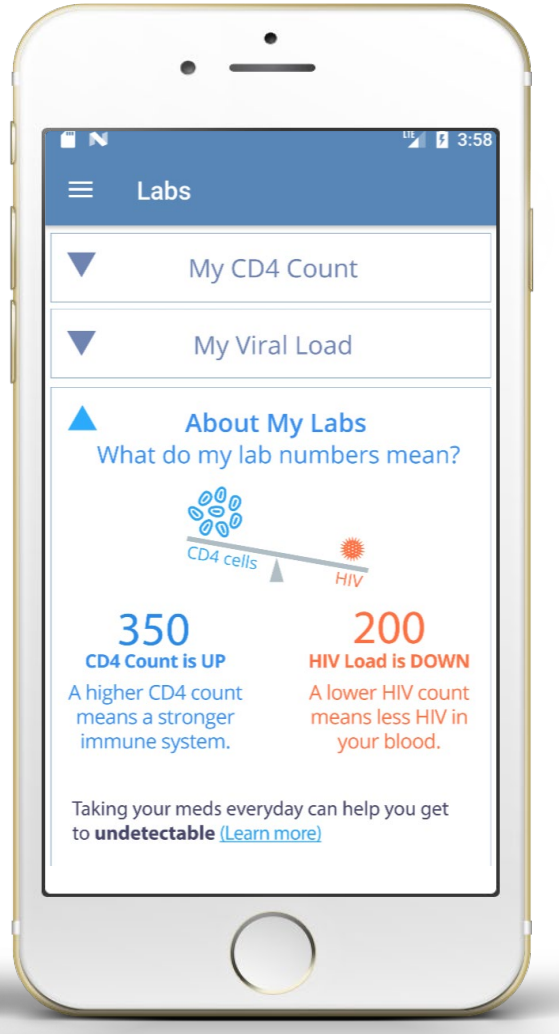
Labs Redesign



Before







After

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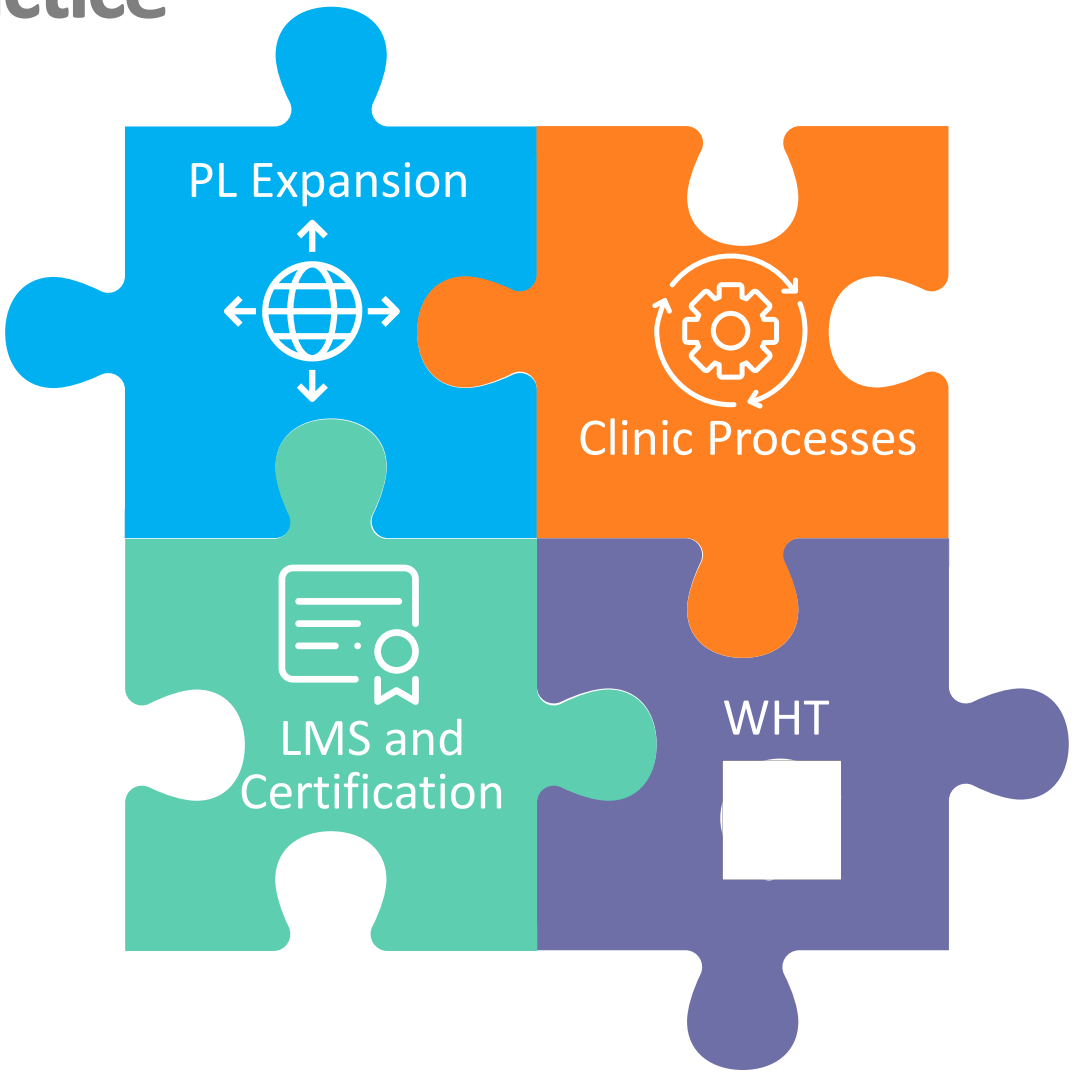
Community of Practice



