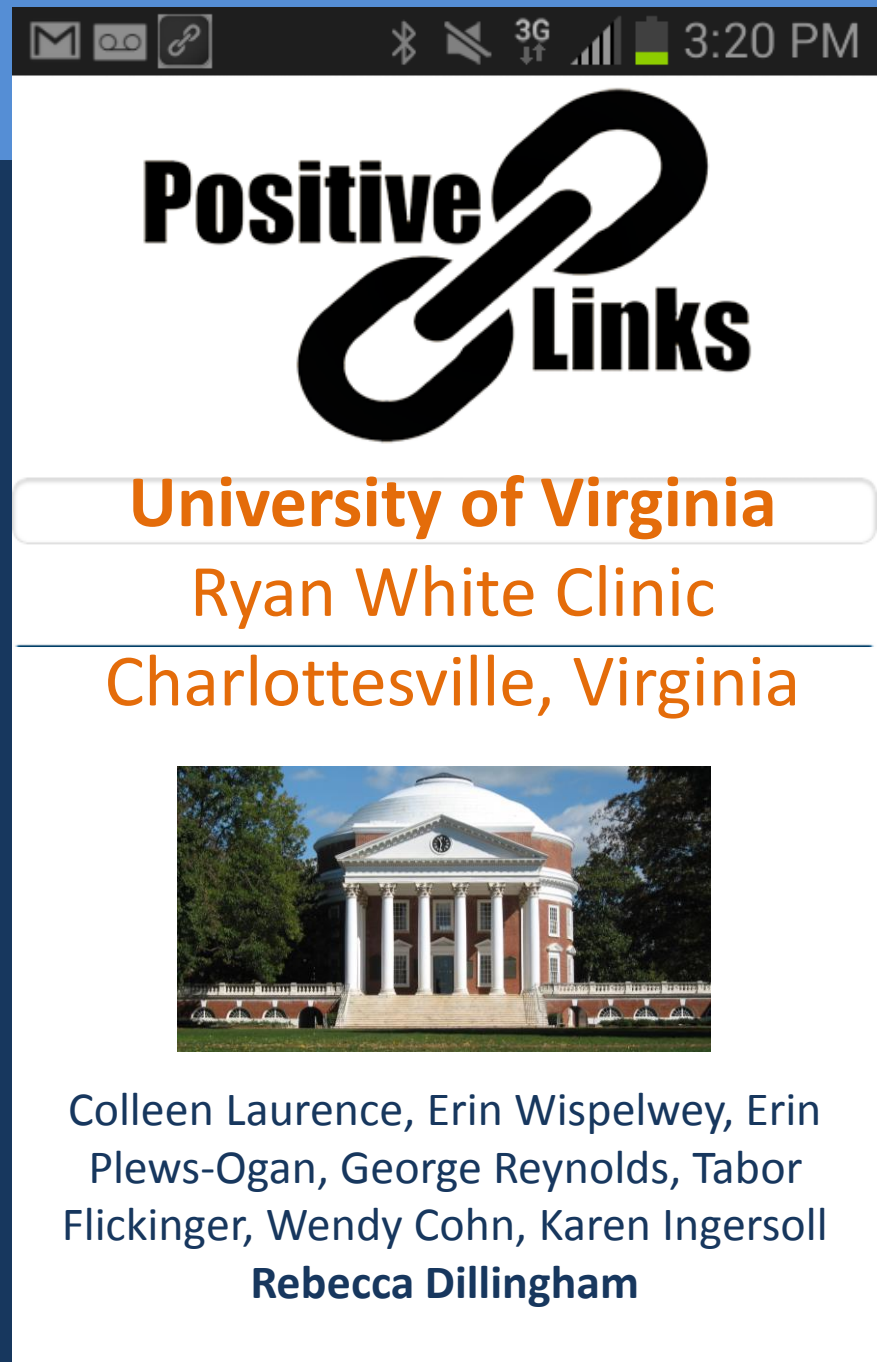



Building  
'Positive Links':  
App Development  
to Promote Health  
and Well-Being in  
PLWH in rural  
Virginia



The image shows a mobile application interface. At the top is a status bar with icons for email, calendar, a link, Bluetooth, a speaker, 3G signal, and battery level, along with the time 3:20 PM. Below this is the app's logo, 'Positive Links', where 'Positive' is in a bold sans-serif font and 'Links' is in a larger, bold sans-serif font, with a large black link icon integrated between the two words. Underneath the logo, the text 'University of Virginia' is displayed in orange, followed by 'Ryan White Clinic' and 'Charlottesville, Virginia' also in orange. A horizontal line separates this text from a photograph of the Rotunda at the University of Virginia. Below the photo, the names of the project team are listed in dark blue: Colleen Laurence, Erin Wispelwey, Erin Plews-Ogan, George Reynolds, Tabor Flickinger, Wendy Cohn, Karen Ingersoll, and Rebecca Dillingham.

