Demonstration Site Summary

# Health eNavigation (Health eNav): A Digital HIV Care Navigation Intervention

Center for Public Health Research San Francisco Department of Public Health San Francisco, CA, USA

In the Ryan White HIV/AIDS Program (RWHAP), Part F: Special Projects of National Significance (SPNS) Initiative

# Use of Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum

Principal Investigator: Sean Arayasirikul, PhD, Sean.Arayasirikul@sfdph.org

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#### **Executive Summary**

The San Francisco Department of Public Health (SFDPH) Center for Public Health Research (CPHR) has developed a digital HIV care navigation intervention for youth and young adults (ages 18-34) living with HIV. The project, called Health eNavigation or Health eNav, provides digital HIV care navigation using social media and digital technologies to 120 youth and young adult men who have sex with men (MSM) and trans women living with HIV. Health eNav is an engagement and retention in HIV care intervention and aims to improve outcomes across the HIV care continuum. This includes but is not limited to timely linkage to care, improved engagement and retention in care, and viral suppression. Health eNav provides participants with six months of digital HIV care navigation which includes the following components: 1) HIV care navigation, 2) health promotion, 3) motivational interviewing, and 4) digital social support. Digital HIV care navigation uses social media and digital technologies to extend supportive care structures beyond clinic walls at times when newly diagnosed, not linked to care, out-of-care and not virally suppressed youth and young adults living with HIV need support most.

#### Introduction

The San Francisco Department of Public Health (SFDPH) Center for Public Health Research (CPHR) developed and tested the efficacy of a digital HIV care navigation intervention, called Health eNavigation or Health eNav, designed for youth and young adults (ages 13-34) living with HIV. Among youth and young adults, linkage to care is relatively high at more than 80%, but there is a steep drop off in retention in care (i.e. <50%) and low viral suppression (i.e. <70%) 12 months from diagnosis. Youth and young adults are a sub-population in particular need of interventions to improve engagement in the HIV care. Many youth and young adults may not have a medical home due to population-specific challenges and barriers, such as homelessness, needs related to identity development, and job insecurity.

Health eNav provides HIV care navigation services delivered digitally using social media and technologies to 120 youth and young adult men who have sex with men (MSM) and trans women living with HIV. The intervention is delivered over a 6month period and includes the following components: 1) HIV care navigation, 2) health promotion, 3) motivational interviewing, and 4) digital social support. Health eNay utilizes an innovative and comprehensive mix of SMS text messaging, social media and digital technologies in combination with navigation services to meet youth where they are. Through the use of technology, Health eNav is able to extend supportive care structures beyond clinic walls at times when newly diagnosed, not linked to care, out-of-care and not virally suppressed youth and young adults living with HIV need support most. Hence, Health eNav is an engagement and retention in HIV care intervention, aimed at addressing critical gaps and barriers to successfully identifying, engaging, and retaining youth and young adults living with HIV in medical care. The goal of Health eNav is to improve outcomes across the HIV care continuum. This includes but is not limited to timely linkage to care, improved engagement and retention in care, and viral suppression.

#### **Rationale and Description of Need**

Much like the rest of the country, the HIV epidemic predominantly affects youth and young adults who are MSM, Latino/a, African American and transgender in San Francisco. Young racial/ethnic minority MSM and trans women are disproportionately affected by HIV and AIDS in the US. Although MSM represent just 2% of the US population, this group accounts for 57% of all new HIV infections and is the only risk group with new HIV infections rising each year.<sup>1</sup> Among populations of MSM, young MSM (YMSM) and racial/ethnic minority MSM are at even higher risk for HIV infection. Nationally almost two thirds of new infections in 2008 occurred among those 13-29 years of age, most of which were among African American and

<sup>&</sup>lt;sup>1</sup> Centers for Disease Control and Prevention. Prevalence and awareness of HIV infection among men who have sex with men – 21 cities, United States, 2008. MMWR Morb Mortal Wkly Rep. 2010;59(37):1201-7.

Latino MSM.<sup>2</sup> Similar to young racial/ethnic minority MSM, young racial/ethnic minority trans women also bear a huge burden of HIV infections in the US.<sup>3</sup> In San Francisco, trans women have the highest HIV prevalence of any risk population (35.5% vs. 22.7% among MSM).<sup>4</sup> Evidence suggests that racial/ethnic minority trans women are at even higher HIV risk compared to their white counterparts.<sup>5</sup> In San Francisco, one in five transyouth were infected with HIV before 25 years of age and 34% of trans women diagnosed with HIV infection were between the ages of 13-29 compared to 21% of all other cases in the same time period.<sup>6,7</sup> Of AIDS cases among trans women in San Francisco, individuals were more likely to be non-white and younger.<sup>8</sup>

Unrecognized infection, due to a low uptake of HIV testing, and poor linkage to care are driving forces of ongoing HIV transmission among young racial/ethnic minority MSM and trans women. It is estimated that unrecognized infections account for as much as 50% of new infections in MSM in the US. Compared to older MSM and White MSM, YMSM (aged 18-29) (63%) and racial/ethnic minority MSM (54%) were more likely to be unaware of their HIV infection.<sup>9</sup> At the time of developing this manual, data from CDC indicated that racial/ethnic minority and younger individuals fare worse along the treatment cascade (Figures below).<sup>10</sup> In terms of linkage to care, 62% of African Americans and 67% of Latinos were linked to care within 3 months of diagnosis compared to 71% of Whites, and only 56% of those age between 25-34 were linked to care compared to about 70% in other age categories. Ultimately, these subgroups were less likely to achieve viral suppression.

Similarly, the burden of HIV in trans women is exacerbated by unrecognized infections and low access to HIV care. In 2012, counseling and testing data from San Francisco public testing sites found that of the 17,898 HIV tests over the year, only 403 HIV tests were conducted with trans women.<sup>11</sup> Conservatively assuming none of those were repeat testers, only 37% of the trans-female population was tested for HIV by public HIV testing sites in San Francisco in 2012. Of those 403, 8 were

<sup>&</sup>lt;sup>2</sup> Ibid.

 <sup>&</sup>lt;sup>3</sup> Herbst JH, Jacobs ED, Finlayson TJ, et al. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. AIDS Behav, 2008;12:1-17.
 <sup>4</sup> SFDPH. HIV/AIDS Epidemiology Annual Report, 2008. San Francisco: San Francisco Department of Public Health (SFDPH); 2008.

 <sup>&</sup>lt;sup>5</sup> Herbst JH, Jacobs ED, Finlayson TJ, et al. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. AIDS Behav, 2008;12:1-17.
 <sup>6</sup> SFDPH. HIV/AIDS Epidemiology Annual Report, 2008. San Francisco: San Francisco Department of Public Health (SFDPH); 2008.

 <sup>&</sup>lt;sup>7</sup> Garofalo R, Deleion J, Osmer E, et al., Overlooked, misunderstood and at-risk: exploring the lives and HIV risk of ethnic minority male-to-female transgender youth. J Adolesc Health, 2006;38(3):230-6.
 <sup>8</sup> SFDPH. HIV/AIDS Epidemiology Annual Report, 2008. San Francisco: San Francisco Department of Public Health (SFDPH); 2008.

<sup>&</sup>lt;sup>9</sup> Ibid.

 <sup>&</sup>lt;sup>10</sup> Hall HI, Frazier EL, Rhodes P, et al. Differences in human immunodeficiency virus care and treatment among subpopulations in the United States. JAMA Intern Med, 2013l173(14):1337-44.
 <sup>11</sup> Unpublished data. San Francisco Department of Public Health (SFDPH); 2013.

confirmed positive (1.9%). Findings from a study of adult trans women living with HIV conducted by our team in the San Francisco Bay Area shows that 77% of participants were linked to care, but only 44% were virologically suppressed.<sup>12</sup> Research has found that trans women with HIV in San Francisco has a significantly higher average aggregate viral load, i.e. "community viral load," compared to other populations.<sup>13</sup> Young trans women are also disproportionately impacted by HIV. Data collected with young trans women in San Francisco found a 7% HIV prevalence,<sup>14</sup> which is in contrast to the estimated local HIV prevalence among adult trans women of 42.4%.<sup>15</sup> The gap between these two prevalence estimates highlights how data on HIV prevalence are a poor substitute for incidence data and suggest that HIV testing and linkage to care is an important need among young trans women in San Francisco.

Internet and mobile technologies, in combination with social network-based approaches, offer great potential to overcome and address barriers to care and effectively disseminate interventions. Traditional delivery methods of linkage and engagement services for HIV care services are not effectively reaching at-risk youth and young adults in a changing environment of how individuals interact and connect with each other. As more individuals now have access to the Internet and other mobile technologies, social networking online and seeking health-related information on the Internet has become increasingly popular, especially among young people and sexual minorities. Recent innovations in online methods for increasing HIV testing, initiating partner interventions and behavioral interventions, HIV care, self-management, and provider care have also demonstrated efficacy comparable to face-to-face interventions.<sup>16, 17</sup> Interventions that leverage mobile technology and social media have also been found to have a greater impact in influencing behavior than radio and television campaigns.<sup>18</sup> There is evidence that social media can be effectively utilized to reach young adults with HIV and STD information and increase condom use.<sup>19</sup> This is particularly relevant to the sociocultural contexts of young racial/ethnic minority MSM and trans women who

<sup>&</sup>lt;sup>12</sup> Unpublished data. Transfemales Empowered to Advance Community Health (TEACH). San Francisco Department of Public Health. 2009.

<sup>&</sup>lt;sup>13</sup> Das M, Chu PL, Santos GM, et al. Decreases in community viral load are accompanied by reductions in new HIV infections in San Francisco. PLoS One, 2010;5(6):e11068.

<sup>&</sup>lt;sup>14</sup> Wilson E, Chen YH, Arayasirikul S, Fisher M, Pomart A, Le V, Raymond HF, McFarland W. Racial disparities in socio-economic factors and HIV-related risk for San Francisco Bay Area trans\*female youth – findings from the SHINE study. In Press at the American Journal of Public Health.

 <sup>&</sup>lt;sup>15</sup> Hall HI, Frazier EL, Rhodes P, et al. Differences in human immunodeficiency virus care and treatment among subpopulations in the United States. JAMA Intern Med, 2013l173(14):1337-44.
 <sup>16</sup> Sullivan PS, Grey JA, Rosser BRS. Emerging technologies for HIV prevention for MSM: what we have learned, and ways forward. J Acqui Immune Defic Sydr, 2013;63(Suppl 1):102-7.

<sup>&</sup>lt;sup>17</sup> Pellowski JA, Kalichman SC. Recent advances in technology-delivered interventions for people living with HIV. Curr HIV/AIDS Rep, 2012;9(4):326-34.

<sup>&</sup>lt;sup>18</sup> Sullivan PS, Grey JA, Rosser BRS. Emerging technologies for HIV prevention for MSM: what we have learned, and ways forward. J Acqui Immune Defic Sydr, 2013;63(Suppl 1):102-7.

<sup>&</sup>lt;sup>19</sup> Bull SS, Levine DK, Black SR, et al. Social media-delivered sexual health intervention: a cluster randomized controlled trial. Am J Prev Med, 2012;43(5):467-74.

experience homophobia and transphobia both within their own racial/ethnic communities and the larger society making them often more hidden and inaccessible through traditional public health outreach efforts.<sup>20, 21</sup> Through accessing and receiving Internet- and/or mobile technology-based HIV interventions, these young racial and sexual minority individuals can remain safe and private. Additionally, since youth and young adults have large social networks online,<sup>22</sup> interventions delivered on the Internet or through mobile technology may have greater diffusion effects. Social network members can provide both tangible and intangible resources or support, which may facilitate or protect against heath-related risks.<sup>23</sup> Furthermore, social network specific norms can affect individuals' attitudes regarding sex, risk behaviors and health-seeking behaviors.<sup>24</sup>

Mobile-based interventions have high promise for engaging youth and young adults in their HIV care. Cell phones represent a common thread for communication among almost all youth and young adults in the US, where approximately 95% of those aged 18-29 own their own cell phone.<sup>25</sup> Importantly, according to the 2012 National Health Interview Survey, more than 70% of those living in wireless-only households (with no landline) in 2011 were at or below 200% of the federal poverty threshold, contradicting the conventionally-held idea that use of mobile technology is concentrated among better-resourced people.<sup>26</sup> In fact, mobile technology is used by almost all Americans in all socioeconomic groups, and by higher percentages of African Americans and Latinos than Whites.<sup>27</sup> Text messaging (SMS) via cell phones has been used to provide sexual health information to young people.<sup>28</sup> A South African study used SMS for all participant interactions from recruitment through final follow-up and found that ten motivational-style SMS messages increased HIV testing rates to a statistically significant degree when compared to the control

 <sup>&</sup>lt;sup>20</sup> Herbst JH, Jacobs ED, Finlayson TJ, et al. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. AIDS Behav, 2008;12:1-17.
 <sup>21</sup> Diaz RM, Ayala G, Bein E, et al. The impact of homophbia, poverty, and racism on the mental health

of gay and bisexual Latino men: findings from 3 US cities. Am J Public Health, 2001;91(6):927-32.

 <sup>&</sup>lt;sup>22</sup> Lenhart, A., M. Madden, and P. Hitlin, Youth are leading the transition to a fully wired and mobile nation, in Pew Internet & American Life Project2005, Pew Research Center: Washington, D.C.
 <sup>23</sup> Berkman LF, Glass T. Social integration, social networks, social support, and health. In: Berkman LF, Kawachi I, eds. Social epidemiology. New York: Oxford; 2000:137-173.

<sup>&</sup>lt;sup>24</sup> Hall A, Wellman B. Social networks and social support. In: Cohen S, Syme L, eds. Social support and health. New York: Academic Press; 1985.