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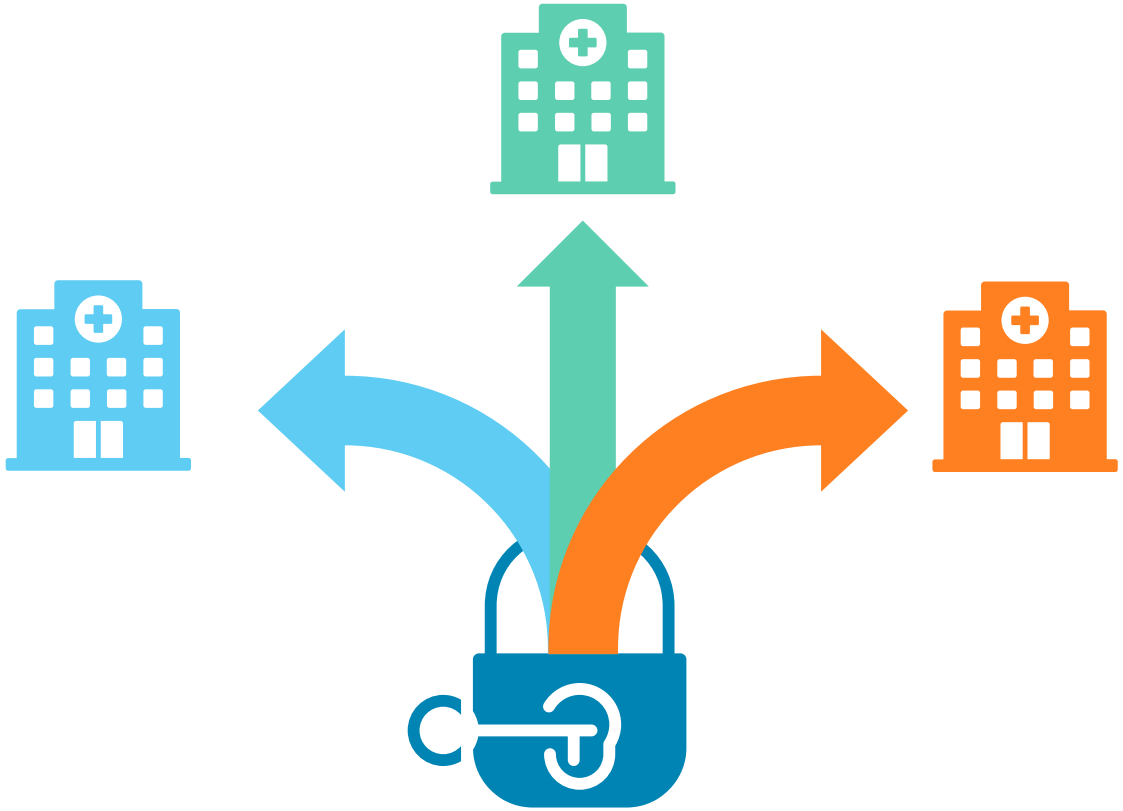
Public – Academic Partnership



Scaling PL to other clinics with a turn key system

VDH VIRGINIA DEPARTMENT OF HEALTH
Protecting You and Your Environment

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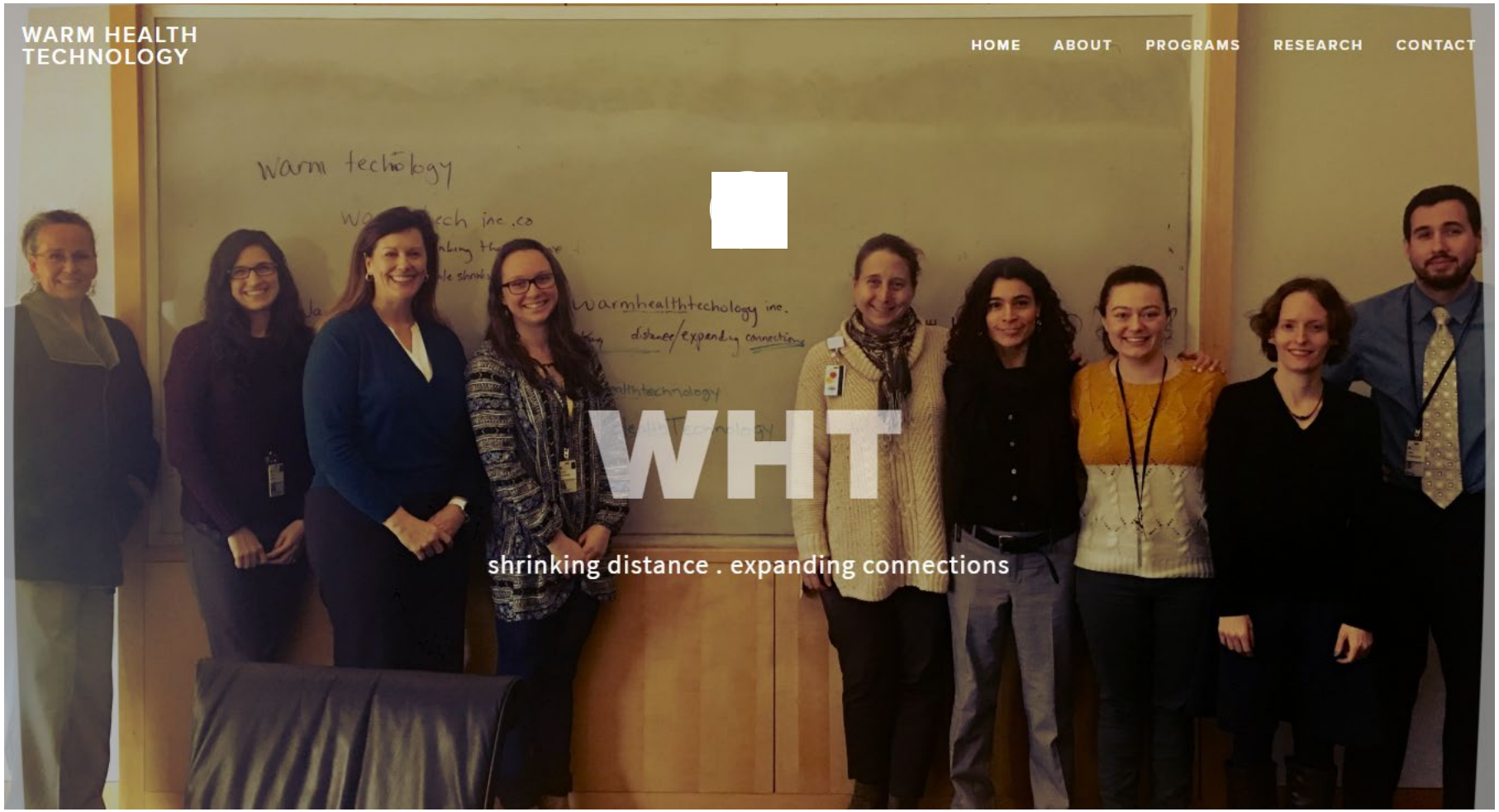
Warm Health Technology



Ethics of Data Safety and Equity of Access

Informatics for Health: Connected Citizen-Led Wellness and Population Health
R. Randell et al. (Eds.)