**Positive Links**

**University of Virginia**  
**Ryan White Clinic**  
**Charlottesville, Virginia**



Colleen Laurence, Erin Wispelwey, Erin  
Plews-Ogan, George Reynolds, Tabor  
Flickinger, Wendy Cohn, Karen Ingersoll  
**Rebecca Dillingham**

# Challenges to Successful HIV Management

- Mental health issues
- Short duration of effect
- Slow reaction time
- **Rurality**
  - Transportation
  - Poverty
  - Isolation
  - Stigma

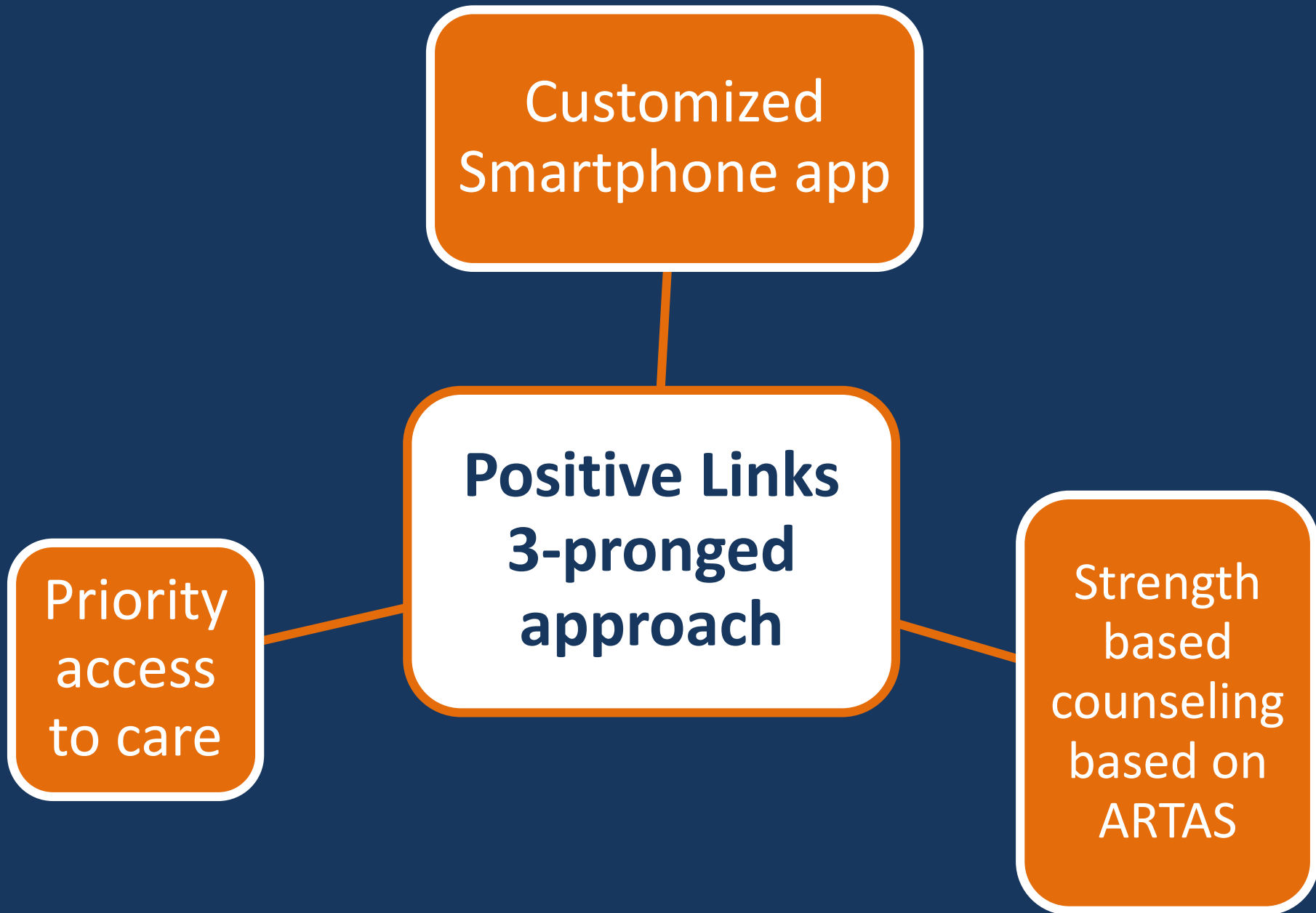
*Smart phones can allow interventions related to one or more challenges when and where needed.*

Customized  
Smartphone app

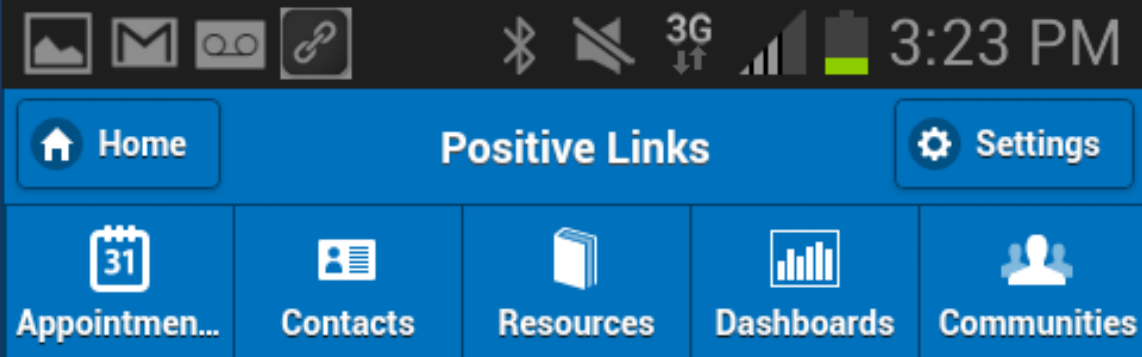
**Positive Links**  
**3-pronged**  
**approach**