<sup>&</sup>lt;sup>25</sup> Dataset: April 2012 – Cell Phones. Pew Internet & American Life Project. Last Accessed 12 December, 2012. http://www.pewinternet.org/Shared-Content/Data-Sets/2012/April-2012--Cell-Phones.aspx.

<sup>&</sup>lt;sup>26</sup> Blumberg SJ, Luke JV. Wireless substitution: Early release of estimates from the National Health Interview Survey, July–December 2011. National Center for Health Statistics. June 2012. Last Accessed 6 October, 2012. http://www.cdc.gov/nchs/data/nhis/earlyrelease/wireless201206.pdf. <sup>27</sup> Ibid.

<sup>&</sup>lt;sup>28</sup> Lim MS, Hocking JS, Aitken CK, et al. Impact of text and email messaging on the sexual health of young people: a randomized controlled trial. J Epidemiol Community Health, 2012;66(1):69-74.

group.<sup>29</sup> Furthermore, the WelTel Kenya1 trial demonstrated that SMS support via weekly messages to participants improved adherence to HAART and increased viral load suppression, when participants were required to respond whether they were doing well or if there was a problem.<sup>30</sup> SMS alerts are also relatively unobtrusive, offering the user confidentiality in environments where HIV is often taboo. Locally, CPHR conducts the National HIV Behavioral Surveillance Study, funded by CDC, and we have found that among a representative sample of MSM in San Francisco, an overwhelming majority of MSM ages 13-34 use the Internet or mobile phone applications, 84% of MSM ages 25-34 and 83% of MSM ages 13-24, respectively.<sup>31</sup>

#### **Target Audience**

The target audience for this intervention includes community-based organizations and local and state jurisdictions that would like to develop a digital HIV care navigation intervention in their existing system of HIV care. Organizations must have an institutional investment and/or interest in using digital technology and in particular, SMS text messaging, to manage a large panel of individuals. Institutional commitment is critical to overcoming implementation challengers and barriers related to digital interventions. For example, for organizations that serve populations with limited or no access to a mobile phone, institutional investment in digital technology may be an important factor in re-allocating necessary resources to bridge the digital gap. Consequently, organizations with feasibility, acceptability and/or needs assessment data related to technology access is highly encouraged.

#### **Intervention Overview**

Health eNav is a digital HIV care navigation intervention that will complement traditional HIV care navigation services. The intervention is specifically designed to target youth and young adults (18-34) MSM and trans women who are newly diagnosed, not linked to care, out of care, or not virally suppressed. Health eNav is comprised of two digital innovations: (1) digital navigation using a SMS text messaging, and (2) digital sensing using ecological momentary assessments. These innovations are described below:

1. Health eNav Innovation: Digital HIV Care Navigation

A website was built to promote a digital presence for Health eNav and served as the digital home and enrollment portal for potential participants. Branded accounts

<sup>&</sup>lt;sup>29</sup> de Tolly K, Skinner D, Nembaware V, and Benjamin P. Investigation into the use of short message services to expand uptake of human immunodeficiency virus testing, and whether content and dosage have impact. Telemedicine and e-Health, 2012;18(1):18-23.

<sup>&</sup>lt;sup>30</sup> van der Kop ML, Karanja S, Thabane L, et al. In-depth analysis of patient-clinician cell phone communication during the WelTel Kenya1 antiretroviral adherence trial. PLoS One, 2012;7(9):e46033.

<sup>&</sup>lt;sup>31</sup> Unpublished data. San Francisco Department of Public Health (SFDPH); National HIV Behavioral Surveillance Study – MSM4 Cycle, 2015.

were created for the following social media platforms to create multiple points of entry into the digital HIV care navigation system and ensured on-going communication, engagement and retention. Social media platforms used included Facebook, Twitter, Tumblr, kik, Snapchat, and Instagram. At enrollment, participants provided comprehensive social media contact information to the Digital Navigator and indicated whether or not they have access to a mobile phone to help facilitate digital navigation services. For participants who did not have access to a mobile phone, a cell phone and one year of cellular services were provided up to 60 eligible participants. Digital HIV care navigation includes the following components: 1) HIV care navigation, 2) health promotion, 3) motivational interviewing, and 4) digital social support.

2. Health eNav Innovation: Digital Sensing

Ubiquitous data collection in real-time by using mobile technology can provide the critical contextual data needed to explain barriers to care engagement. Ecological momentary assessment (EMA) is a behavioral medicine method to collect data close in time to experience and in the participants' natural environment, shedding light on the dynamics of behavior in real-world settings. EMA modules are delivered to participants in the form of a short text-based survey to sense early indicators of barriers and facilitators to HIV care. The EMA questions gauge participants' emotional affective state, substance use, internalized stigma, and other risk behaviors known to directly affect care engagement and medication adherence. Data captured in the EMAs facilitate timely personalized referrals, prompt digital care circle discussions, and inform our understanding of early predictors in the HIV care continuum.

#### **Intervention Description**

#### **Intervention Approach and Theoretical Framework**

Issues that youth and young adults living with HIV experience are complex, requiring a combination of digital and social media technologies and clinical and community based interventions to achieve positive change. To impact health outcomes and reduce the spread of HIV, traditional medical care services must change and move outside of clinical settings to incorporate social service systems, digital and social media technologies, and address social determinants of health. Health eNav is firmly grounded within the theory of the Patient-Centered Medical Home (PCMH) Model, and is supplemented with aspects from the Chronic Care Model. The intervention also uses innovative strategies based in best practice models such as the Continuous Relationship Model.

Health eNay is designed to improve health outcomes through a proactive, patient centered, service oriented, accessible, and cost effective PCMH Model.<sup>32</sup> This PCMH Model uses a care team approach to provide patients focused and culturally relevant services; strong provider-patient relationships; the elimination of barriers to care; and increased efficiency and quality of care. Services are provided by a care team that includes a medical provider, nurse, medical assistant and a medical case manager. Data has shown that patients who see the same care team routinely promote strong relationships, resulting in better continuity of care and increased treatment adherence. In addition to the PCMH Model, Health eNav delivers HIV care that aligns with the Chronic Care Model which has six criteria: 1) Organization and leadership that supports high quality chronic care and ongoing quality improvement activities; 2) Linkage to community resources to increase access to needed services in a community-driven, cost-effective way; 3) Patient self-management support through the use of individual and group interventions that empower patients to take an active role in their health; 4) Coordinated delivery system design across multiple providers; 5) Clinical decision support that incorporates evidence-based practice guidelines; and 6) Clinical information systems that support information sharing and proactive care.<sup>33, 34</sup>

Within the PCMH model, strong provider-patient relationships are critical, which is implemented through Digital Navigator within Health eNav. Multiple research studies have shown that linkage programs without follow up are less successful

<sup>&</sup>lt;sup>32</sup> Jackson GL, Powers BJ, Chatterjee R, et al. The patient-centered medical home. A systematic review. Ann Intern Med. 2013;158:169–178.

<sup>&</sup>lt;sup>33</sup> Wagner, E. H., Austin, B. T., & Von Korff, M. (1995). Improving outcomes in chronic illness. Managed care

quarterly, 4(2), 12-25.

<sup>&</sup>lt;sup>34</sup> Wagner, E. H., Austin, B. T., & Von Korff, M. (1996). Organizing care for patients with chronic illness. The

Milbank Quarterly, 511-544. http://dx.doi.org/10.2307/3350391

with people that require more intensive, ongoing support.<sup>35</sup> Several strategies have been recommended to enhance the capacity of outreach services to respond to the needs of these vulnerable individuals: remaining involved with the client in the referral process (e.g., helping clients with scheduling appointments, assisting with transportation, providing emotional support); informing new staff of client needs and characteristics; providing follow-up support to both client and new staff as needed; and providing advocacy on behalf of the client as needed.<sup>36</sup> Continuous relationship models have been regarded as the preferred model for people with more complex needs because of the need to preserve continuity of care in times of transition.<sup>37</sup>

#### **Target Population**

Health eNav was designed for and was tested with youth and young adults, ages 18-34, living with HIV who identify as MSM or a trans woman regardless of racial/ethnic background. Participants must also meet at least one of the following criteria:

- Newly diagnosed with HIV (or people who have tested HIV positive for the first time within the last 12 months prior to enrollment)
- Not linked to HIV medical care (or people who are aware of their HIV infection status but have never engaged in care or never had an HIV medical visit after being diagnosed with HIV)
- Out-of-care (or people diagnosed with HIV more than 12 months prior to enrollment who had a gap in their HIV care that was >6 months, within the last 24 months)
- Not virally suppressed (or people who have a viral load of ≥200 copies/mL at their last lab test)

<sup>&</sup>lt;sup>35</sup> Maulsby C; The Positive Charge Intervention Team, Charles V, Kinsky S, Riordan M, Jain K, Holtgrave D. Positive Charge: Filling the Gaps in the U.S. HIV Continuum of Care. AIDS Behav. 2015 Feb 12.

<sup>&</sup>lt;sup>36</sup> Sullivan KA, Schultz K, Ramaiya M, Berger M, Parnell H, Quinlivan EB. Experiences of women of color with a nurse patient navigation program for linkage and engagement in HIV care. AIDS Patient Care STDS. 2015 Jan;29 Suppl 1:S49-54.

<sup>&</sup>lt;sup>37</sup> Morse, G. A., Calsyn, R. J., Miller, J., Rosenberg, P., Gilliland, J., & West, L. (1996). Outreach to homeless mentally ill people: Conceptual and clinical considerations. Community Mental Health Journal, 32, 261–274.

# Intervention Typology

Program Summary	Social Media Intervention Overview	Evaluation Summary	
Health eNavigation (Health eNav), <b>San</b>	Intervention type	Evaluation Comparison Group – No	
Francisco Department of Public Health	Adapted from prior intervention		
<b>(SFDPH)</b> (San Francisco, CA)	Adjunct to existing services	HIV Health Outcome Measures	
		Increase HIV testing/Positivity rate/	
<u>Target Population</u>	<u>Technology Platforms Used</u>	HIV awareness: No	
Age: 18-34	Facebook: Yes	Immer links a for a source time and the	
Gender: All	Mobile App: Yes (new)	Improve linkage/engagement in care: Yes	
Race/Ethnicity: All	Social Media: Yes	Improve retention in care: Yes	
Sexual Orientation: All (primarily MSM and	Text Messaging: Yes, automated + live	Improve medication adherence: Yes	
Transwomen)	Website: Yes	Improve viral suppression: Yes	
Transwomeny	<b></b>	<b>Improve utilization of support services</b> : No	
Sample Size: 120 HIV+	Functions		
Language: English	Communication: Yes	Improve health literacy: No	
Sotting: Clinic and hospital	Education: Yes		
Setting. Chine and hospital	Reminders	Other Rvan White Part Fundina	
	General: Yes	other tyun white ruler unding	
<u>Inclusion Criteria</u> Unaware of HIV status: No	<b>Medical appointments</b> : Yes, automated + personalized	Parts A, C, D, F	
	Medication adherence: Yes, automated + live		
Newly Diagnosed: Yes	<b>Self-monitoring / tracking</b> : Yes. Rx adherence +		
Not linked/engaged in care: Yes	medical appts.		
Not retained in care/Out of care: Yes	Social support/networking: Yes		
Not adherent to HIV medication: Yes			
Not virally suppressed: Yes			

#### **Intervention Core Elements / Components**

Health eNav provides HIV care navigation services delivered up to 6 months digitally (e.g. SMS). There are four core components to Health eNav: 1) HIV care navigation services, 2) health promotion and education, 3) motivational interviewing, and 4) digital social support.

*HIV Care Navigation*. HIV care navigation guides patients in knowing where, when, and how to access all health and related services, and increases access to appropriate resources. HIV care navigation services include the coordination of and/or referrals to the following services: (1) primary medical care, (2) specialty care, (3) mental health care and substance abuse services, (4) imaging and other diagnostic service, (5) laboratory services; (6) health insurance, (7) housing, and (8) benefits/entitlements/public assistance.

*Health Promotion and Education*. Health promotion and education ensures optimal health literacy for all patients by providing information on the biology of HIV, disease management, communication with providers, risk reduction and healthy behavior, and ART adherence. Health promotion content is tailored, personalized and specific to the needs of each participant and documented in their care plan (see Appendix O) and updated on an on-going basis. Health promotion and education messages are delivered via SMS text messaging and in a way that is suitable to meet patients' education, developmental, language, gender, sexual and cultural needs.

*Motivational Interviewing.* Motivational interviewing is a technique and a style of counseling that can help resolve the ambivalence that prevents patients from realizing their personal goals. Motivational interviewing builds on Carl Rogers' optimistic and humanistic theories about people's capabilities for exercising free choice and changing through a process of self-actualization. The therapeutic relationship for both Rogerian and motivational interviewers is a democratic partnership. Motivational interviewing is directive and aims at eliciting self-motivational statements and behavioral change from the client in addition to creating client discrepancy to enhance motivation for positive change.<sup>38, 39</sup> Motivational interviewing activates the capability for beneficial change that everyone possesses.<sup>40</sup> Although some people can continue change on their own, others require more formal treatment and support over the long journey of recovery. Even for clients with low readiness, motivational interviewing serves as a vital prelude to later therapeutic work. These motivational interviewing techniques

<sup>&</sup>lt;sup>38</sup> Davidson, R. (1996). Motivational issues in the treatment of addictive behaviour. *Psychotherapy, Psychological Treatments and the Addictions*, 173-188.

 <sup>&</sup>lt;sup>39</sup> Miller, W. R., & Rollnick, S. (2012). *Motivational interviewing: Helping people change*. Guilford press.
 <sup>40</sup> Rollnick, S., & Miller, W. R. (1995). What is motivational interviewing?. *Behavioural and cognitive Psychotherapy*, 23(4), 325-334.

are applied in the text messaging conversations delivered by the Digital Navigator to the patients to encourage behavioral change.