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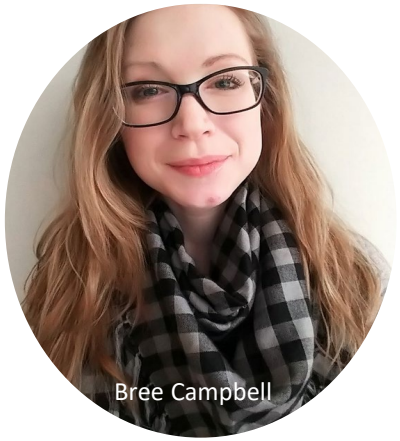
doi:10.3233/978-1-61499-753-5-363

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[a1] and Declan O'SULLIVAN[a]
[a] *School of Computer Science and Statistics, Trinity College, Dublin 2*



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

Taylor & Francis
Taylor & Francis Group

EDITORIAL

Check for updates

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

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PL Research

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

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

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

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

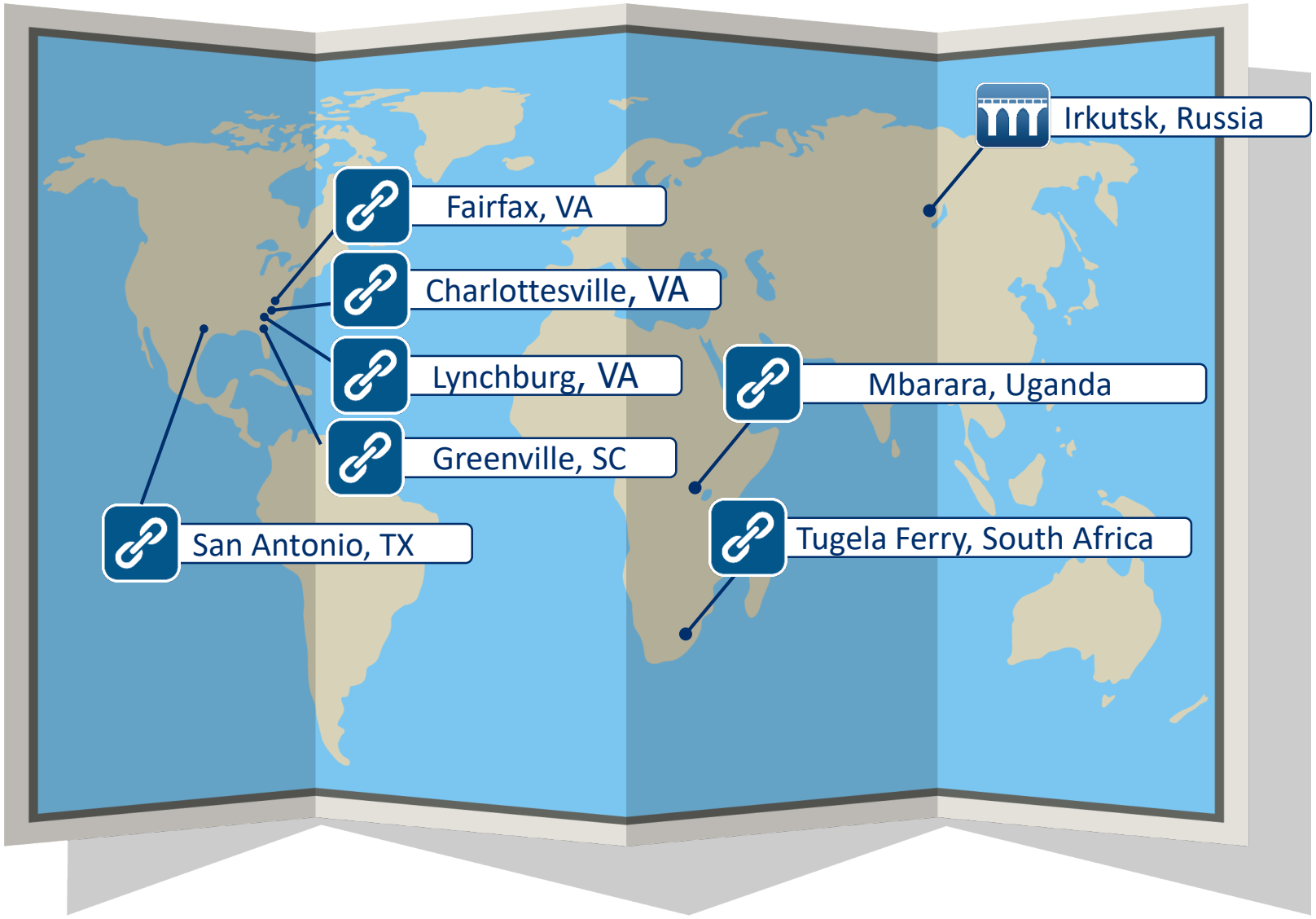
Secure Messaging Through PositiveLink Communication in a Clinic-Affiliated Living with HIV