Priority  
access  
to care

Strength  
based  
counseling  
based on  
ARTAS



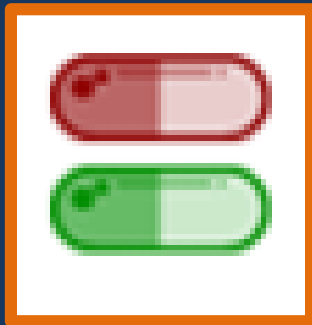
# App vs Text Interventions

	
App	Text
<ul style="list-style-type: none"><li>• Consumer demand</li><li>• Rich media views, videos and community functions</li><li>• More secure</li><li>• Can send more messages without added cost</li></ul>	<ul style="list-style-type: none"><li>• Better studied</li><li>• Phones are cheaper</li><li>• Harder to crack phone screens when dropped</li></ul>

# Strategies to Promote Retention



Shrink “distance”



Role Induction and Self-monitoring



User-based design

# Linking with Clinic



Appointmen...



Contacts

2014-03-12 10:41:16

Check in with Kathryn Dort

When: 2014-03-13 at 08:00:00

Where: UVA Ryan White Clinic

Confirm: ☒ Yes ☐ No

Proposed  
Alternate  
Date:

Submit

Contacts

## Positive Links Coordinators

Point person for the Positive Links program; meets with clients to discuss starting treatment, address barriers to care.

### Colleen Laurence MPH

Phone: (434) 465-9818

Email: cel2j@virginia.edu

West Complex, Hospital Drive, 5th floor, 1300 Jefferson Park Ave. , Charlottesville, VA, 22908

### Erin Wispelwey

Phone: (434) 465-9816

# Ecological Momentary Assessments

## Daily Queries


### My Notifications

☐ Did you take your meds today?

Wednesday May 21, 2014 - 10:05 AM

 What is your Stress Level right now?

Tuesday May 20, 2014 - 4:00 PM

 How is your Mood right now?

Tuesday May 20, 2014 - 11:00 AM

2014-03-10 16:00:03

What is your Stress Level right now?



Low



High

8

Explain (if you like):

Had to work a double shift

Submit

2014-03-10 10:05:02

Did you take your meds today?

☐ Yes

Explain (if you like):

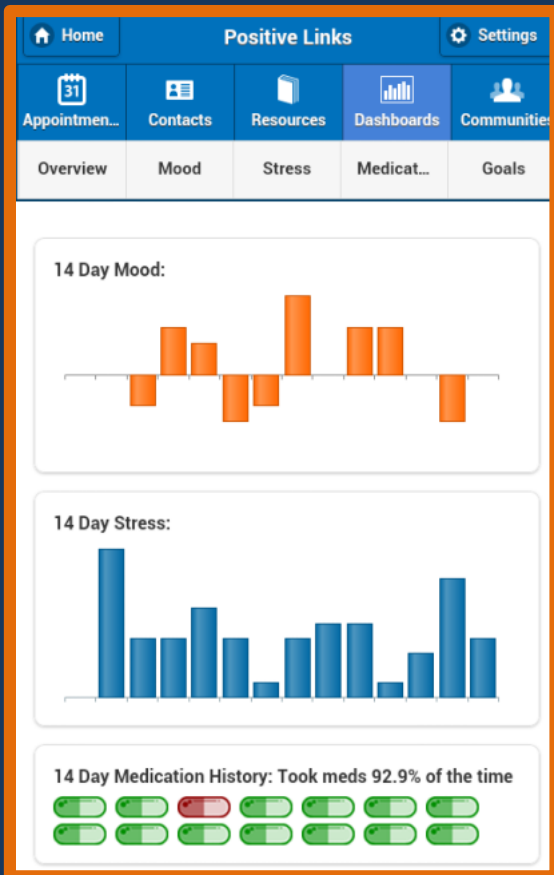
Submit

"Every Morning, Like  
Washing my face"