*Digital Social Support*. The program provides patients with maximal access to social support from a Digital Navigator. The Digital Navigator maintains an open, non-judgmental space with participants and provides social support through engaging in active listening, joint problem-solving, and peer counseling on an as needed and ongoing basis during the 6 month intervention period. They may also provide counseling to assist with disclosure where feasible, and/or facilitate referrals to external social support providers (e.g. community based organizations) when appropriate.

#### Implementation

#### **Pre-Implementation Activities**

Prior to implementation, a number of activities were conducted to prepare for implementation and support recruitment activities and potential participant education. After hiring and training staff with regards to intervention implementation, we sought to develop an online presence and formalize text messaging platform agreements. We developed a website to point potential participants to and created content to educate potential participants about participation in the intervention. We also created corresponding social media and social network accounts to create multiple points of engagement with the intervention. All of these social media and networking accounts cross-references each other. In addition, we also executed contracts with digital technology vendors for text messaging and for mobile phone hardware and service. Once these activities were completed, we tested implementation of digital technologies and the intervention to fine-tune protocols and procedures.

#### **Community Advisory Boards**

Engaging and obtaining input from community participants and stakeholders were critical to the design and implementation of Health eNav. In the pre-implementation phase, input from two community advisory groups, the Bridge HIV Community Advisory Group (CAG) and the Transgender Advisory Group (TAG), were obtained. Both groups consisted of advocates and stakeholders who served the target population as well as community members that were a part of the intended target population. Input from these groups were used to develop and pilot local evaluation constructs and measures. Feedback on marketing plans and recruitment strategies were also obtained. Ongoing engagement with community advisory groups and local provider and stakeholder networks (e.g. SF HIV Care Council and SF Getting to Zero Coalition) are essential to ensuring intervention relevance, dissemination of findings, and development of a sustainability plan after the intervention.

#### Marketing, Outreach and Recruitment Partners

A multi-pronged recruitment strategy was used. We convened a Leadership Committee, a group of stakeholders to champion access to public health clinics for recruitment. To support recruitment, we identified, met and procured memoranda of understanding with recruitment partners. By leveraging partnerships with SF DPH's HIV care navigation service network, HIV testing sites, and Data-to-Care Initiative as well as engaging with the community-based HIV care navigation system, Health eNav was able to recruit 120 participants into the program. The SF DPH HIV care navigation system is driven by the LINCS (Linkage, Integration, Navigation and Comprehensive Services) team. By actively participating in a citywide navigator network and being well-connected with HIV testing sites that have no on-site clinical services, it provided opportunities to deliver Health eNav to those who would benefit most by the intervention. Working with the local HIV Surveillance group allowed the program to identify out-of-care patients in the target population and use digital navigation to promptly bridge access to HIV care. Leveraging these partnerships provided a comprehensive referral system from which to recruit and enroll participants in the program. Additionally, potential participants were screened and recruited directly from social media platforms and on the Internet.

# **Procedures / Protocols**

Policies and procedures and intervention protocols were developed for this project, including the following:

- Referral Mechanisms and Follow-Up Procedures
- In-Office Procedures
- Monthly Reporting Procedures
- Health eNav Written Informed Consent
- Health eNav Locator Form with Social Media Contact Info
- Health eNav Field Incident Report
- Procedures for Using Social Media for Digital Navigation
- A Primer for Digital Navigators on Social Media Platforms
- Noteworthy Free mHealth Applications for Digital Navigation
- In-Person Enrollment Procedures
- Digital HIV Care Navigation Procedures

# Key Staffing Roles, Attributes, and Training

There are two key staff that are integral to the intervention: 1) the Digital HIV Care Navigator and the 2) Data Manager. The Digital HIV Care Navigator plays an important role as primary interventionist. They screen, enroll, and consent participants into the intervention. In addition, they also engage with participants on a one-on-one basis during the six-month intervention. They work with clinical staff to monitor participants' linkage and engagement in medical care and utilize various forms of digital and social media to engage and retain participants for follow-up. It is important that the Digital HIV Care Navigator be familiar with the population, preferably a peer, and a high user of digital technology, text messaging and social media. The Data Manager also has an important role. The Data Manager assists the Digital HIV Care Navigator in providing check-ins using other supportive databases such as electronic medical records. In this intervention, the Digital HIV Care Navigator was employed at 100% FTE and the Data Manager was employed at 20-30% FTE. The Digital Navigator was trained on the intervention protocols and procedures and also received training on health promotion and motivational interviewing techniques

#### Lessons from the Field

We were able to serve and providing digital HIV care navigation to 120 youth and young adults living with HIV in San Francisco. Some of our successes, lessons learned and challenges/barriers are described.

#### **Successes**

#### Delivering Personalized Social Support

The project was able to deliver personalized social support to youth and young adults living with HIV through innovative use of digital technology. For example, one participant was transitioning HIV care providers and did not want their digital HIV care navigator to accompany them to the appointment. However, while they were in the waiting room, the participant was having a very difficult time fighting to not internalize the stigma from being in an HIV clinic. He went on to have a difficult conversation with his new care provider. Meanwhile, he was able to speak with their personal digital HIV care navigator through this difficult clinical encounter. The digital HIV care navigator served as a caring source of support to listen to and support this participant; and as a result, this participant was able to work through his feelings of stigma and other negative emotions to maintain linkage and engagement in care.

#### Collecting Real-Time Data

The project was able to collect timely individual-level data securely through mobile devices. After enrollment, participants receive daily text message surveys for 90 days on a variety of topics, including mental health and substance use. These data can impact individuals' linkage, engagement and retention in HIV care. They are reviewed by the HIV care navigator who can deliver personalized social support depending on how participants responded to text surveys. For example, one participant went approximately 30 days with no feelings of depression or anxiety. Suddenly, the participant started to indicate that he was feeling anxious or depressed. The digital HIV care navigator checked-in with the participant via text message and found out that he hasn't been able to successfully get a job even after multiple interviews. The digital HIV care navigator was able to provide timely emotional and informational support to a participant that may not have shared this kind of information to their usual care provider.

#### **Challenges/Barriers**

#### The Importance of Collaborative and Translational Communication

Technology vendors can be siloed. Some technology vendors may not have experience in health care, public health, or research. These disciplinary boundaries may make it challenging in translating or communicating your research or public health needs, causing delays in development. Effective communication to foster understanding of purpose and organizational context will help aid negotiations and scoping a project appropriately.

# Keep Your Eye on the Front End and the Back End

It is important to emphasize both how the technology looks (front end or user interface) and how it is structured in its programming code (or the back end) as this can impact how data and meta-data are collected and databases are structured. For example, meta-data are data collected on the back end. While the primary data might be text messages, types of meta-data might include date, time, geolocation, etc. It may be important to consider how the data are collected, including meta-data, and how the data are structured. For example, does the technology measure time using a 24-hour clock versus a 12-hour clock? Will the project need to calculate time? If so, the 24-hour clock might be a better measure to compute a new time variable using two time measurements. While seemingly minor, a detail like this might require a redesign with a hefty price tag, especially if there is a limited budget for adjustments.

# Agree on a Contract that Lives On for the Length of a Project

When entering a contract with a technology vendor, create a contract that spans the entire length of the project if possible. Important issues may include: key software updates, on-going technical support, new features, etc. This will allow additional adjustments to be made along the way.

# Tips for Implementation

- Offer an alternative work schedule to incorporate flexibility in providing digital navigation and support conversations with participants at times that they prefer and are most accessible.
- Prioritize initiating conversations with participants who have a higher acuity level versus those who have lower acuity.
- Develop a quick reference guide of resources to provide participants.
- Utilize peers as digital HIV care navigators.
- Implement creative ways to spark a conversation, quickly.
- Conduct a comprehensively assessment of participants' social media imprint/presence and provide digital HIV care navigation using all the platforms participants actively use.
- Use direct, succinct, but conversational language, especially with SMS text messaging and participants with limited literacy.
- Use alternative media such as .gifs, emojis, memes, etc., if technology platform permits.
- Use non-HIV related messages to develop rapport and build trust.

- Be responsive in real-time, if at all possible. While SMS text messaging is asynchronous, make an effort to be quick to respond when participants choose to engage.
- Carve out time to engage in a more lengthy text message session in real-time. Designate a day and time in the week to conduct a quick text message chat.
- Develop and integrate a feedback loop for digital HIV care navigation to inform primary care and the care team.
- Consider SMS text messaging as an additional method for evaluating participants who may have "fallen out of care" and/or when a particular mode of communication (e.g. phone number) is no longer viable.
- Incorporate an assessment process to understand individuals' attitudes toward digital technology. Assess whether or not a digital intervention is suitable for a participant or not.
- Do not use digital HIV care navigation to replace traditional navigation with high acuity participants.

#### **Monitoring and Evaluation**

#### Aims

- To determine the feasibility and acceptability of Health eNav, a digital HIV care navigation intervention, among young people living with HIV in San Francisco.
- To evaluate the efficacy of Health eNav to improve health outcomes along the HIV care continuum.

#### **Monitoring Progress**

- Conduct biweekly project meetings to address recruitment/enrollment barriers and effective strategies
- Conduct quarterly and as needed meetings with project leadership group to engage in group thinking and problem solving

#### **Participants / Sample for Local Evaluation**

- Participants must meet the following eligibility criteria:
  - Be HIV-positive
  - Be between the ages of 18 and 34
  - o Identify as MSM or trans woman
  - Be newly diagnosed or not linked to care or out of care or not virally suppressed
  - Live in San Francisco
- All participants participated in the multi-site evaluation and the local evaluation.

#### **Methods for Local Evaluation**

- Data collection comprised of the following:
  - Socio-behavioral surveys at baseline and in six-month intervals for 18 months
  - Semi-structured, qualitative interviews at baseline/enrollment
  - Collection of metadata on the back end of text messaging platforms
  - Medical chart data
  - Costing data
- Qualitative assessment of intervention feasibility and acceptability
  - Semi-structured interviews conducted with 16 participants who represented diverse age, race, and gender identity, and experienced a wide-range of difficulty engaging with the intervention and diverse HIV care continuum outcomes.
- Data collection tools and protocols can be found as appendices

#### **Results for Local Evaluation**

# Acceptability of Ecological Momentary Assessments Among Young People Living With HIV

Overall, most participants (14/16, 86%) who were qualitatively interviewed found the EMA surveys to be acceptable. Five of 16 (31%) participants cited that the surveys were easy to complete. Two participants reported that they enjoyed having the EMA surveys as part of their daily routine. Others (4/16, 25%) reported EMA participation was motivating, citing that completing the EMA surveys proved that they had the ability to commit to something and it was an opportunity to talk about uncomfortable topics such as sex or drugs. One participant said they "felt important" when asked questions about themselves on a daily basis. Few participants (3/16, 19%) felt unfavorably about the EMA surveys. For one participant, completing EMA surveys was an added burden and responding was a low priority in the context of other stressors in their life; however, they did find the remuneration motivating. One participant simply was uninterested, and another participant felt paranoid when they were in public and received a notification to begin their EMA survey. Regardless of whether participants found the EMA surveys to be favorable, some participants (4/16, 25%) found the surveys to be repetitive or redundant.

In terms of survey length and duration, only two (13%) felt that the surveys were too long or should be offered over a shorter duration of time. Most (9/16, 56%) suggested administering the surveys over a longer period of time to make a habit out of medication adherence and other self-monitoring skills they learned from the EMA surveys. They also felt that a longer EMA duration would allow them to see more positive or negative growth and become more accustomed to having a daily routine.

Many participants felt that the EMA surveys had a positive impact on their lives. Most participants (9/16, 56%) felt that EMA surveys improved self-monitoring of behaviors/mood and offered reminders to take HIV medications. Many (6/16, 38%) reported that the EMA surveys created a designated time for self-reflection regarding mood, habits related to substance use or sexual behaviors, and medication adherence. Specifically, one participant learned to ask themselves "What am I doing?" and "What can I change?" For one participant who regularly used substances, the EMA surveys were something to look forward to. For three other participants, the EMA surveys were similar to talking to a friend or having a loved one check up on them; EMA surveys increased their engagement in social relationships and community. In some cases (3/16, 19%), EMA surveys improved moods or habits. However, three participants (19%) reported no impact of the EMA surveys on their lives. Not all participants were in a stable situation to reap benefits from the surveys, citing housing (1/16, 6%), personal crises or stress (1/16, 6%), or phone turnover (2/16, 13%) as barriers.

Several participants cited health-related benefits from the EMA surveys. Seven (44%) felt that they received more insight into their physical and mental health status or cared more about their health. Half the sample felt they had more agency in managing their health care, citing confidence in changing doctors (1/16, 6%), adhering to medical appointments (3/16, 19%), knowing their rights as a patient (1/16, 6%), and being better able to report about their health and habits during

doctor's visits (1/16, 6%). One participant credited the EMA surveys for helping monitor their viral load and CD4 count.

#### Acceptability of Digital Navigation Among Young People Living With HIV

There was high acceptability of digital HIV care navigation among participants. Overall, 14 participants (87.5%) thought that the digital navigation fit into their daily lives and successfully served the purpose of improving HIV care engagement. Most people found the content and services provided through digital navigation to be acceptable and to benefit their HIV care (13/16, 81%). Participants felt encouraged by participating in digital navigation to stay engaged in their care. For example, one participant remarked, "One of the times I went to the doctor and we [participant & digital navigator] were corresponding the entire time. I was in the waiting room and actually in the doctor's office texting the digital navigator and discussing the questions that I was going to ask the doctor and some of the information that I wanted to make sure to tell her. I needed the digital navigator to help me remember the questions that were important for me to ask which was good because I had always been told to write things down before. That was the first time I actually went to my doctor's appointment prepared." Digital navigation provided instrumental support such as referrals to other resources, information and emotional support, and leveraged motivational interviewing techniques to help support participants' behavior change. Most participants (11/16, 69%) felt that six months of digital navigation is a good amount of time for them to acquire new knowledge, information and engage with their HIV care. Three participants said six months of digital navigation was too short and would have liked if the intervention extended beyond that.

