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

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.
Positive Links
3-pronged approach

Customized Smartphone app

Priority access to care

Strength based counseling based on ARTAS
## App vs Text Interventions

<table>
<thead>
<tr>
<th><strong>App</strong></th>
<th><strong>Text</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer demand</td>
<td></td>
</tr>
<tr>
<td>Rich media views, videos and community functions</td>
<td></td>
</tr>
<tr>
<td>More secure</td>
<td></td>
</tr>
<tr>
<td>Can send more messages without added cost</td>
<td></td>
</tr>
<tr>
<td>Better studied</td>
<td></td>
</tr>
<tr>
<td>Phones are cheaper</td>
<td></td>
</tr>
<tr>
<td>Harder to crack phone screens when dropped</td>
<td></td>
</tr>
</tbody>
</table>
Strategies to Promote Retention

- Shrink “distance”
- Role Induction and Self-monitoring
- User-based design
Linking with Clinic

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

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?

8

Explain (if you like):
Had to work a double shift

Submit

“Every Morning, Like Washing my face”
A look back at daily responses

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

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 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

Local Video

Welcome to the Ryan White Clinic
06:53 secs

Dealing with Stigma
02:18 secs

Videos
Audio
FAQs

Living with HIV

Do I need to quit my job now that I have HIV?

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...

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).
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!

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%]

Gender
- Male: 24%
- Female: 73%
- Transgender (M to F): 3%

Male Risk Factors
- MSM: 50%
- heterosexual: 42%
- MSM, heterosexual: 4%
- MSM, IDU: 4%
- MSM, heterosexual, IDU: 4%
Participant Demographics

**Race/Ethnicity**
- 46% Hispanic
- 30% White, non-Hispanic
- 12% Black, non-Hispanic
- 9% Multiple Races
- 3% Refused

**Time from Diagnosis to Enrollment**
- Range: 1 day - 12.37 years
- Mean: 1.28 years

**Lab Values at Baseline**

<table>
<thead>
<tr>
<th>Test</th>
<th>Mean [range]</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 cells</td>
<td>557 [25-1819]</td>
</tr>
<tr>
<td>Viral Load</td>
<td>14,768 [0-124,000]</td>
</tr>
</tbody>
</table>
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?

- 85% yes
- 15% no

Type of Contract

- 64% Contract
- 36% Pay as you go

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

- iPhones: 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

- Medication: Response rate
  - Response: 42%
  - No Response: 58%

- Stress: Response rate
  - Response: 47%
  - No Response: 53%

- Mood: Response rate
  - Response: 47%
  - No Response: 53%
“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

- 33% posted
- 67% never posted


- 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

• 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
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 ease 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 thought 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)