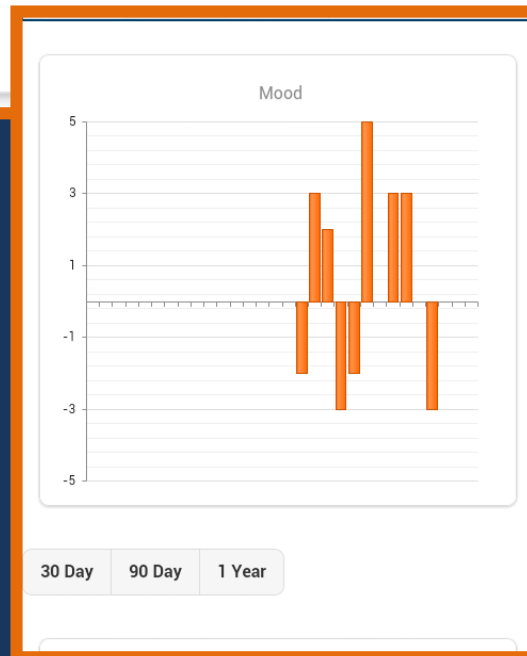
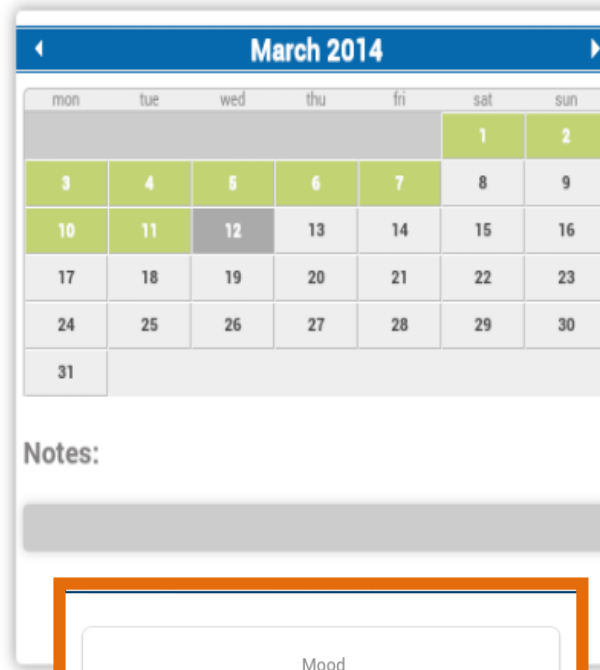


## Dashboards

A look back at daily responses



## Medication History



## Weekly data feedback



### Weekly Summary March 30-April 5



#### Meds

7/7 questions answered. Reported 100% adherence.



#### Stress

7/7 questions answered. Average stress 6.1. This is 3.3 higher than last week.



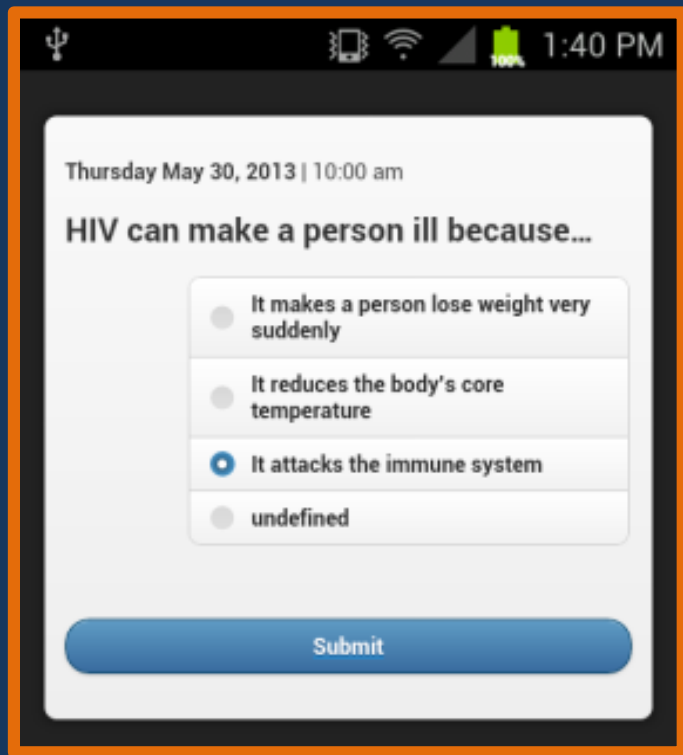
#### Mood

7/7 questions answered. Average mood 4.3. This is 2.1 higher than last week.

Are you reaching your health goals? If not let the Positive Links team know how we can help!

OK

# Quiz Questions

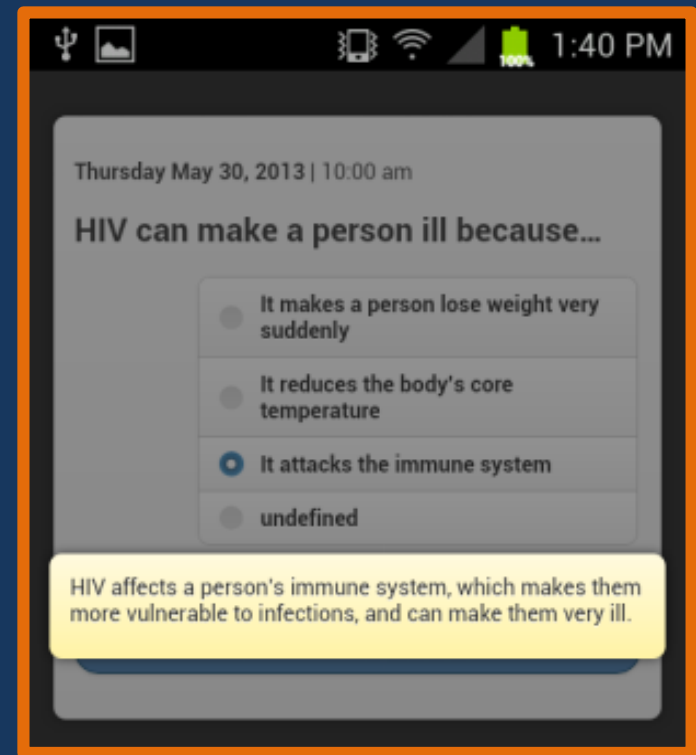
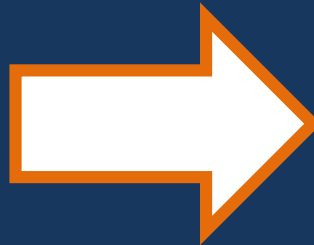


Thursday May 30, 2013 | 10:00 am

HIV can make a person ill because...