All participants that were interviewed (16/16, 100%) felt that digital navigation resulted in an improvement in HIV care and engagement. One participant said, "It helped me to remember that things are okay, the stigma is still there, but as long as you live healthy and do what you need to do, you're fine! I also gained information that I would have never had thought through digital navigation, like new meds that they're coming out with, the new tests that they're trying to do, and the things that they're trying to do to help us live longer and healthier lives. I would have never of done that sort of research by myself. This access was beneficial." Another participant said, "It [digital navigation] helped me get undetectable and stay undetectable. It helped me make sure I made it to my appointments and just keep me on track with knowing where my life was and where I was going medically."

#### Preliminary Outcomes and Intervention Effects on Viral Suppression

Changes in mean changes in HIV care continuum outcomes were evaluated over time (from baseline to 18 months). The following outcomes were analyzed.

Source	Outcome	Response levels
Medical chart data	Viral suppression	1 = < 200 copies/mL; 0 = otherwise
ACASI data	HIV-related medical visit in past 6 months	1 = Yes; 0 = No
ACASI data	Viral load test in past 6 months	1 = Yes; 0 = No
ACASI data	Currently taking ART	1 = Yes; 0 = No
	Ability to take ART among participants current taking ART	Continuous (range = 1-6)
ACASI data	Virally suppressed	1 = Yes; 0 = No or Don't
		know

Presentation of the results begins with plots showing changes in mean outcome levels over time based on the observed data. Random-effects regressions are used to estimate outcome trajectories over time and draw statistical inference.

#### Statistical methods applied medical chart data

Viral load data points were not aligned across participants over the follow-up period. Therefore, it was not practical to calculate means at discrete time points. Plots show viral suppression outcome trajectories that are estimated at each follow-up time point using locally weighted least squares (loess) regression. Each plot shows three outcome trajectories for participants with a new HIV diagnosis (within a year of the baseline assessment), participants with a more established HIV infection, and all participants.

Random-effects logistic regressions were fit to model changes in the probability of viral suppression over time. Models included an intercept term, time as a continuous covariate, and random effects for each participant. Plots suggest curvilinear outcome trajectories, but we were unable to get curvilinear time trends to fit. Time was modeled as a linear trend. Odds ratios (OR) and 95% confidence intervals (CI) are presented for the odds of viral suppression for each additional 30 days in the study. Models were fit to two subgroups of participants (i.e., participants with a new diagnosis and participants with established infection) and the entire sample.

#### Statistical methods applied to ACASI data

Plots show mean outcome levels at each time point, including baseline, 6, 12, and 18 months. Each plot shows three outcome trajectories for participants with a new HIV diagnosis (within a year of the baseline assessment), participants with a more established HIV infection, and all participants.

Outcomes were modeled using random-effects logistic regressions for the probability of the outcome occurring (e.g., an HIV-related medical visit), except the outcome for the ability to take ART. Ability to take ART was treated as a continuous measure and modeled using linear random-effects regression for mean changes in

ability. Similar to medical chart analyses, models included an intercept term, time, and random effects for each participant. Time was modeled as a categorical covariate. OR are shown for binary outcomes and compare the odds of the outcome occurring for each follow-up time point versus the baseline timepoint. Estimated mean differences between each follow-up time point and the baseline assessment are shown for the continuous outcome (ability to take ART). Models were fit to the subgroup of participants with established infection and the entire sample. We had difficultly fitting models to the subgroup of newly-diagnosed participants due to the smaller sample size.

# Viral Suppression Time Trends for SFDPH 1.00 -0.75 Proportion Virally Suppressed 0.50 0.25 -**Diagnosis** Type <12m(N=28) All(N=112) 0.00 --365 ò 3m 6m 12m 18m 24m 900 -630 **Days From Baseline Assesment**

Medical chart data results



Model	Beta Estimate	OR	95% CI	P-value
Overall	0.08	1.09	(1.05, 1.13)	0.00
Established Cases (>12 Mo.)	0.07	1.07	(1.03, 1.12)	0.00
Recent Cases (<12 Mo.)	0.15	1.16	(1.06, 1.27)	0.00

The plot shows an increase in viral suppression rates over the study period. Not surprisingly, rates of viral suppression were lowest at baseline and increased the fastest over the follow-up period among newly-diagnosed participants versus participants with established infection. Visual findings were reflected in the regression results. Odds of viral suppression for every 30-day period in the study were 1.07 [95% CI = 1.03-1.12] among participants with established infection and 1.16 [95% CI = 1.06-1.27] among newly-diagnosed participants.

#### ACASI data results

Plots showed increases in the probability of self-reported current ART utilization and viral suppression over the follow-up period. This was reflected in the regression results. The odds of ART utilization and viral suppression at each follow-up increased compared to baseline. Effects appeared to be driven more by newlydiagnosed participants as odds ratios were smaller in the subsample of participants with established infection versus the entire sample. For example, the odds of current ART utilization at 12 months versus baseline was 3.9 [95% CI = 1.4-10.9] in the entire sample and 2.2 [95% CI = 0.7-7.3] in the subsample of participants with established infection.

# Appendix A: Procedures for Using Social Media for Digital HIV Care Navigation

## 1.0.0 Staff Facebook Page

Staff Facebook Page is for engaging and retaining clients and is to be used exclusively for work purposes. Staff must comply with upgraded security measures as discussed in section 1.3 before adding any research subjects to friends list. Staff must not Facebook "friend" person not in study unless these are other staff to prevent subject identity disclosure. The following sections are listed in the order of operation necessary to create a secure staff Facebook page.

#### 1.1.0 Create Account

- Sign up for a Facebook account by registering a work e-mail to Facebook. Do not use personal e-mail to avoid breach of subject private health information (PHI).
- Name associated to account should only include staff first name or preferred name but not include staff last name (to protect staff privacy).
- Last name should be a generic team name assigned by department research director. -Names should not intentionally or unintentionally disclose any PHI information through subject affiliation (e.g. AIDS Office, HIVNAV, etc.).
- See Figure 1 below.

#### Figure 1: Example of Generic Team Last Name "Shine"



#### 1.2.0 Staff Profile

- Staff must upload a professional image of self. Staff must not include any PHI disclosing information in picture (e.g. HIV Banner, PHI Paperwork / PHI Computer Screens, etc.).
- Staff must limit the amount of personal information displayed in Facebook profile (aka "Timeline").
- By default, Facebook displays Birthday on Timeline, staff must set this to private by clicking on the drop down arrow menu next to the birthday and

clicking "Only Me."

• Staff must not include personal information such as personal phone number, email, address, relationship status, religious and political beliefs.

# 1.3.0 Upgrade Privacy Standards to Account

It is easy on Facebook for any unauthorized individual to access subject names or faces. In order to prevent the unintended disclosure of subjects, staff must **follow the order of operations listed in this section before adding subjects to his/her friends list**.

# **1.3.1 Set Friends List Private**

- First invite another study Staff member to "Friends" list on Facebook.
- Once other Staff has been added to "Friends" list, a "Friends" section will appear in timeline.
- Next to the "Friends" label on the timeline there will be a drop down menu. Click the drop down menu and select "Edit Privacy."
- An "Edit Privacy" Window will pop up. Change Privacy to "Only Me" on both "Who can see your friend list" and "Who can see the people and lists you follow." This will prevent unintended persons from seeing subjects on Staff profile. See Figure 2 and 3.



#### Figure 3: "Friends" list Privacy - Select "Only Me"

Hz 200	Edit Privacy	×
And	Friend List Who can see your friend list? Remember: Your friends control who can see their friendships on their own timelines. If people can see your friendship on another timeline, they'll be able to see it in news feed, search and other places on Facebook. They'll also be able to see mutual friends on your timeline.	Only Me
Intro     Describe Who You Are	Following Who can see the people and lists you follow? Remember: The people you follow can see that you're following them.	a Only Me 🔻
+ Add Info About You	Learn More	Done

#### **1.3.1 Uploading Privacy Settings**

- Under the drop down menu, top lower corner of Facebook profile, click "Settings." (see Figure 4)
- A new window will appear, click "Privacy" on the left side panel of the Facebook page (see Fig 5). Set the privacy values to match those listed in Figure 5.

#### Figure 4: Location of "Settings" in Facebook Profile

f Carlos Lebowski		-		Q	🔲 Carlos Ho	me Find Friends	1. 🖉 🛞 🛛 🛲 👻
Ø							Create Page
							Create Group Find Groups
							Create Ads Advertising on Facebook
	Carlos L	ebows.	ki		Update Info	View Activity L	Activity Log
Add Photo	Timeline	About	Friends	Photos	More 🔻		Settings
							Log Out
Carlos, where do you work?	4/9 complete	× 2	Status 🖻 Pl	hoto / Video 🛛 🖹	Life Event		Help Support Inbox
I don't work for an organization	~		What's o	on your mind?			Report a Problem

Find friends			Home Find Friends	28 🖪 🕲 🗎 🖴 🤅
of General	Privacy Settings and	l Tools		
	Who can see my stuff?	Who can see your future posts?	Friends	Edit
Timeline and Tagging		Review all your posts and things you're tagged in		Use Activity Log
Blocking () Language		Limit the audience for posts you've shared with friends of friends or Public?		Limit Past Posts
Notifications	Who can contact me?	Who can send you friend requests?	Everyone	Edit
<ul> <li>Mobile</li> <li>Followers</li> </ul>	Who can look me up?	Who can look you up using the email address you provided?	Friends	Edit
🔝 Apps 🗗 Ads		Who can look you up using the phone number you provided?	Friends	Edit
💳 Payments 📀 Support Inbox		Do you want search engines outside of Facebook to link to your profile?	No	Edit
Videos				

#### *Figure 5: Change "Privacy" to match the following settings*

• Next, on the left panel, click "Timeline and Tagging." Update the Settings to those listed seen in Fig. 6

Figure 6: Timeline and Tagging Settings

Find friends		Q Carlos Ho	ome Find Friends	<u> 11 (5</u> (8) ) All -
o <sup>®</sup> General ₿ Security	Timeline and Tagging	Settings		
	Who can add things to my timeline?	Who can post on your timeline?	Only Me	Edit
Timeline and Tagging     Blocking		Review posts friends tag you in before they appear on your timeline?	On	Edit
Language	Who can see things on my timeline?	Review what other people see on your timeline		View As
Notifications Mobile		Who can see posts you've been tagged in on your timeline?	Only Me	Edit
Followers		Who can see what others post on your timeline?	Only Me	Edit
🔝 Apps 🕡 Ads	How can I manage tags people add and tagging suggestions?	Review tags people add to your own posts before the tags appear on Facebook?	On	Edit
Payments Support Inbox		When you're tagged in a post, who do you want to add to the audience if they aren't already in it?	Only Me	Edit
Videos		Who sees tag suggestions when photos that look like you are uploaded?	No One	Edit

• Next, on the left side panel, click "Followers" and update settings to those seen in Figure 7.

# Figure 7: Update "Followers Settings"

Find friends		🔍 📃 Carlos Home Find Friends 🔐 💭 🌑 斗 👻
o <sup>®</sup> General <b>≅</b> Security	Follower Settings	
<ul> <li>Privacy</li> <li>Timeline and Tagging</li> <li>Blocking</li> <li>Language</li> </ul>	Who Can Follow Me	Followers see your posts in News Feed. Friends follow your posts by default, but you can also allow people who are not your friends to follow your posts. Use this setting to choose who can follow you. Each time you post, you choose which audience you want to share with. Learn more.
<ul> <li>Notifications</li> <li>Mobile</li> <li>Followers</li> </ul>	Want to know what follow	ers can see? View your public timeline.
<ul> <li>Apps</li> <li>Ads</li> <li>Payments</li> <li>Support Inbox</li> <li>Videos</li> </ul>		

• Next, on the left side panel, click "Apps." These settings are to prevent unwanted Apps to access subject information. Under the "Apps, Websites and Plugins" click "Edit" and select "disable." See Figure 8 below.

Figure 8: Disable Apps from Accessing Facebook Information

Security	App settings		
🚇 Privacy	Logged in with Facebook Logged	in Anonymously Search	h Apps
<ul> <li>Timeline and Tagging</li> <li>Blocking</li> <li>Language</li> </ul>	On Facebook, your name, profile picture, cover people and apps. Learn why. Apps also have ac	hoto, gender, networks, username, and user id are always publicess to your friends list and any information you choose to make	icly available to both e public.
<ul> <li>Notifications</li> <li>Mobile</li> </ul>	You haven't logged into any apps with Facebook	. Learn More about Facebook Login.	
Followers	Apps, Websites and Plug	ins 🌍 Apps Others	Use
Apps       Image: Ads       Image: Payments       Support Inbox       Videos	Lets you use apps, plugins, games and we Facebook and elsewhere. Disabled. Edit	bsites on People who can see your info can brin they use apps. Use this setting to con information people can bring Edit	ng it with them when trol the categories of with them.
	Old Versions of Facebook for This setting controls the privacy of things you pracebook mobile apps that do not have the init selector, such as outdated versions of Face BlackBerry. Expression of the privacy of things you privacy of the privacy	Mobile ine audience ebook for	

#### 2.0.0 Facebook Fan Page

The benefit of a Facebook Fan Page is to help create awareness or visibility about a particular campaign, program, or study. A Fan Page does not have any group

members, but allow for member of the public to "Like" the Study and send messages to the administrator of the page.