Development of Positive Linkage and Retentio

TBM

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

Where we are



Available in English, Spanish, Russian, and isiZulu

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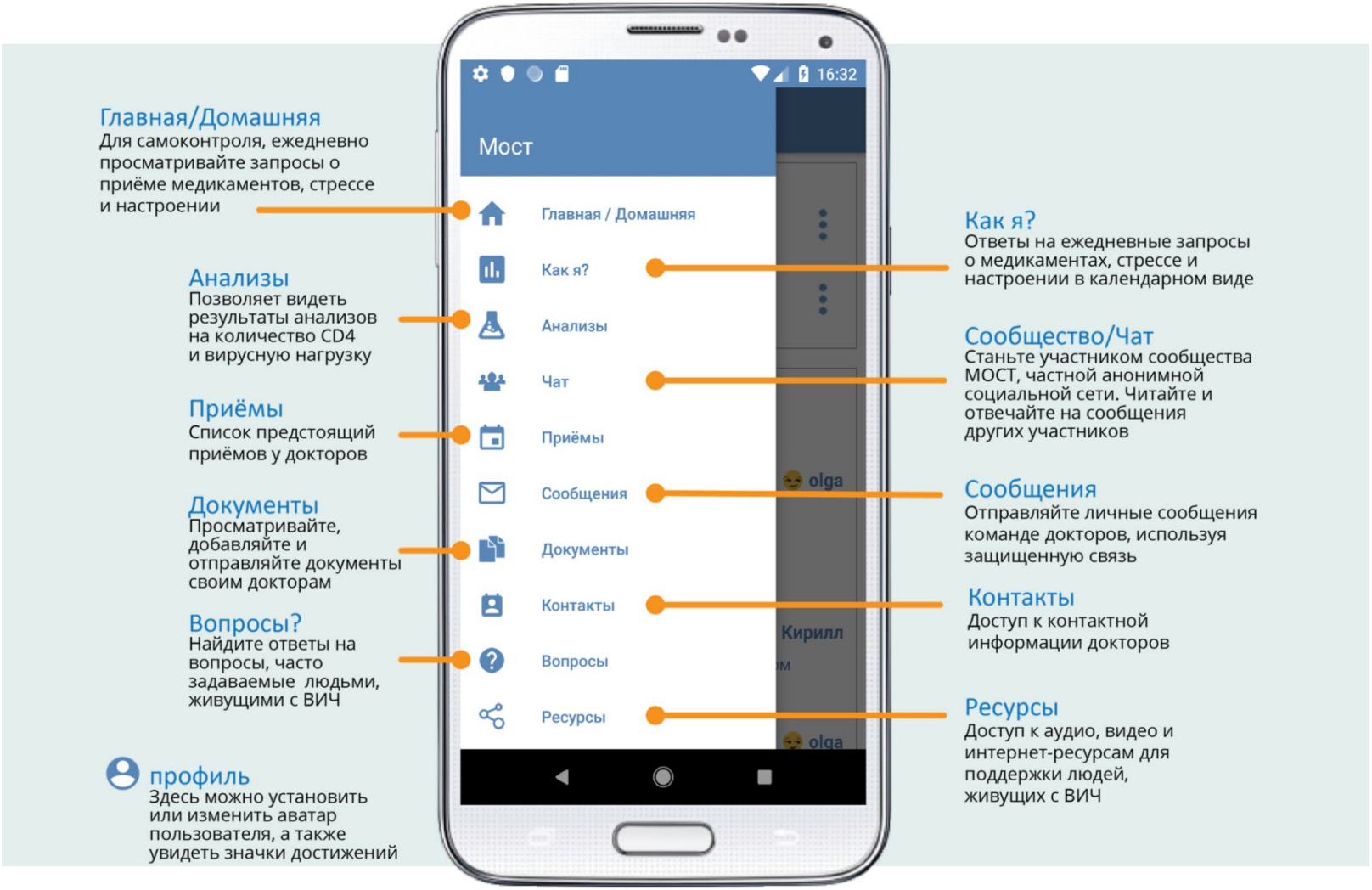
PositiveLinks Irkutsk

Открыть и Главная



Главная/Домашняя
Для самоконтроля, ежедневно просматривайте запросы о приёме медикаментов, стрессе и настроении

Анализы
Позволяет видеть результаты анализов на количество CD4 и вирусную нагрузку

Приёмы
Список предстоящий приёмов у докторов

Документы
Просматривайте, добавляйте и отправляйте документы своим докторам

Вопросы?
Найдите ответы на вопросы, часто задаваемые людьми, живущими с ВИЧ

профиль
Здесь можно установить или изменить аватар пользователя, а также увидеть значки достижений

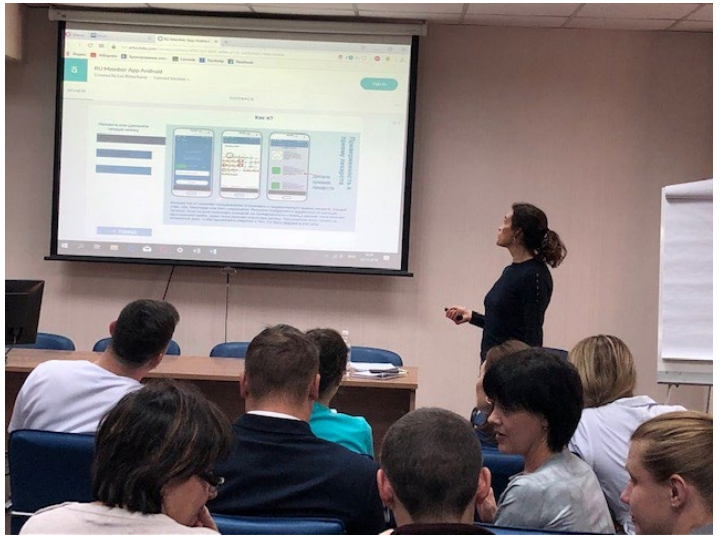
Как я?
Ответы на ежедневные запросы о медикаментах, стрессе и настроении в календарном виде

Сообщество/Чат
Станьте участником сообщества МОСТ, частной анонимной социальной сети. Читайте и отвечайте на сообщения других участников