- ☐ It makes a person lose weight very suddenly
- ☐ It reduces the body's core temperature
- ☒ It attacks the immune system
- ☐ undefined

Submit



Thursday May 30, 2013 | 10:00 am

HIV can make a person ill because...

- ☐ It makes a person lose weight very suddenly
- ☐ It reduces the body's core temperature
- ☒ It attacks the immune system
- ☐ undefined

HIV affects a person's immune system, which makes them more vulnerable to infections, and can make them very ill.

# Information about Living Well with HIV



## Resources

Videos

Audio

FAQs

### Living with HIV

8

+ Do I need to quit my job now that I have HI...

- Am I going to die?

HIV is really a chronic illness. Studies have shown that, on average, people with well-controlled HIV live as long as people without HIV.

+ It seems like many people misunderstand ...

+ Where can I find a support group?

+ What do I need to do to live a healthy life w...

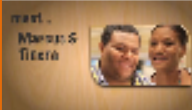
+ Does it matter what I eat?

## Local Video

Welcome to the Clinic

### Welcome to the Ryan White Clinic

06:53 secs



### Dealing with Stigma

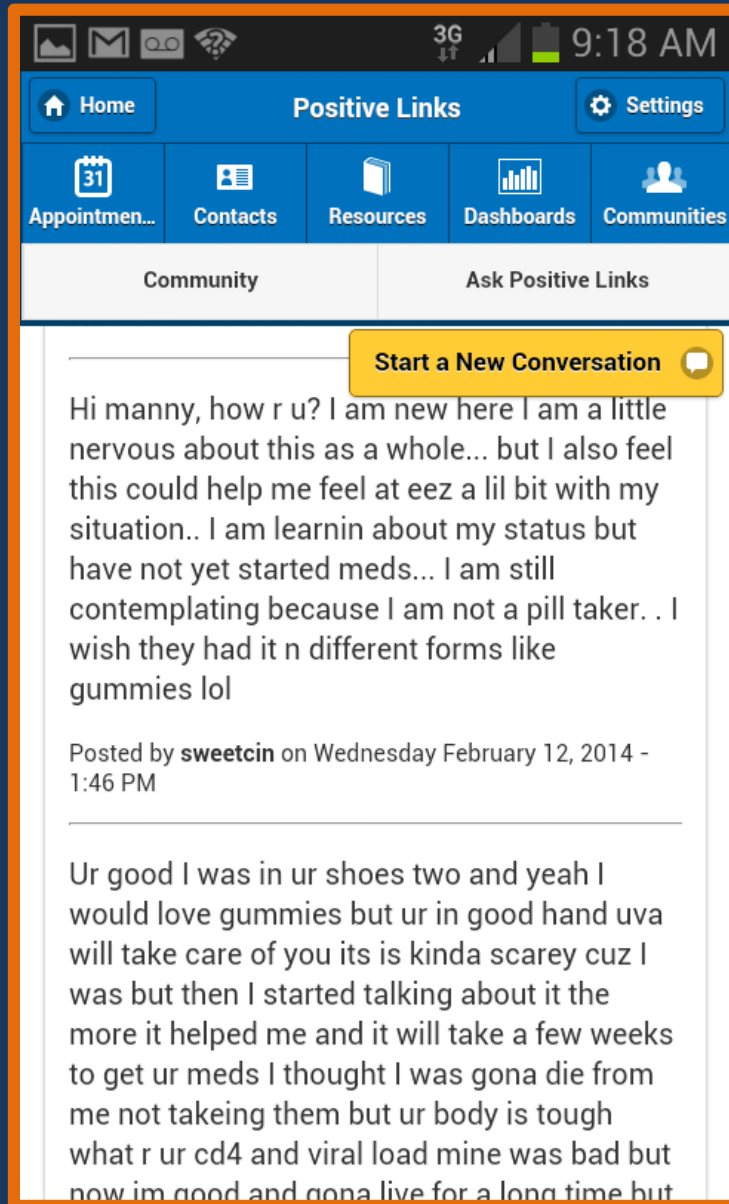
02:18 secs

5 Minute Mindful Breathing

### 5 Minute Mindful Breathing

Led by John Schorling, MD. UVA Mindfulness Center Audio Recordings. 10 mins.

# Community Message 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” (Participant 31295).**

# Weekly Interest Posts

## Discussion Topics

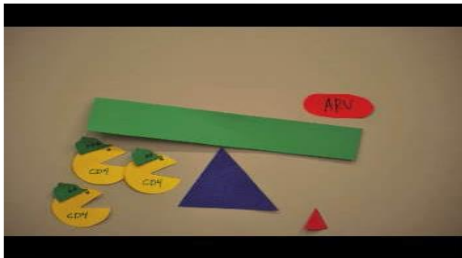
3:39 PM

Chapter 3 video: non adherence 1

Hi Positive Links family

A few weeks ago our quiz question was about ARV resistance. Resistance occurs when the medicines you may be taking for your HIV disease can not stop the virus from making more copies of itself.