# 2.1.0 Lessons Learned and Best Practices

- **DO NOT** Post Pictures of Study Subjects or Personal Health Information
- **DO NOT** Post Information about any Subject
- **IF ANY UNCERTAINTY** arises on what to post check with Study Director.
- **UPDATE REGULARLY** with images, infographics, and resources
- Page should specify the purpose of the project and a brief description
- Page should specify organization carrying out project
- Page should specify location of site and contact phone number
- Review performance of posts via Facebook Page Insights to learn more about who is the page reaching

# Figure 9: Example of a Study Fan Page

Bridge HIV Medical Research Organization	• Community
Timeline About	Photos Reviews More •
530 people like this	Bridge HIV March 17 at 9:00am · @
38 people have been here	Meet Bridge HIV's new Community Programs Manager Josephine Ayankoya, MPH.
Invite friends to like this Page	Josephine attended #CROI2016 last month and as a member of AVAC's PxROAR program, she has written a blog post where she reports and
4.4 of 5 stars · 10 reviews View Reviews	reflects on the conference.
ABOUT	
SY St Off Jan	AVAC S
₱ 25 Van Ness Ave, Ste 100 Save San Francisco, California	Global Advocacy for HIV Prevention
<ul><li>(415) 437-7400</li></ul>	
http://www.BridgeHIV.org/	

# 3.0.0 Building a Facebook "Secret" Group

In Facebook comes the ability to create a group to send out mass messages or keep participants updated regarding study. A Facebook group tied to a study requires an additional layer of privacy to prevent revealing private information such as the identity of participants. Below are a list of settings required to protect study subject identities.

#### 3.1.0 Upgrade Privacy Standards to Group

# Staff must **follow the order of operations listed in this section before adding subjects to the group.**

First, create a group by going to the Facebook homepage and clicking "Create Group" located on the left side menu (See Fig. 10)



*Figure 10: Location of "Create Group" is Circled Red in this Illustration* 

Once selected, a menu will appear titled "Create New Group." Enter a "Group Name" that does not reveal or disclose any potential PHI information (e.g. HIV Positive Group, Folks Who Use Heroine, etc.). For purposes of this illustration, the group name is "Secret Group Name." Set the Privacy to "Secret" so that "only members can find the group and see posts." Also, make sure to add a staff member to your group as your first member, otherwise you won't be able to create a group. Then click "Create" (See Fig. 11).

Create New Group	
Group Name	Secret Group Name
Members	andresshinestudy@gmail.com ×
	Suggested:
Favorites	Add this group to your favorites.
Privacy	Public Anyone can see the group, its members and their posts.
	Closed Anyone can find the group and see who's in it. Only members can see posts.
	Secret Only members can find the group and see posts.
	Cancel Create

*Figure 11: Create New Group Set to "Secret"* 

Facebook will then ask you to pick an icon to represent your group. This is optional. You can "skip" or pick an icon. Once this step is complete, you will be taken to the "secret" group (See Figure 12).

From now on, the Facebook "secret" group will appear on your homepage's left menu. In the illustration below, the group, "Secret Group Name" can be seen on the left side menu.

# Figure 12: Facebook Secret Group



Now click the button on the right of the "Notifications" button, this is located on the top right corner of the "secret" group homepage. A drop down menu will appear, select "Edit Group Settings" (See Fig. 13).


# *Figure 13: Button on the right of "Notifications," Select "Edit Group Setting"*

Once in the Group Settings section, under "Membership Approval" select "Any member can add members, but an admin must approve them" (this will prevent people from adding members to the group who are not in the study). Then scroll all the way down, and change "Posting Permissions" to "Only admins can post to the group" and check the box "All group posts must be approved by an admin." Then click the "save" button (See Fig. 14).

# Figure 14: Update "Secret" Group Settings



An optional step is to create a unique URL for the group and e-mail address. The email address will allow for the creation of posts using e-mail. This option is found in the group settings page under "Web and Email Address" then click the button "Customize Address." Then a pop up menu appears. Do not include any PHI revealing info in the group URL or e-mail (See Fig. 15)

Figure 15 – Customizing Group URL and E-mail

*Figure 15: Customizing Group URL and E-mail* 

Customize Web and Email Address	
Create a name should be less	e to use for your group's web and email address. Names than 50 characters.
	secretgroupname
	facebook.com/groups/secretgroupname secretgroupname@groups.facebook.com
Note: Once you customize your address, you won't be able to change it.	
	Customize Address Cancel

Note: invites to the group will appear in the e-mail of the person invited by an administrator. They then need to accept in order to become a "member" in the group.

Next, set up administrators to manage and post in the "Secret" group. The creator of the "secret" group by default is made into an administrator. Under the "Members" tab from the "secret" group, pick a staff member to be an administrator. Click "Members" tab, then click the gear next to the photo of the member and pick "set as admin" (See Fig. 16). Consideration should be given as to whom is an administrator. Administrators should be limited to study staff as administrators have the ability to post or add members to the group.

## Figure 16: Creating Administrator Profiles



# 4.0.0 Protecting Private Health Information Over Facebook

Although in previous sections privacy settings for Facebook have been maximized to prevent breach of subject identities, Staff is still responsible over the content posted online and over possible breach of information via the physical devices or hardware used by Staff which may give access to personal information. Below are a few suggestions in order to comply with HIPAA when on social media.

### 4.1.0 Complying with HIPAA Privacy While Online

- **DO NOT** Post any information (including name or any descriptor) about a subject online
- **DO NOT** write messages or comments on subjects personal Timeline, Pictures, etc.
- **DO NOT** communicate with subjects outside of private chat one to one messages inbox on Facebook (**Note: Facebook Chat / Messaging is NOT Secure**)
- **DO NOT** Tag subjects on Facebook (this may unintentionally expose subject identities)
- **DO NOT** make any comments about diagnosis, substance use or mental health condition of subject on Facebook or any other social media
- Limit conversations with subjects to referral or check-ins. Avoid providing details that may indirectly reveal HIV, mental health, or substance use status (e.g. "HIV Medical Appointment," "Substance Group

Appointment")

- Take any personal medical conversations offline or ask subject to switch to secure messaging App provided by study (Facebook Chats are NOT secure).
- If subject has additional questions regarding diagnosis or wants confirmation of diagnosis, ask them to call the office for more details. **Staff cannot provide medical details over Facebook. This is to prevent disclosing information to an account hijacker.** (Say, "To protect your privacy, I am unable to talk about specifics regarding medical information over Facebook, but we can talk about this over the phone or the Health-E Nav App")

# 4.2.0 Complying with HIPAA Privacy on Your Physical Device

- Never leave Facebook session open on a computer or cell phone
- **Never** send or read messages to subjects in an environment where messages may be read by an unauthorized person (e.g. in a crowded bus with people behind you)
- Always Sign Out from Facebook when not in front of computer or cell phone trying to communicate with subjects (even if cell phone is in your possession)
- **Staff Facebook Account should have a strong password** (At least 7 characters long, containing one uppercase letter, one lowercase letter, one number, and one symbol)

# 5.0.0 Important Considerations for Digital Navigation on Social Media Platforms

Before using Facebook or any other social media platform, take into consideration the following recommendations when developing any plans that involve communication and engagement.

- 1. State and understand all the objectives for the account: Do you want to highlight content, spark action, or encourage awareness of an issue? Clearly know the objectives that will help you determine if the account can help you meeting larger goals
- 2. Understand your target audience: Make sure to know your intended audience(s) to help you better develop and communicate important messages that will prompt them to take action.
- 3. Resources: Make sure to have enough staff or resources to create content and manage the Facebook page or social media account. Designate management to ensure all activity projected on the accounts are viable.
- 4. Identify the best platform: Knowing your intended audience is important and you can determine if should develop a Facebook page or another account on another social media platform. Content can be accessed different by different audiences. Use social media platform that will best fit your project, audience, and staff.

Projects and programs should always consider what the best practices should be when developing a Facebook page or any other account on a social media platform.

- 1. Keep content easy: Watch the length of posts, comments, and messages. Additional information can make the post uneasy and hard to engage with.
- 2. Maintain a set schedule: When using Facebook it is important to set a posting schedule. It gives your audience a sense of consistency for your online presence. It will also help ensure that the account is active and encourage more engaged users. Try posting daily, or every other day based on your audience(s).
- 3. Create and manage promotional activities: Promote your Facebook page as much as possible by inviting user to like it or sharing it on their personal walls. Promotion is a strong recommendation to maintain high engagement and retention in the account activity.
- 4. Have strong communication: Use correct language and have a strong online presence as support to your audience(S) Engage with your target audience by liking their statuses, tagging them on relevant information. Provide content that will offer engagement like group chats, events, games, quizzes/challenges, and a series of multimedia information. Keeping strong communication will overall help retention activity with the facebook page or social media account.
- **5.** Evaluation: It is always important to have an evaluation component in every project. It will help measure the success or failures of all social media activities. Monitor the amount of activity or traffic on your page, it will give you an idea the level of your online presence.

# **Appendix B: A Primer on Social Media Platforms**

Navigating through the plethora of social media may seem daunting. This primer aims to provide insight into an array of common social media platforms used by many young adults. This section is organized by a description of these platforms, information required for a researcher to create an account, ways to locate study participants, and tips on how to engage study participants.

### 1. Facebook

Facebook is an online social platform that allows users to connect with people, organizations, and friends, who work, study, live and engage around them. Facebook provides many features like sharing multimedia posts, which users are able to learn about different people and organizations. Creating an account on Facebook, a user needs to provide their full name, a valid email address, password, their gender, and birthday.

Facebook has multiple modes of communications. On their open chat platform, users are able to post publicly on their own walls or the walls of other users. Their component of direct messaging is a two-way messaging platform, meaning that their chat can be with one or more users in a direct message thread. The platform allows users to send texts, pictures, videos, and links. This platform also shows a user's online status. Facebook is a geospatial enabled platform, and allows users to post their location on any of their posts. Facebook is available on a web platform and mobile platform. Facebook offers a separate mobile messenger app, solely for messaging.

Strategies for engagement and retention:

- Create private groups and invite clients to participate in an open discussion about particular topics
- Highlight posts that will promote the project
- Tag users on relevant information
- Ask users to do something within the post or content such as share, like, or comment
- Post additional information for clients who are posting their thoughts
- Don't remove comments from clients
- Respond to any questions or comments as soon as possible
- Give supportive feedback to clients thoughts or stories they share publicly or directly
- Provide engaging content like quizzes, polls, or links to live events for clients
- Provide content that is easily transparent for other social media accounts like twitter or youtube.
- Post supportive messages, links, photos and videos in private groups/messages
- Navigate clients to helpful pages, articles, and services

- Infuse personality in connecting with clients over Facebook
- Develop posts that will trigger action and provide motivation
- Boost engagement with visual content
  - Create content that will attract your clients and make them more inclined to communicate with you
  - Visual content is easier to understand and it evokes motivation more easily than written posts
- Tailor all content posted
  - Open-platform content anything posted in private groups/anything posted on public wall of our profile
    - One-way platform content tag clients names on Facebook posts
    - Two-way platform content anything transmitted through private group chats and/or direct messages
  - Offer personalized encouragement
    - Devote time to interact with clients via comments, direct messages, and tagging their names on links

Strategies for location:

- Find clients using email addresses all major webmail services like hotmail, gmail, yahoo are supported
- Display name
- Phone number
- "Find people" tab, where you can search by gender, age, relationship status, birthday
- Based on information in the education and work section of clients profiles
  - o Name
  - o School names high school universities

# 2. Instagram

Instagram is a photo sharing network that allows users to upload media taken with a phone/tablet within the Instagram network and throughout other popular social networks. The application offers special image apps that users can apply to their content before posting publicly. Creating an account on Instagram, a user has the option to sync and link to an existing Facebook account. However, if the user doesn't want to use their Facebook account, they can sign up with a valid email address. Instagram also requires a username, password, full name, and birthday. Instagram features an open and two-way platform for communication. A user communicates through comments on pictures where you can mention other users or apply a hashtag to their comment. The direct-messaging feature allows users to send a picture, video, or text privately to other users. Instagram is geospatial capable and gives the option to enable the feature whenever. The location will post on top of their photo the user posts. Instagram is available on web platform and mobile platforms. Strategies for engagement and retention:

- Create visual updates that are personalized and shared publicly to directly to users
- Create specific hashtags geared towards particular projects (e.g. #digitalnavigation)
- Motivate and encourage your audience to use that hashtag when they make a post or to receive updates.
- Make a private profile and only approve select users/clients so only they can see what is posted and shared on the profile.
- Post supportive visuals that will trigger motivation

• Maintain interaction with clients via posts, comments, and direct messages. Strategies for location:

- Use the search bar and explore tab to locate a profile
- Users can search usernames/full names, hashtags, and locations.
- Use keywords that clients may use- Instagram will attempt to find users with that word in their name or user information
- Select the "tags" option, type in a search query to find posts that have been "hash tagged" with the same terms
- Once you find the profile- hit "follow" to add the client to the circle of people followed
- Locate users through contact information- follow through address book feature
- Use Instagram's sync feature with Facebook
  - Access settings
  - Select the option "Facebook friends"- able to see a list of Instagram users who are also friends with you on Facebook

# 3. Snapchat

Snapchat is a mobile application that allows users to send a series of texts, photos, and videos which are called snaps to their friends. The app allows the sender to draw or insert text on the snap and determine how many seconds (1-10) the recipient can view it before the file disappears from the recipient's device. Snapchat offers an array features like special filters, sending money (SnapCash), live events around the world, and news updates on the discover page. Snapchat requires a user to provide a valid email address, username, password, and phone number to make an account.