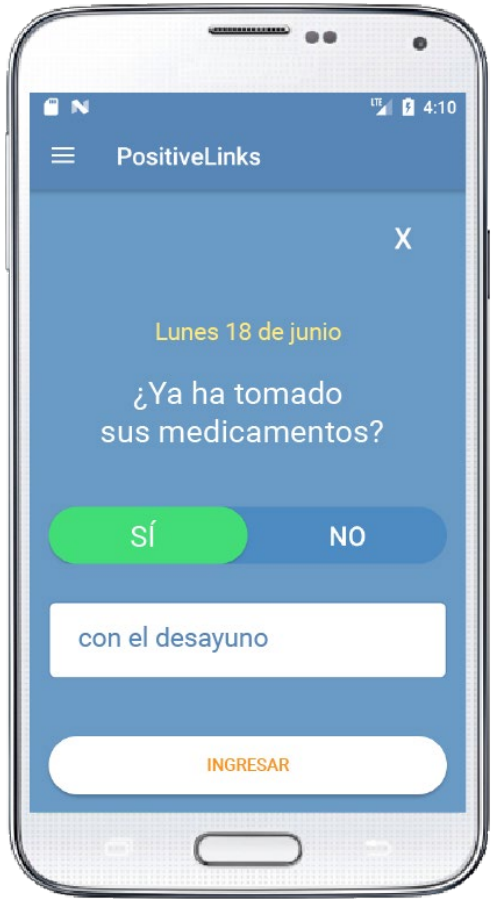
Сообщения
Отправляйте личные сообщения команде докторов, используя защищенную связь

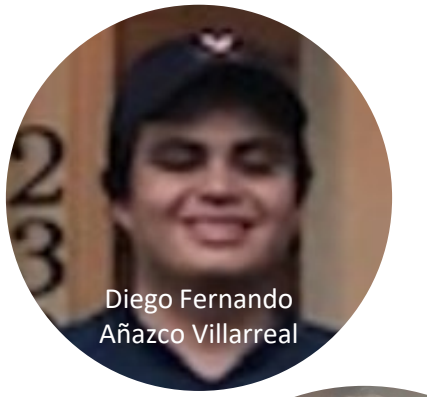
Контакты
Доступ к контактной информации докторов

Ресурсы
Доступ к аудио, видео и интернет-ресурсам для поддержки людей, живущих с ВИЧ



PositiveLinks Spanish





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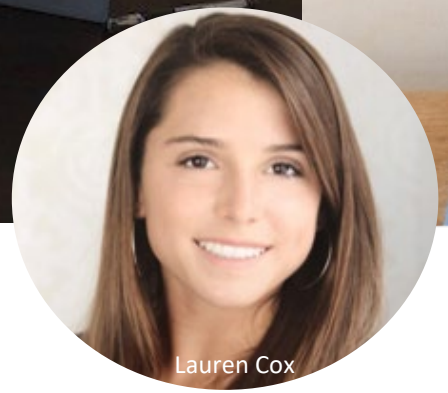
Tugela Ferry, South Africa | Mbarara, Uganda



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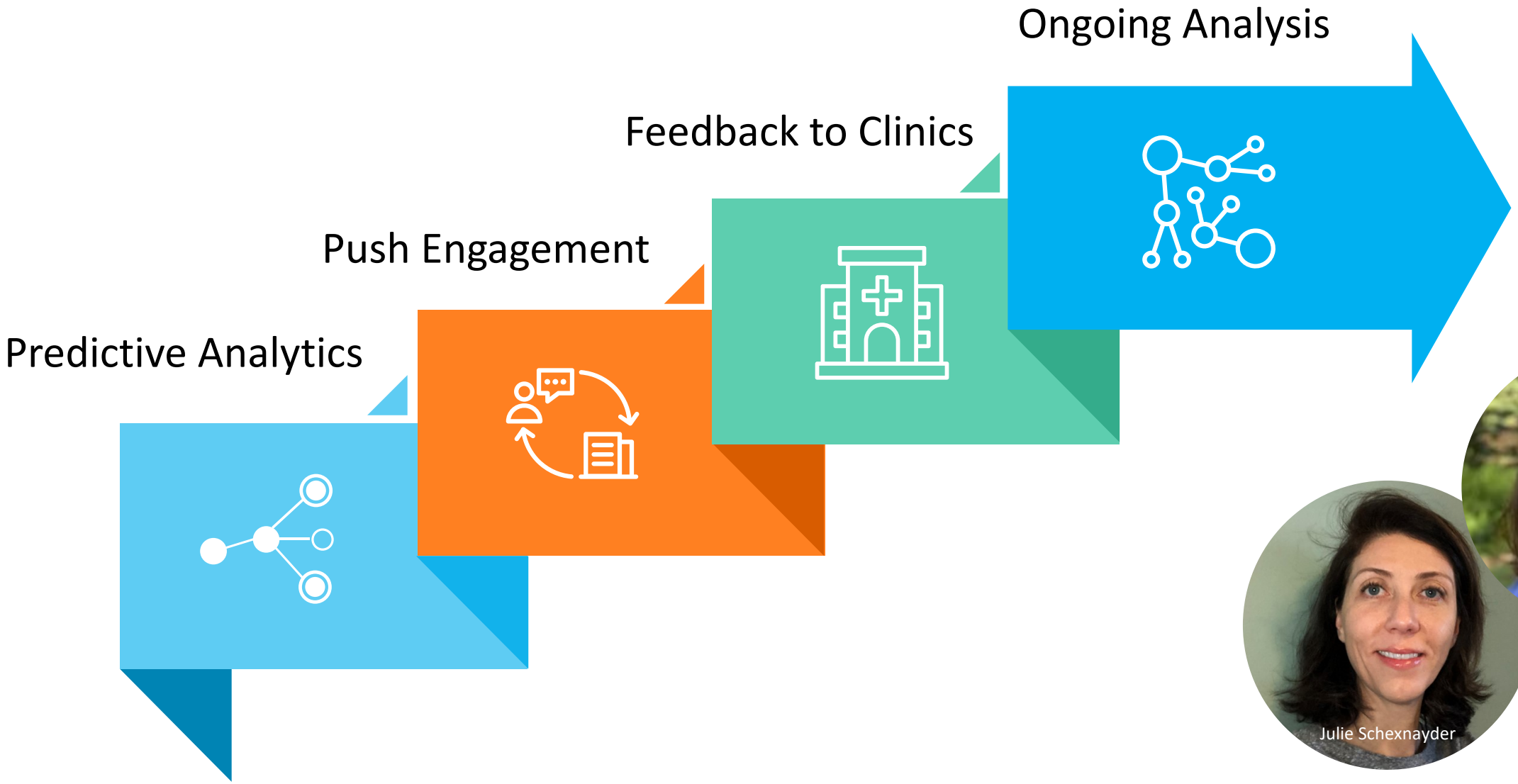
Next Steps