The best way to prevent resistance is to keep HIV from replicating. If it is not reproducing, the virus can not mutate and make new strains of HIV that are drug- resistance. Antiretroviral drugs keep HIV from reproducing. And that is why it is important to take all your HIV medications on time and consistently. When you do that, your medications can do a better job of keeping the virus under control and keep it from mutating into strains that won't respond to treatment.



Click on the link below (view this message in the community section, first) to see a video that explains this!

## Posts to lighten the mood

9:24 AM

Home Positive Links Settings

Appointment... Contacts Resources Dashboards Communities

Community Ask Positive Links

Funny Friday- Start a New Conversation

Hi Positive links family, In this classic City Slicker's scene, Ira and Barry claim they can name the perfect ice cream flavor to go with any meal. What is your favorite ice cream flavor? Is there a certain meal you like to eat it with?

<https://www.youtube.com/watch?v=4pbVxyL-OeM>

Posted by **PositiveLinksTeam** on Friday April 4, 2014 - 3:31 PM

I would say oreo ice cream. After eating some fried chicken with mac and cheese and sweet peas

Posted by **tweety** on Friday April 4, 2014 - 7:03 PM

# Participant Demographics

(N=33 as of 3/31; current N = 40)

## Age

Average Age: 33 [Range 18-55]

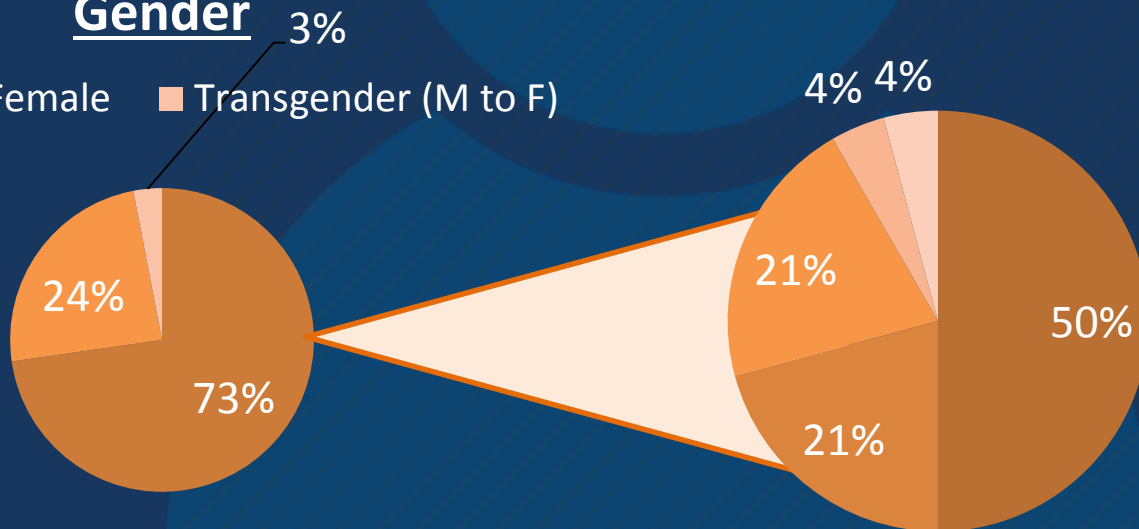
Participants under 30 years: 16 [48%]

## Male Risk Factors

- MSM
- heterosexual
- MSM, heterosexual
- MSM, IDU
- MSM, heterosexual, IDU

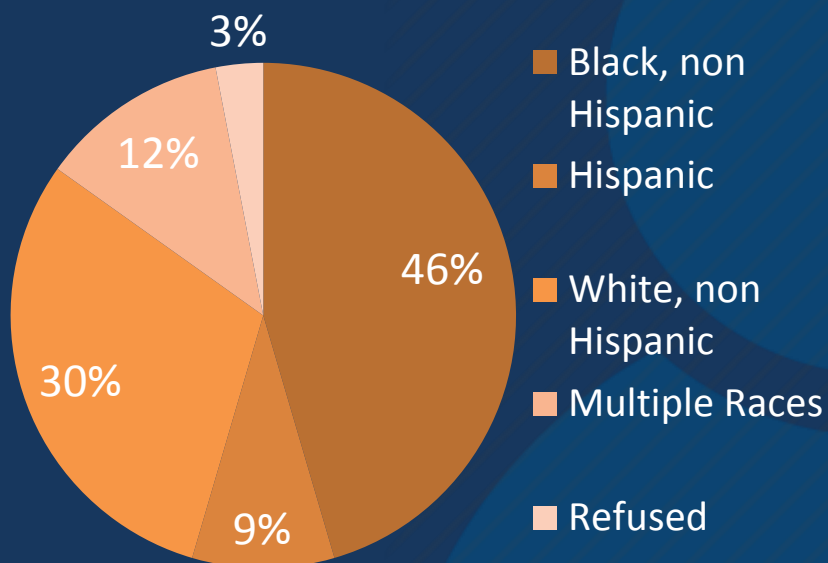
## Gender

■ Male ■ Female ■ Transgender (M to F)