With Snapchat, a user can send snaps to a single recipient or multiple recipients. Each recipient has their own thread, which opens a two-way platform for users to chat directly with each other. If two users have their thread open, they can live chat via video similar to Apple's FaceTime. Users can also send snaps to their "story" which makes the snaps public to their followers. Snapchat is geospatial enable and users can apply a special filter to their snap that will show where they are. Snapchat does not show user's online status. This application is available only on a mobile platform.

Strategies for engagement and retention:

- Create, tailor, and send snaps that are personalized and visually engaging
- Send videos as face-to-face engagement
- Utilize live chat feature to talk and engage with clients directly
- Use Snapchat's money feature to compensate clients who completed assignments or participation
- Post appealing snaps to make public announcements for clients to receive
  - o Events
  - o Trainings
  - o Updates
- Utilize the time feature to send information that is sensitive or can't be accessed at a later time
- Encourage clients to send snaps when they have questions about something
- Ask clients to reply to main account with an indicator for confirmation (a thumbs up picture)
- Send snaps to story and clients of live events (conferences, health discussions, etc)
- •
- Send short consistent snaps to clients to build relationship
- Utilize all the Snapchat tools to make snaps fun, engaging, and personalized
  - o Timer
  - o Drawing tool
  - o Emoji keyboard
  - Special content filters

Strategies for location

- Users can search for each by
  - o Username
  - o Phone number
  - o Address book
  - Snapchat QR code
  - o Snapchat users who are nearby

# 4. Twitter

Twitter is a "microblogging" social network where users can send and read messages known as tweets (text-based posts of no more than 140 characters). Twitter is used to share and view links, videos, opinions, news professional info, and personal status. To create with Twitter, a user needs to provide full name, phone number, username, and password.

Twitter offers multiple platforms for modes of communication like one and two-way platforms. Users can send direct messages and mention each other in tweets. Twitter is geospatial enable and allows users to show their location on their tweets. Twitter can be synced to apps like foursquare and swarm that will post check-ins. Twitter does not show users' online status. Twitter is available on web and mobile platforms.

Strategies for engagement and retention:

- Create private lists and invite clients/users
  - Use private lists as a tweet-style open discussion/forum
- Create a twitter name that is a unique identifier
- User twitter abbreviations to engage with clients
- Make sure to follow back all clients
- Mention clients publicly to promote connection and online activity (e.g. Have a good day @healthenav!)
- Personalized tweets geared towards additional information
- Direct message clients links or other useful educational materials
- Encourage clients to use hashtags that are geared toward the project
- Tweet supportive messages, links, photos, videos, and gifs
- Use the quote feature and quote clients on tweets that are motivational, engaging, and supportive
- Tweet information that will boost action and motivation
- Use visual and media content
- Tailor all tweets when they are public, in mentions, and direct messages
- Tweet personalized encouragement for clients to attend events or community discussions

Strategies for location:

- Search for clients using
  - o Email address
  - o Username
  - o Full Name
  - o Hashtags

# 5. Tumblr

Tumblr is a microblogging platform that allows users to post photos, quotes, links, music, and videos from browsers, phones, desktops, email or wherever the user happens to be. Users can customize pages, from colors, to themes, or altering HTMLs. To create an account a user needs to provide a valid email address, full name, and username. Users can also personalize their URL for direct linkage to their online profile.

Tumblr uses direct messaging as a way to communicate with other users on the platform. When users reblog pictures or texts, they can mention another users name and communicate via the "notes" on a particular piece of content. Tumblr is not a geospatial platform and doesn't show when their users are online. Tumblr is available on web and mobile platforms.

Strategies for engagement and retention:

- Utilize the blog aspect of Tumblr and post visual posts that will motivate clients
- GIFs are a very popular form of content on Tumrblr- use GIFs to engage clients
- Create an open profile and give login info to clients to help build a community blog where clients can post things that are motivational or personal stories.
- Post creative text-based posts that project personality to help engage clients and for them to follow the blog
- Alter the appearance of the blog to be approachable online, use an interesting and fun URL
- Make the posts open for discussion on the notes section of the content
- Use Tumblr as a creative tool to engage and connect with clients

Strategies for location:

- Search clients using :
  - o Email
  - o Full name
  - o Username
  - o Hashtags

# 6. Youtube

YouTube is an online platform that is made for video streaming and sharing. Users can search any video content like tutorials, music videos, shows, and live events. YouTube requires a separate account with google to sign in.

YouTube only has an open platform for modes of communication. Users can communicate through comments on videos or use their google account to message someone. YouTube is not a geospatial enabled platform and does not show users' online status. YouTube is available on web and mobile platforms.

Strategies for engagement and retention:

- Create a channel to provide video information, education, motivational, and personalized videos for clients
- Create a "show" about topic that people go through every
  - Regular conflicts
  - Ways to deal with depression
  - o Health outreach
- Develop engaging and thoughtful names to the videos
- Provide a brief explanation of videos made and posted
- Promote any videos made on other social media platforms like facebook or twitter
- Utilize video tags (video tags are keywords used by viewers to easily locate your video and are also used by search engines to determine the video search

results)

- Categorize any videos posted by group (e.g. Health information/ Technology)
- Develop and maintain a YouTube playlist for videos and direct clients to a playlist
- Invite clients to be part of the channel and shows to discuss real issues or make update videos
- Host live Q & As
- Create digital media videos that will motivate clients to further their care and stay engaged in care
- Assign clients to use YouTube to find other helpful videos and channels that relate to your project
- Utilize the term vlogging and encourage your clients to vlog their process of support and their own thoughts going through situations.

Strategies for location:

- Users can search only by
  - o Name
  - o Channel Name

# 7. Spotify

Spotify is a platform to stream music from 25 million songs. Users are able to create and share playlists on their own profiles. There are three versions of Spotify that users can use. Spotify premium (\$9.99/mo) that allows users to search and listen to any song with no advertisements and on demand. Spotify basic (\$4.99/mo) which has advertisements but can play on-demand. Free Spotify allows users to listen to limited music and use the radio station. To create an account with Spotify, a user needs to provide an email address, password, full name, date of birth, and credit card info (depending on which version you want).

Spotify does offer a two-way platform for communication which allows users to send songs directly to other users with the format of texts. Spotify is not a geospatial enabled platform and does not show users' online status. Spotify is available on web and mobile platforms.

Strategies for engagement and retention:

- Create playlists that can motivate clients
- Use songs to connect with clients and build rapport
- Find and share playlists that will help boost moods or help facilitate depression
- Sync with Facebook and let your clients know what music you are listening to

Strategies for location:

• Search clients by

- o Email
- o Name
- o Facebook

# 8. Soundcloud

Soundcloud is a social sound platform that allows users to create sounds, songs and upload them to share publicly on blogs, sites, and social networks. Soundcloud only requires an email address, full name, and username to make an account. Soundcloud uses a two-way platform that allows users copy the links to the song and/or playlist that will allow users and non-users to view and listen to the song. Soundcloud is not a geospatial enabled platform and does not show users' online status. Soundcloud is available on web and mobile platforms.

Strategies for engagement and retention:

- Create playlists that can be shared to clients
  - Playlist that will help with creativity
  - Calm and/or boost moods
- Sync with Facebook

Strategies for location:

- Search clients by
  - o Name
    - o Username
    - o Email

# 9. Tindr

Tindr is a matchmaking mobile application that connects users' Facebook profiles to provide pictures and ages for others to view. Tindr uses GPS technology, where users set a specific radius to have the option to match with anyone within that distance. Tindr requires a Facebook account and asks for additional information like email address, age, location, and gender.

Tindr uses a two-way platform for communication. If the two users are a match they are able to send messages to each other. Tindr is geospatial enabled and allows users to set their radius for possible matches. Tindr does show users' online status to start a conversation. Tindr is only available on mobile platforms.

Strategies for engagement and retention:

• Make an account that focuses on providing information about HIV or other health information for people who match with the account

Strategies for location:

• Unable to search for clients, everything is based on if the user matches with you and based off radius of location.

# 10.Grindr

Grindr is a geosocial network application geared towards gay and bisexual men. Users can locate other men within close proximity. To create an account with grindr a user needs to provide a valid email address, their name and username, date of birth, and residence. Grindr has a two-way platform for communication and all messages sent and received are between two users and private. Grindr is a geospatial enable platform and does show users' online status. Grindr is only available on mobile platforms.

Strategies for engagement and retention:

- Create an account that is providing information and education about HIV
- Act as an online counselor to other users
- Go to gay venues in your area and be on site if somebody asks for HIV information
- If user discloses their status on their profile or through direct message, screen them if they would be eligible to be part of your project

Strategies for location:

- Users are only found by the proximity
- Unable to search for users on this application
- Interact with users based on location and radius
- Go to gay venues and see who is online and active around that proximity

# 11.Yik Yak

Yik Yak is a smartphone application that allows users to pseudo-anonymously create and view discussion threads within a 5 mile radius. All a user needs to create an account is an active and valid phone number. The mode of communication for Yik Yak is an open platform which allows users to chat anonymously and openly on discussions and threads. Yik Yak is a geospatial enable platform and does not show users' online status. Yik Yak is available on web and mobile platforms.

Strategies for engagement and retention:

- All posts fare anonymous and public
  - Direct clients to an anonymous discussion that relates to their issue
- Clients are able to see posts that are nearby
- Start an anonymous discussion and thread and tailor content that touches on important discussion points
- This platform is not very good for sensitive topics/users on this platform can be rude

Strategies for location:

- Posts are anonymous
- Users are anonymous
- Unable to search or trace users

# 12.Pinterest

Pinterest is a social media platform that allows users to "pin" images from any web page to boards on their profiles. Pinterest has an array of topics, pictures, stories, and boards for users to access at any time. Popular boards usually contain arts and crafts, do it yourself (DIY) projects, food recipes, home décor ideas, costumes, and fashion. To create an account a user must provide a valid email address, name, and password.

Pinterest has multiple modes of communication like open platforms and two-way platforms. Users are able to comment on each other's pins and there is a direct messaging feature. Pinterest is not a geospatial enabled platform and does not show users' online status. Pinterest is available on web and mobile platforms.

Strategies for engagement and retention:

- Pinterest uses "walls" and "pins", utilize those tools to motivate clients and trigger engagement
- Create a profile and give login information to clients to help build community wall
- Be create with text-based posts
  - Use personality to engage clients to follow the profile
- Make the walls approachable, fun, and motivating
- Use as a creative tool to help engage clients and build rapport

Strategies for location:

- Clients can be searched
  - o Email
  - o Username
  - o Name
  - Finding what their interests are and searching those pins
  - Direct messaging

# 13.WhatsApp

WhatsApp is a cross-platform instant messaging application. All phones can operate on it (iPhone, Blackberry, Android, Windows Phone, and Nokia). This application allows users to exchange texts, images, videos, and audio messages for free through an internet connection. Users need to provide a name/username, phone number, and password to create an account. WhatsApp has a two-way platform for communication and allows users to just talk to one other user via sms text messaging. WhatsApp is not a geospatial enabled platform and does show users' online status. WhatsApp is only available for mobile platforms.

Strategies for engagement and retention:

- Develop motivational text messages that can be sent out at particular times for each client
  - Medication reminders
  - Doctor appointment reminders
- WhatsApp only operates via wifi or internet only
  - Provide where to go to get free internet
- Send personalized photos and videos to the clients
- Use the application to build communication through text messaging

Strategies for location:

- Clients can be searched by:
  - Phone number from address book
  - They must have the WhatsApp app downloaded on their phone
  - Have to have their personal information saved in order to connect
  - o Username
  - o Full Name

# 14.Vine

Vine is a free mobile application that enables users to record and share a 6 second video clip. Vines are usually short and full of content. To make a Vine account a user needs to provide full name, username, email address, birthday, gender, and location. Vine has an open and two-way platform for communication, users are allowed to mention and comment on videos, and use the direct messaging feature. Vine is not a geospatial platform and does not show users' online status. Vine is only available on mobile platforms.

Strategies for engagement and retention:

- Post short vines about HIV information and education
- Utilize filters to engage with clients
- Make vines personalized to boost motivation
- Send direct messages to keep clients engaged
- Use vine to make videos and then save them to send through other applications

Strategies for location:

- Clients can be searched by
  - o Name
  - o Username

o Email Address

# 15.Kik

Kik is an instant messenger application for mobile devices so users can transmit and receive messages, photos, videos, sketches, mobile web-pages, and other content through an internet connection. To make an account on Kik a user needs to provide an email address, password, and username. Kik only has a two-way platform for communication which is direct messaging other users. Kik is not geospatial enabled and does show users' online status. Kik is only available on mobile platforms.

Strategies for engagement and retention:

- Develop motivational and tailored text messages to send to different clients
- Provide where to go to get internet connection
- Send content that will boost moods
- Send daily reminders for medication and doctor appointments

Strategies for location:

- Search clients by
  - o Username
  - o Email
  - Phone number

# 16.Google+

Google + is an integrated social platform that dovetails with YouTube, Gmail, and other google services. Users create their own network with other users via "circle". Users can customize content, suggest connections between people. This platform builds collaborative Hangout aps that bring people together. Users can add a google + share button to their page and it lets other users share what they want, when they want, with whom they want. To create an account on Google + a user needs to provide full name, username, password, birthday, gender, phone number, and email address. If the user has a google account, they can just sign in using that login information.

Google + has an open and two-way platform for modes of communication. Users can send direct messages and communicate through comments. Google + is a geospatial enabled platform and does not show users' online status. Google + is available on web and mobile platforms.