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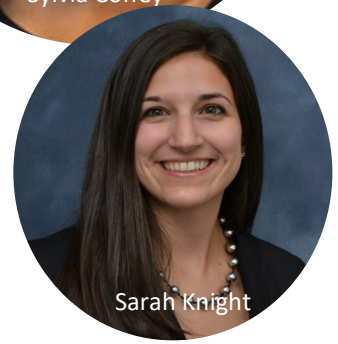
Adaptations

We partnered with Greg Gerling, UVA Associate Professor of Engineering Systems & Environment for student collaboration on app design.

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.

Sylvia Coffey


Sarah Knight

UVA Health

Adaptations

We partnered with Dr. Nassima Ait-Daoud Tiouririne and Kelly Schorling, LCSW to develop HOPE.

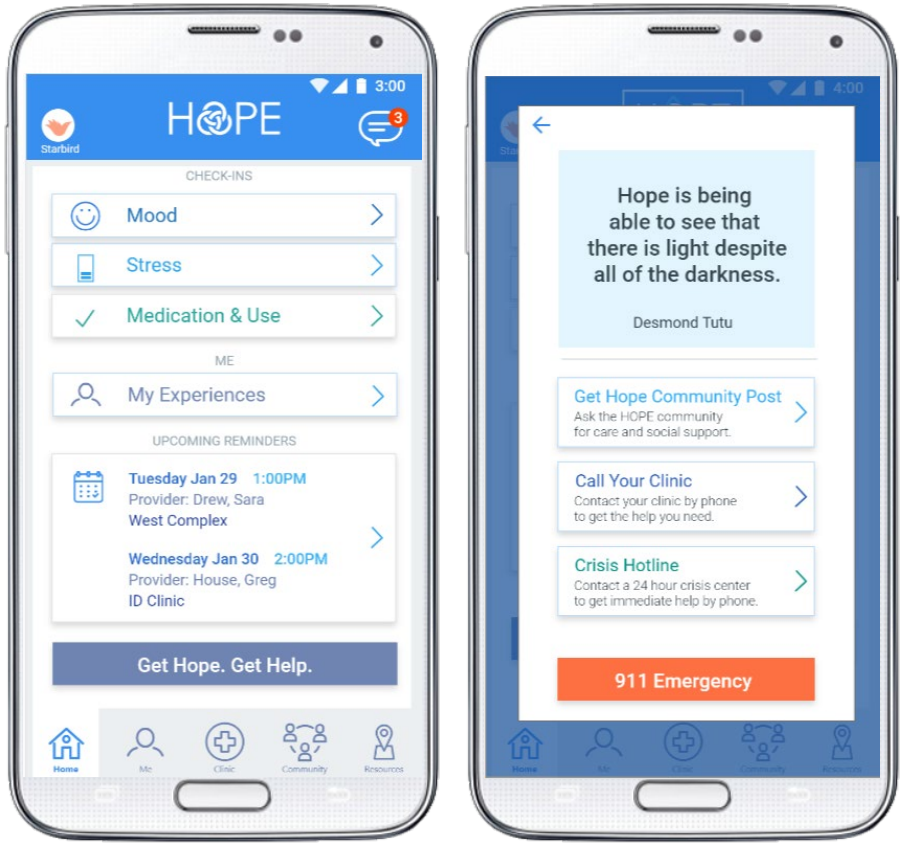
Chelsea Canan

Jackie Huynh

Bill Harrington

Marika Waselewski

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.