# Participant Demographics

## Race/Ethnicity



## Time from Diagnosis to Enrollment

Range: 1 day- 12.37 years

Mean: 1.28 years

## Lab Values at Baseline

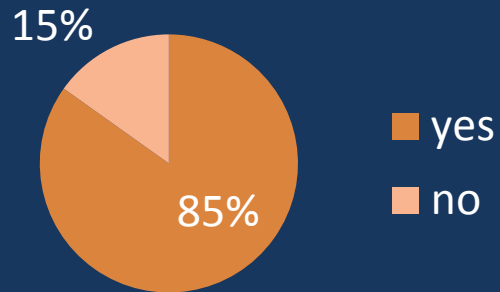
	Mean [range]
CD4 cells	557 [25-1819]
Viral Load	14,768 [0-124,000]

# Transportation to Clinic

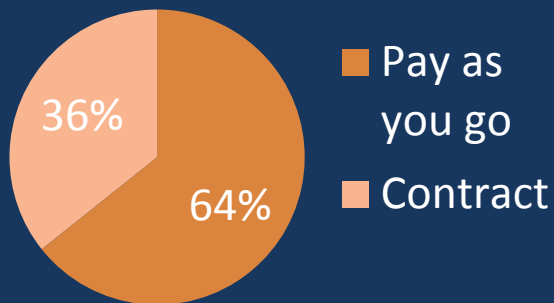
- Participants travel on average 38.24 Miles to Clinic. [SD 37.48] (Range, 1-126)
- Participants travel on average 50.27 minutes to clinic [SD 34.74] (Range 2-127)

# Cell Phone Use Baseline

## Do you own a cell phone?



## Type of Contract



**17 of those with phones (28) had smartphones (51.5%)**

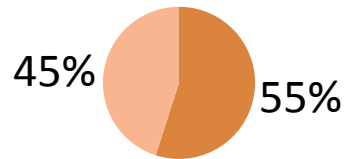
**I Phones: 6 (35%)**  
**Androids: 11 (65%)**

	Cost per Month in \$
Average [SD]	38.24 [37.48]
Range	0-135

# Response to EMA

12,560 queries with 6,902 responses

■ Response ■ No Response



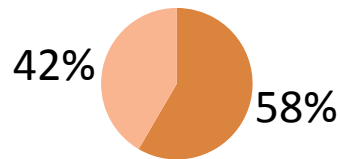
Medication

Stress

Mood

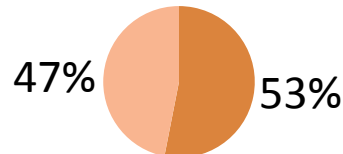
Response rate

■ Response ■ No Response



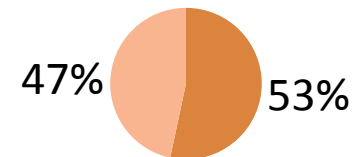
Response rate

■ Response ■ No Response



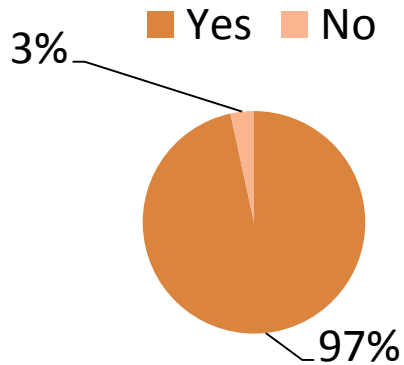
Response rate

■ Response ■ No Response



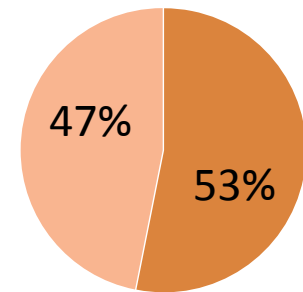
# Response Type

## Medication Response



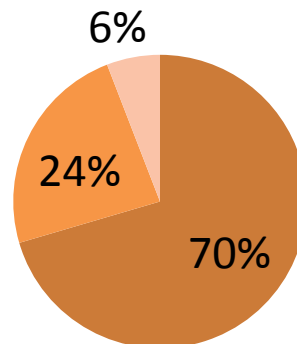
## Mood Response

■ High Mood ■ Low Mood



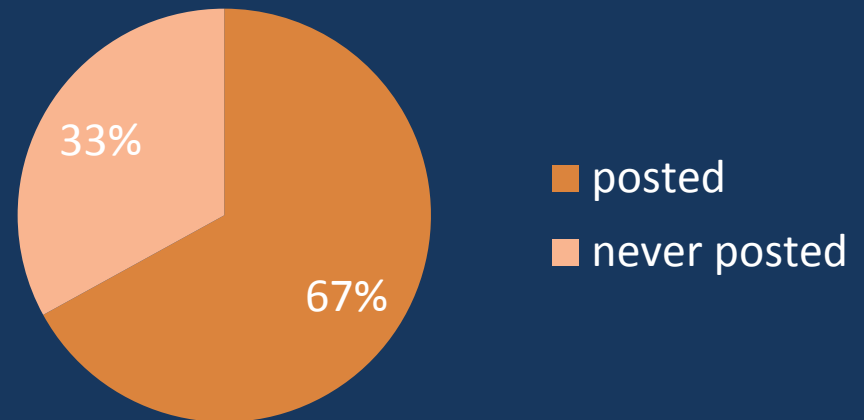
## Stress Level

■ Low ■ Medium ■ High



**“I don’t actually see anyone for counseling or anything but having the app it’s kind of like having a counselor I guess only because you get to talk with people who are actually going through the situation and everything” (Participant 88554).**

## Ever posted on the Community message board



### Community Board Posts 9/25/2013- 3/31/014

Participants who have posted average 28 posts (SD: 28.6)

The Community Message board has averaged 22 posts per week (SD: 19.4)

Average percent participation by Positive Links users each week was 27% (SD:12.6%)

# Usability Interviews

After the participants have the phone for 3 weeks they are invited to provide feedback on their experience with the app .