Strategies for engagement and retention:

- Create circles with different clients (e.g. high risk, low risk) these circles better assists who should connect with each other
- Post tailored information publicly or in the various circles that are established

- Post information about HIV education, location of services, dates of community events and open discussions
- Offer personalized encouragement through messaging and posts
- Develop and post content that will keep clients engaged and boost motivation
- Connect circles together
- Create a community page and link that page for clients to share their own content

Strategies for location:

- Search clients by
  - o Username
  - o Name
  - o Email address
  - o Circles

# 17.Scruff

Scruff is a mobile application for gay men that use geolocation technology to connect users together. The home interface of this app displays a grid of user profile picture, arranged to farthest away. User tap a picture and that opens a users' profiling displaying options to chat, send a "woof", save the profile as a favorite. Users also have the option to "unlock" private photo and video albums, and other shared information. To make a scruff account, users need to provide email address, name, username, birthday, and location. Scruff offers a two-platform for communication; users can send direct messages to each other. Scruff is a geospatial enabled platform and allows users show their location based on proximity and radius. Scruff does show users' online status and it is made for mobile platforms.

Strategies for engagement and retention:

- Create an online account to provide educational information
- Act as live counselor
  - o Relay any information related to sexual health
  - Send out educational information
  - Where to go for HIV services- list of service providers
- Screen them for your project
- Go to gay venues to see who is around that area, can be easier to provide in person information

Strategies for location:

- Unable to search for users
- User can only be found by proximity and who is online

# 18. OkCupid

OkCupidis is a free online dating, friendship, and social networking site. The site offers many features like member-created quizzes and multiple choice-questions that help people get better connected. OkCupid requires a valid email address, username, and password to create an account. The site gives the opportunity for users to reveal as much as possible, there are sections a user can complete if they want that information on their profile.

The side supports multiple modes of communication, including instant messages and emails. The site is not geospatial enabled and does show users' online status. OkCupid is available for web and mobile platforms.

Strategies for engagement and retention:

- Make an account to chat with people to build a relationship
- Tailor information given out to particular clients
- Give out information about HIV and safe sexual health practices
- Act as online counselor
  - Where to go for services
  - Educational information
  - Boost motivation

Strategies for location:

- OkCupid sets up an algorithm for users to find similar users
- Clients can be searched by selecting "Find a user" in the drop down box
  - o User's full name
  - o Username
  - o Email address

# 19.Hornet

Hornet is a social application for gay men to meet. It uses geolocation technology to connect guys who are nearby. Hornet embraces diversity and has introduced hashtages and allows users to post 100s of photos on their profile. Hornet is set by proximity and radius to make connections. Information required to make an account with Hornet is name, username, date of birth, location, and email address. Hornet uses a two-way platform for communication allowing users to direct message each other. Hornet is a geospatial enabled platform and shows users' online status. Hornet is available on web and mobile platforms.

Strategies for engagement and retention:

- Create an online account to provide educational information
- Act as live counselor
  - o Relay any information related to sexual health
  - Send out educational information
  - Where to go for HIV services- list of service providers
- Screen them for your project

• Go to gay venues to see who is around that area, can be easier to provide in person information

Strategies for location:

- Unable to search for users
- User can only be found by proximity and who is online

# 20. Jack'd

Jack'd is a geospatial app that allows guys to look for and meet other guys within close proximity. To create an account with jack'd, users need to provide a valid email address, their name and username, date of birth, and location. Jack'd has a two-way platform for communication and all messages sent and received are between two users and private. Jack'd is a geospatial enable platform and does show users' online status. Jack'd is only available on mobile platforms. Strategies for engagement and retention:

- Create an account that is providing information and education about HIV
- Act as an online counselor to other users
  - o Relay any information related to sexual health
  - Send out educational information
  - Where to go for HIV services- list of service providers
- Go to gay venues in your area and be on site if somebody asks for HIV information
- If user discloses their status on their profile or through direct message, screen them if they would be eligible to be part of your project

Strategies for location:

- Unable to search for users
- User can only be found by proximity and who is online

# Appendix C: Noteworthy mHealth Applications for Digital Navigation (No Cost)

### AIDSinfo HIV/AIDS Guidelines

#### Description:

This app gives users unlimited mobile access to federally approved HIV/AIDS medical practice guidelines. They are clinical guidelines that offer an array of recommendations approved by panels of experts for the treatment of HIV infection in adults, adolescents, pediatrics, and perinatal groups. They also provide recommendations for the treatment of HIV-related opportunistic infections in the same groups. The application is provided free from the National Library of Medicine at the National Institutes of Health.

#### Functionalities:

- Receive HIV information and guidelines
- Stay up to date on the most recent information
- Know clinical recommendations for different groups
- Treatment recommendations for different groups
- Know which recommendations are being utilized
- Gain a better understanding of the guidelines

Where to download: Apple App Store/ Google Play Store

### HIV Testing and Care Services Locator

#### Description:

This app is a location-enabled application that allows users to locate and find service providers that are near them. The app is directed to testing services, housing providers, health centers and other services providers that are directed towards HIV. The app connects users by providing where the service provider is located and phone number.

### Functionalities:

- Patients will be able to locate different service providers near their location
- Get contact (phone #, address) to the services providers
- Be aware of the different service providers
- What the service providers do and what they treat

Where to download: Apple App Store/ Google Play Store

### Breathe2Relax

### Description:

This app is a stress management tool that educates users on the effects of stress on the body. It provides detailed information, instructions, and exercises to assist users to learn a particular stress management skill called diaphragmatic breathing. Through stress management, breathing exercises have been shown to decrease the body's 'fight-or-flight' (stress) response, assist with mood stabilization, anger control, and anxiety management. This app can be accessed on the individual level or with a professional healthcare worker.

## Functionalities:

- Use when patients may feel stressed or overwhelmed with medications and appointments
- If done with digital navigator, can assist in building rapport with patient
- Patients will learn exercises that will keep them at ease when feeling stressed
- Learn about the diaphragmatic breathing technique
- Use when they feel stressed about lack of support
- Help their mental health positively progress

Where to download: Apple App Store/ Google Play Store

# Optimism

## Description:

This app allows users to chart and keep track of their moods. Overall this app helps users develop strategies for managing depression, bipolar, or other mental health conditions. They learn what may trigger their mental health and help them recognize warning signs of a decline. The app provides detailed charts and reports by email delivery, which uses feedback creating concrete starting points for exploring things that may be affecting their mental health. The reports can be used by health professionals to help them get a better idea of their client's mental health strategies.

# Functionalities:

- Patients learn about mental health strategies
- They can chart their moods when they are feeling depressed when it comes to HIV
- Recognizing personal signs that decline their mental health
- Keep tracking of their own moods, offers an opportunity for being self-aware
- Give to digital navigator to give starting points how they feel, know which topics are touchy

Where to download: Apple App Store

# **Big White Wall**

# Description:

Big White Wall acts as a liaison for users who are experiencing tough times. They provide anonymous support 24/7 to anyone struggling with a range of common behavioral health issues, worries, and concerns. The app connects users to effective

support services like trained professional staff, open anonymous communities, guidelines for self care for anxiety and depression. Provides different methods that can improve mood and overall well-being.

### Functionalities:

- Help patients who are experience a mental health emergency
- Patients can keep their identity anonymous
- Connect patients to a direct service
- Connects patients with other people who are experiencing similar issues
- Allows patients to feel comfortable and act as a peer advocate
- Helps patients build self-confidence and bravery to face issues related to depression and anxiety

Where to download: Apple App Store/ Google Play Store

## Equanimity

## Description:

Equanimity provides users with many features like timer setting, journaling, displays graphical tracking giving clear feedback. It allows users to learn meditation expertise techniques whether their level of meditation.

## Functionalities:

- Patients learn how to meditate
- Gives the patients an ideal companion for meditation
- Helps build strong mental health techniques
- Patients learn how to be self-aware and take notes

# Where to download: Apple app store

# My Chart

### Description:

My Chart accounts are made through user's healthcare providers so they are able to access their information. Once that account is created users are allowed access to their lab results, appointment information, current medications, immunization history through their mobile device.

# Functionalities:

- Patients can see when their appointments are
- The type of medications they are on
- Gives patients easy accessible to their own health information
- They will have mobile access to results

Where to download: Google Play Store

## Dosecast

#### Description:

Dosecast helps users with their medication adherence. It is an easy to use app that helps users to take their medication, vitamins, or birth control pills on time. It provides reliable features, flexible scheduling, dose history, refill alerts, and access to a drug database if there are any questions.

#### Functionalities:

- Patients can use this for their antiretroviral therapy
- If they any questions about the drugs they are taking
- Help build strong medication/treatment adherence support

Where to download: Apple App Store/ Google Play Store

#### MediSafe

#### Description:

Users use this app to stay safe with their meds and are able to keep track of blood pressure, glucose and other measurements. The results from medisafe can be shared with doctors to track better outcomes more quickly. The app also has a medication reminder so missing medications won't happen.

#### Functionalities:

- Help patients remember when to take their HIV meds
- Patients can build stronger medication regimens
- Can share their information with digital navigator to show when and if they did take their medications
- It can be used for multiple conditions, of if they are taking medications for more than one condition
- Give patients a sense of self-management

Where to download: Google Play Store

### Medhelper Pill Reminder

#### Description:

Med Helper allows users to track prescriptions, gives alarms for when medication needs to be administered. This app also provides reminders when doctor appointments are and when the prescription needs to be filled. Med Helper lets users track vital signs and export detailed reports to their doctor, nurse or caregiver.

#### Functionalities:

- Helps patients remember when to take their HIV med
- Print out detailed information about their medical adherence

- Doctor appointment reminder
- Prescription refill reminder
- Track vital signs and medical adherence

Where to download: Apple App Store/ Google Play Store

#### SAM: Self-Help for Anxiety Management

#### Description:

SAM offers a range of self-help methods for people are want to learn about maintaining and managing their anxiety. This app supports users in learning about anxiety and practicing self-help methods to facilitate anxiety. It generates personalized anxiety toolkits and helps users manage situations that are associated with anxiety.

Functionalities:

- Patients learn how to manage anxiety inclined situations like going to a provider
- Techniques to control anxiety if they miss an appointment or medication
- Patients can use SAM to build their own toolkits in case they are feeling overwhelmed
- SAM can be used with a digital navigator and help patients control anxiety attacks

Where to download: Apple App Store/ Google Play Store

# Appendix D: Digital Navigation Training Modules

### **General HIV Information**

- <u>HIV Basics</u>
- <u>HIV Life Cycle: Bio-Interactive Video</u>
- Basic HIV Biology Part 1: Viral Replication

#### Delivering HIV Results

• Delivering HIV Test Results and Effective Referral

### HIV Treatment

- <u>Treatment Cascade YouTube Video</u>
- <u>Strategies to Enhance Patient Adherence: Making it Simple</u>
- FDA-Approved HIV Medicines

### **Retention in HIV Care**

• <u>Webinar: Retention in HIV Medical Care: Risk Factors, Interventions, and</u> <u>Identifying Those in Need of Support</u>

### Health Issues for PLWHA

- <u>Weight gain, weight loss and HIV</u>
- <u>Chronic Pain in Patients Living with HIV</u>
- <u>HIV-Associated Lipodystrophy: Where are we now?</u>
- <u>Does cannabis use complicate the HIV continuum of care?</u>
- <u>Non-Infectious Complications of HIV</u>
- <u>Opioid Addiction Treatment and HIV</u>
- <u>Recreational Drugs, HIV and ART</u>

#### **Population Specific Resources**

- <u>Counseling Latino Patients</u>
- Transgender Women, Hormone Therapy and HIV

#### PrEP Resources

- Navigating Sexual Health in the Era of PrEP
- <u>PrEP Action Kit</u>
- <u>PrEP Training Videos</u>

## **Appendix E: Determining Eligibility and Procedures**

Individuals interested in enrolling in Health eNav will provide the following information to determine eligibility, and using the following procedures:

- First name
- Last name
- Middle initial (can be left blank, but all other data elements are required)
- Mothers maiden name
- Date of birth
- Current gender

Eligibility Criteria	Procedures
1) Are newly	1. Referral from HIV provider, HIV testing site, or other
diagnosed [tested	Navigator
HIV positive within	2. Search for potential client in ARIES
the last 12	3. If located in ARIES, add client to Health eNav roster
months],	and search date of last medical visit.
	4. Record date of diagnosis from diagnosis letter
2) Aware of their	uploaded on ARIES
HIV infection	5. Record date of last medical visit
status, but have	6. Record date and value of last CD4 count value
never been	7. Record ART prescription status and date reported
engaged in care	8. If not located in ARIES, follow-up with referral
[not linked or	source to determine eligibility.
engaged care],	
	If potential client was referred from an HIV provider, HIV
3) Dropped out of	testing site or other Navigator, ARIES record should exist.
HIV care [not	Case reporting for those newly diagnosed will occur within
retained in care];	48 hours of identifying a new positive. If no record exists,
or	confirm new diagnosis and new record status with DPH case
	reporting and create new ARIES record.
4) Have not	
achieved viral load	Important ARIES Data Elements:
suppression [not	<ul> <li>date of diagnosis (diagnosis letter upload)</li> </ul>
virally	<ul> <li>date of last medical visit</li> </ul>
suppressed].	<ul> <li>date of last CD4 count and value</li> </ul>
	<ul> <li>date of last viral load count and value</li> </ul>

## Appendix F: Health eNav Standard Operating Procedures

#### **Referral Procedures**

- 1. Navigator or Community Provider Referral
  - a. Navigator will contact Digital Navigation
- 2. Self-Referral Procedure
  - a. Website, Email, Phone and Text Message
    - i. Contact Participant using any appropriate method, preferably phone call or in-person
    - ii. Assess Eligibility
      - 1. Aged 18-34?
      - 2. Identify as MSM of trans woman?
      - 3. HIV-positive?
        - a. Newly Diagnosed?
        - b. Not linked to care?
        - c. Out of Care?
        - d. Not virally suppressed?
    - iii. Assess Income
    - iv. Assess San Francisco Residency
    - v. Remind Participant to bring HIV Diagnosis Documentation to In-Person Enrollment
    - vi. Schedule In-Person Enrollment Meeting within 7 days