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Components of Success

PL SUCCESS

USAGE

High and Long term usage

EVIDENCE

Clinically Significant impact

IMPACT

Impact Related to usage

WARMTH

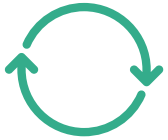
Users Feel supported

ENTHUSIASM

From users, team, and collaborators

PROCESS

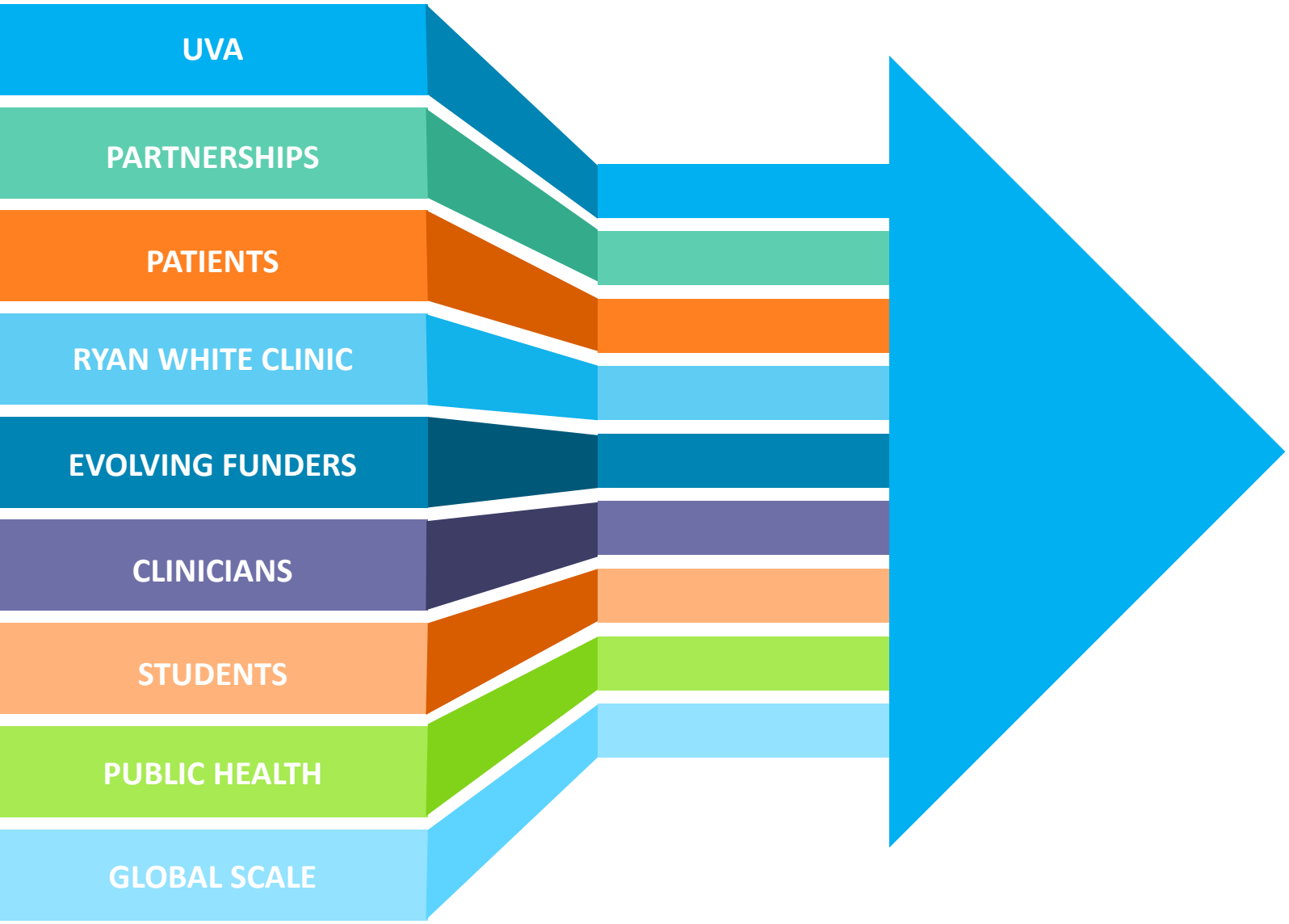
User-centered design



R&D

Ongoing research to 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

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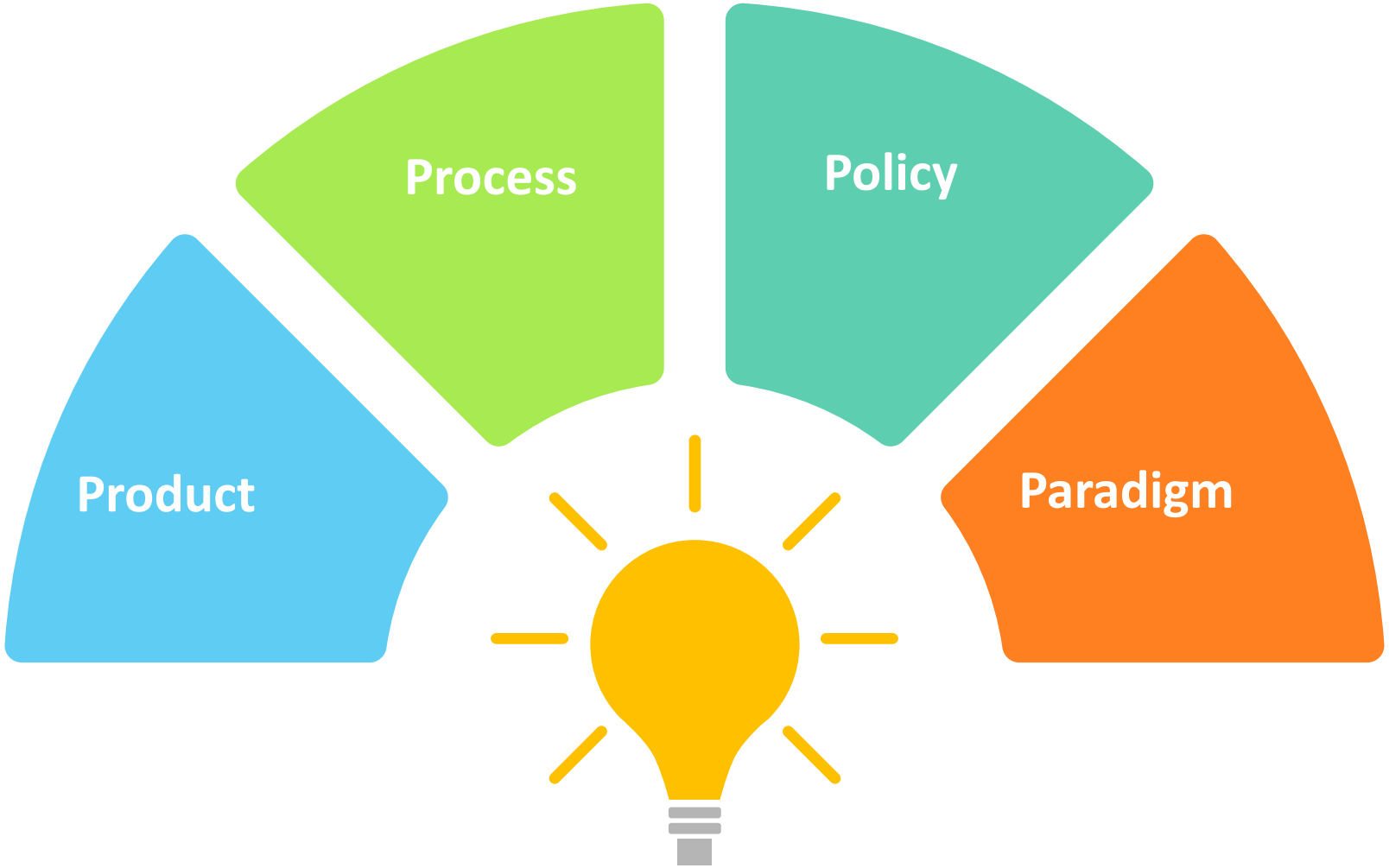
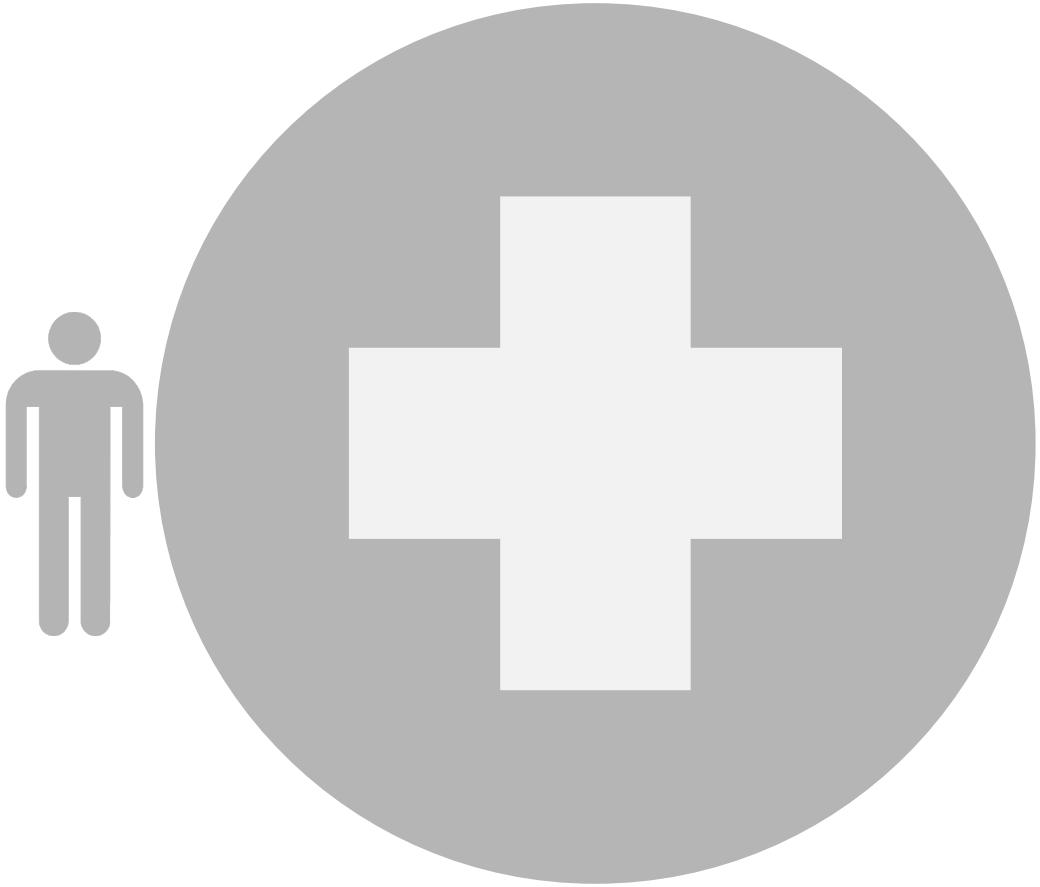
Innovations