Don't use military time, it's confusing



Accessing the app is a bit frustrating. The buttons are too small, especially tough with the mood and stress scales.



Wants to see jokes by the PL Team on the message board, helps keep everyone happy

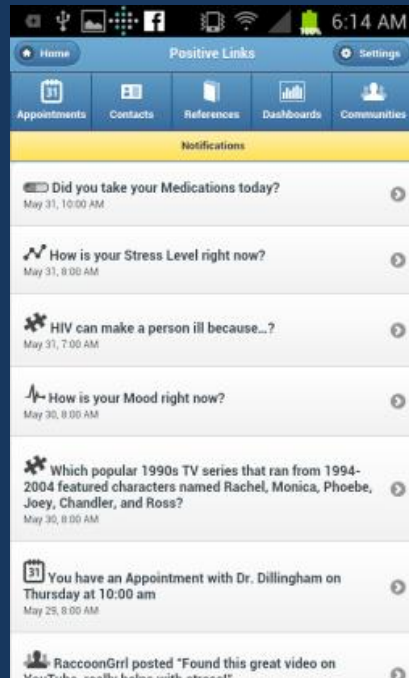
(Regarding the CMB) It's a lot of support – No matter what your situation is, you can find some kind of support there. I've been supported, for example, when I need that extra boost and even when I'm happy and just have a question and you can get positive response.

# Challenges

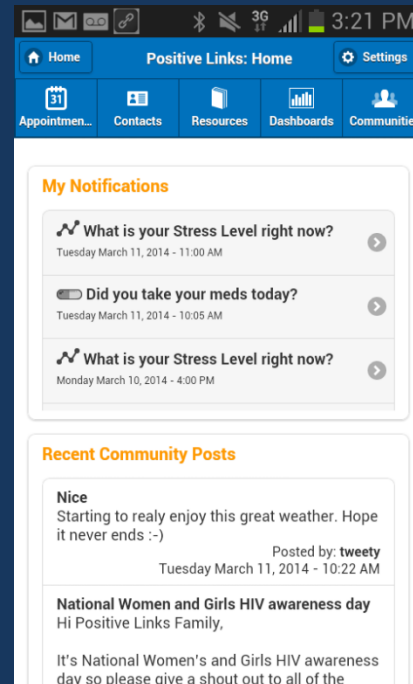
- Tech issues
- Managing crises and disagreements on the community message board
- Lower app usage among users who have another phone
- Low uptake of formal strength based counseling sessions
  - Linkage to mental health services
  - Informal Check-ins with PL coordinators
  - Graduating from the project

# Lessons Learned

- Link theory and user feedback
- Small changes help keep the app user friendly



Version 1.2



Version 1.3

- Use data in real time
- Balance technology with strong interpersonal relationships

# Thank you

Providers, staff and patients at the University of Virginia Ryan White Clinic



Health Decision Technologies



Ntelos wireless



AIDS United and the MAC AIDS Fund



IAPAC



# Conversation on the Board

1) "I am new here I am a little nervous about this as a whole... but I also feel this could help me feel at eez a lil bit with my situation.. I am learnin about my status but have not yet started meds... I am still contemplating because I am not a pill taker. .. I wish they had it n different forms like gummies lol" (Sweetcin)

2) "Ur good I was in ur shoes **two** and yeah I would love gummies but ur in good hand uva will take care of you its is kinda scarey cuz I was but then I started talking about it the more it helped me ... **I thought I was gona die from me not takeing them but ur body is tough ...and gona live for a long time**" (Manny)

3) "Amen to that Manny. And hello sweetcin. Welcome to the family. **And here I thaught I was the only one who likes gummies.**" (Tweety)

4) “Hi all n thank u for the welcome... **I want to start takin meds b it t my biggest fear is not keepin up with them...** I have been taken other meds for ova 20 years n **I have stopped n started so many times because I get tired if swallowing pills...** n I know if I do that I cant choose when n when to not rake them... **how long have you been taken meds n do u eva miss a dose??**” (Sweetcin)

5) “I have been taking these meds for a month and a half or so. I missed a few times and I had to **get one of those weekly pill holders.** Because I kept forgetting if I toke them are not. But ever sence I got the weekly holder thingy I have been doing good. **When the docs see I was missing meds I was shocked they said they might take me off.** They kept saying his isnt the bad Maybe we should take him off until he is ready. **Oh hell no.** I won't to stay like this. So when the through that in my face. **I really started to crack down on my meds. They are my life line. As long as you remember that you will do just fine.** “(Tweety)