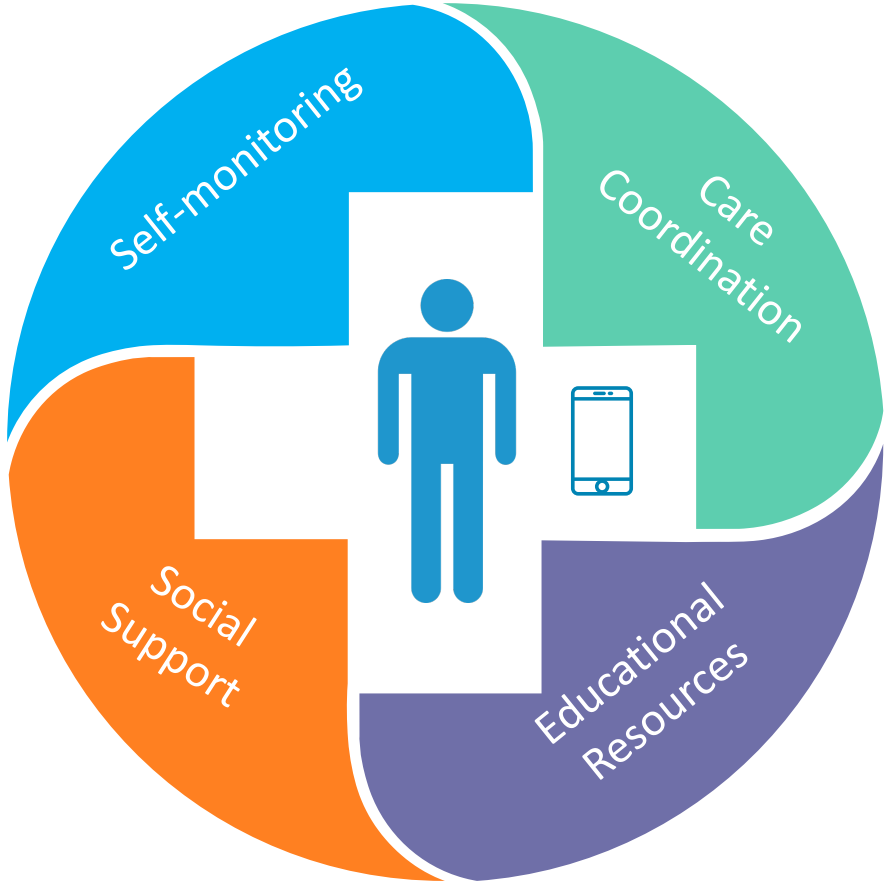


Innovation Effectiveness

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

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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.

ELTON JOHN AIDS FOUNDATION

AIDS United
Every Person. Every Community

nTelos wireless

Health Decision Technologies

MAC AIDS FUND

NIDA National Institute on Drug Abuse

VDH Virginia Department of Health
Protecting You and Your Environment
www.vdh.virginia.gov

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