### In-Person Enrollment Procedures

- 1. Assess Eligibility
  - a. Aged 18-34?
  - b. Identify as MSM of trans woman?
  - c. HIV-positive?
    - i. Newly Diagnosed?
    - ii. Not linked to care?
    - iii. Out of Care?
    - iv. Not virally suppressed?
- 2. Obtain Written Informed Consent
- 3. Obtain Written Consent for ARIES and Share
  - a. Complete Income Assessment Form
  - b. Complete HIV Diagnosis Form
  - c. Complete San Francisco Residency Form
  - d. Complete ARIES Search Criteria Form
  - e. Provide Participant with ARIES Information Sheet
- 4. Complete Medical Release Forms
- 5. Complete HIPPA Forms
- 6. Complete Locator Form
- 7. Complete Baseline Cross-Site Survey
  - a. Save and Rename File as "Cross Baseline YEARMMDDA-Z"

- 8. Register and Activate Sparrow Phone (if applicable)
  - a. Deliver Phone Training to Participant
  - b. Discuss Phone Safety and Terms
- 9. Determine SMS Text Messaging Platform mSurvey OR TigerText
  - a. If phone does not have a data plan, register phone in mSurvey by Text2Join code
    - i. Enter Name
    - ii. Enter Participant ID
    - iii. Enter Participant Referral Source
    - iv. Enter Participant Status
      - 1. New Infection Client
      - 2. Out of Care Client
    - v. Enter Participant Condition
      - 1. Condition 2A: No Phone, Digital Navigation
      - 2. Condition 2B: Own Phone, Digital Navigation
    - vi. Conduct Example Survey
      - 1. Staff completes first question with Participant
      - 2. Participant completes remaining questions with Staff
  - b. If phone has a data plan, register phone in TigerText
    - i. Participant downloads the TigerText app
    - ii. Log onto TigerText
    - iii. Create an account for Participant
    - iv. Participant activates the account
- 10. Build Health eNav Directory on Phone
  - a. Save Convos Phone Number as "Digital Navigator Convos"
  - b. Start Convos SMS Thread
  - c. Save Digital Navigator Cell Phone as "Health eNav Emergency"
  - d. Save mSurvey Phone Number as "Health eNav Survey"
- 11. Describe EMA Surveys Schedule
  - a. Random Daily Surveys
  - b. Non-Random Daily Surveys
    - i. Identify best AM time to receive Non-Random Daily Surveys
    - ii. Identify best PM time to receive Non-Random Daily Surveys
- 12. Assign Participant to EMA surveys
  - a. Log onto mSurvey
  - b. Add Participant to Random Daily Surveys Panel
  - c. Add Participant to Non-Random AM Survey Panel
  - d. Add Participant to Non-Random PM Survey Panel
  - e. Describe Treatment Adherence Daily Reminders
    - 1. Assess Eligibility and Interest
    - 2. Identify best time(s) AM or PM to receive daily reminders
- 13. Administer Qualitative Interview
- 14. Complete Comprehensive Care Plan
  - a. Assess Participant Acuity
- 15. Discuss Digital Navigation Components

- a. Roles and responsibilities
- b. Boundaries
- c. Change talk
- d. Comprehensive Care Plan Priorities and Next Steps
- 16. Complete Procedure Checklist
- 17. Complete Receipt
- 18. Remunerate Participant

## In-Office Procedures

- 1. Register Participant in ARIES (must be inputted into ARIES within 40 hours)
  - a. Six criteria for record creation
    - i. First name
    - ii. Last name
    - iii. Middle initial (can be left blank all else are required)
    - iv. Mothers maiden name
    - v. Date of birth
    - vi. Current gender
  - b. Look up Participant Agency Search
    - i. Search by Last Name for Field
    - ii. Add Participant to CPHR Virtual Agency
    - iii. Upload Income Form (every six months)
    - iv. Upload HIV Diagnosis form
    - v. Upload San Francisco Residency Form (every six months)
    - vi. Add service type and service time to Health eNav Program
  - c. Look up Participant System Search
    - i. Search by Full Record Criteria
    - ii. Add Participant to CPHR Virtual Agency
    - iii. Upload Income Form (every six months)
    - iv. Upload HIV Diagnosis form
    - v. Upload San Francisco Residency Form (every six months)
    - vi. Add service type and service time to Health eNav Program
  - d. Unable to locate Participant
    - i. Confirm Case Reporting and Call DPH Help Line
    - ii. Never leave client identifiers on voicemail or email
    - iii. Get determination of authentic new record or duplicate
  - e. Create New ARIES Record for Participant (IF AND ONLY IF DPH SAYS SO)
    - i. Add Participant to CPHR Virtual Agency
    - ii. Upload Income Form (every six months)
    - iii. Upload HIV Diagnosis form
    - iv. Upload San Francisco Residency Form (every six months)
    - v. Add service type and service time to Health eNav Program
- 2. Tablet Data Transfer
  - a. Transfer Cross-site Baseline Files on Tablet to USB

- b. Transfer Local Baseline Files on Tablet to USB
- c. Transfer Cross-site Baseline Files on USB to Desktop
  - i. Save in Folder: USB > Health eNav > Data > Cross-Site Evaluation > Baseline
- d. Transfer Local Baseline Files on USB to Desktop
  - i. Save in Folder: USB > Health eNav > Data > Local Evaluation > Baseline
- e. Transfer Cross-site Baseline Files on USB to Desktop
  - i. Save in Folder: Computer > Shared Drive > HIV EPI > Behavioral Surveys Team > Health eNav > Data > Cross-Site Evaluation > Baseline
- f. Transfer Local Baseline Files on USB to Desktop
  - i. Save in Folder: Computer > Shared Drive > HIV EPI > Behavioral Surveys Team > Health eNav > Data > Local Evaluation > Baseline
- g. Transfer Data File to Data Warehouse
  - i. Open Baseline Data Warehouse
  - ii. Drag and drop QAD File to Data Warehouse window
  - iii. Drag and drop Completed survey file to data warehouse
  - iv. Confirm transfer
  - v. Save Data Warehouse

## Assigning and Discontinuing A Sparrow Phone with Participants

- 1. Assess participant's eligibility.
  - a. If participant is eligible to participate, but has no mobile phone, you may offer participant a Sparrow phone to participate.
- 2. Sparrow phones are already activated.
- 3. Have participant complete the Sparrow Survey.
- 4. Have participant read and sign the Phone Agreement.
- 5. Emphasize the following:
  - a. This is so you can connect with your Digital Care Navigator and your medical care team using a smartphone. In exchange, you agree to stay connected, keep us updated and provide feedback.
- 6. Review the terms and conditions of non-response.
  - a. If the participant does not respond to phone calls or texts for any 7day period, the Digital Navigator will spend 7-days attempting to reach the participant to remind them about the terms and conditions in the Phone Agreement.
  - b. If the participant does not respond to phone calls or texts for a 14-day period, the Digital Navigator will consider suspending service, and consider extraneous factors (e.g. housing status, incarceration, acute crisis, hospitalization, etc.)
  - c. If the participant does not respond to phone calls or texts for any 30day period, the Digital Navigator will discontinue service.

# Initiating Participant Conversations in mConvos

- 1. If participant has a mobile phone with no data plan, enroll participant in mConvos.
- 2. The Digital Navigator will log into mConvos at: <u>mConvo Login Page</u>
- 3. Click "Compose" to compose an initial message to participant
  - a. Enter participant's phone number using this structure (+1213555888)
  - b. Enter an introductory message in the message box
  - c. Click "Send"
- 4. Engage in a short text message conversation with participant.
- 5. Save the number in the participant's phone as "Digital Navigator."

# Enrolling Participants in Daily EMA Survey (mSurvey)

- 1. Research staff will describe the daily survey, including the following details:
  - a. Daily surveys will be sent to you via SMS text at approximately the same time every day for 90 days.
  - b. Each daily survey will take a few minutes to complete.
  - c. Try and complete each survey when you first receive it. The survey will close after 20 hours and you will not be able to complete that day's daily survey until the next day.
    - i. Assess with participant when they have the most time during the day to complete the short survey (try to minimize risk of forgetting or ignoring the text).
  - d. You will earn \$1 for the completion of each survey.
  - e. Your honest responses will help us provide better HIV care and support services. Please take the time to read, take and answer the survey so it represents your experiences.
  - f. You will earn a \$100 bonus if you complete the survey 90% or more of the time. To be safe, take the survey every day.
- 2. Research staff will ask participants to select from the following options to receive their daily survey:
  - a. Morning (8AM)
  - b. Afternoon (12PM)
  - c. Evening (8PM)
- 3. Research staff will complete the following:
  - a. Save this phone number as "Daily Survey": 617-826-9932
  - b. If participant is enrolling in MORNING surveys to be sent at 8am, text the joincode "8AM2017" to the daily survey number.
  - c. If participant is enrolling in AFTERNOON surveys to be sent at 12pm, text the joincode "12PM2017" to the daily survey number.
  - d. If participant is enrolling in EVENING surveys to be sent at 8pm, text the joincode "8PM2017" to the daily survey number.
- 4. Enter 4-digit participant ID two times and follow instructions.

- 5. Pass the phone to the participant and observe the participant's interaction with the survey.
- 6. Make note of any corrections as you go along with the participant through the enrollment survey.
- 7. During the ART section, assess the participant's accurate understanding of ART.
- 8. If participant does not know what ART is or had an incorrect understanding of ART, at the end of the enrollment survey, educate and clarify with participant the meaning of ART. And that ART will be used in the daily survey to refer to HIV medication.
- 9. At the end of the survey, remind participant that they will receive \$1 for every completed survey and \$100 bonus for completing more than 90%. To be safe, complete the survey every day.
- 10. Also remind the participant:
  - a. Their daily survey will start tomorrow.
  - b. Their selected time morning (8AM), afternoon (12PM) or evening (8PM).
  - c. They will have 20 hours to complete their survey, before it closes until the next day.
  - d. To delete each survey after completion to protect their confidentiality and privacy.
  - e. We will see you in 3 months.
- 11. Finally, save the phone number that is sending the EMA daily surveys as "Daily Survey."

# Activating Tiger Connect

BEFORE ENROLLMENT VISIT:

- 1. Set up User Account in Tiger Connect using the information below:
  - a. Participant's name
  - b. Participant email
  - c. Participant phone number
- 2. When creating User Account, set User Role to "Customer" and Save User Profile
- 3. Set Message Lifespan to 30 Days instead of 5 Days and Save Profile

# WITH THE PARTICIPANT DURING ENROLMENT VISIT:

- 1. Have Participant download Tiger Connect App to their device
- 2. Have Participant hand the device to Research Staff
- 3. Research Staff will log participant into the app using the email provided on their eligibility screen form
- 4. Research Staff will enter the following password when prompted: password1
- 5. Research Staff will follow the verification steps as prompted.
- 6. Once set up, Research Staff will instruct Participant to complete the following steps:

- a. Under Settings, change the password on the device (needed to log into the app if the Participant logs out)
- b. For added security, you can set up a PIN every time you log into the app. To do this, under settings, turn on PIN lock, set-up a PIN, confirm PIN, and set PIN duration for 5 minutes.
- 7. Once security measures have been set up, Research Staff will log on to Tiger Connect send Participant a message directly to the Participant to initiate a connection and a conversation thread.
- 8. Research Staff will explain to Participant that all conversations will happen on the Tiger Connect platform, securely and confidentially.
- 9. Save (415) 243-6956 as "Health eNav" text or call only in emergency.
- 10. Research Staff will instruct Participant to notify us immediately of any phone number or device changes.
- 11. Research Staff will friend Participant on Facebook and any other social media platform they use.

# Appendix G: Digital HIV Care Navigation Procedures

There are four components to Digital HIV Care Navigation: 1) HIV care navigation, 2) health promotion, 3) motivational interviewing, and 4) digital social support. These four components and its procedures are described and outlined below:

- a. HIV Care Navigation
  - i. HIV care navigation guides patients in knowing where, when, and how to access all health and related services, and increases access to appropriate resources.
  - ii. HIV care navigation services covered in this section include the coordination of:
    - 1. Primary medical care
    - 2. Specialty care
    - 3. Mental health care and substance abuse services
    - 4. Imaging and other diagnostic service
    - 5. Laboratory services
    - 6. Health insurance
    - 7. Housing
    - 8. Benefits/Entitlements/Public Assistance
  - iii. Upon enrollment, the Program will work with participants to develop a tailored, Comprehensive Care Plan.
  - iv. The Program ensures that the participant has the requisite information for all relevant appointments and access to services by:
    - 1. Reviewing the Comprehensive Care Plan with the participant at the conclusion of every study visit at baseline, 3-months, and 6-months.
    - 2. Providing the participant with reminders of upcoming appointments or plans in the following ways:
      - a. Text
      - b. Phone call
      - c. Email
      - d. Digital media (for example, a direct message on their preferred social media platform)
    - 3. Reminder phone calls are documented on the Comprehensive Care Plan.
  - v. The Program ensures that the patient will be referred to the requisite resources for all relevant appointments and service access identified on the Comprehensive Care Plan.
  - vi. The Program ensures appropriate referrals to transportation resources whenever they are required.
  - vii. The Program would assist the patient in scheduling and rescheduling appointments, if possible.
  - viii. The Program ensures appropriate referrals to childcare resources whenever they are required.
- ix. The Program monitors its success at providing navigation services by following up with the service provider the same day as the scheduled service in all instances to ensure the participant attends their relevant appointments.
- x. In order to ensure that confidentiality law or related institutional policies does not preclude ready transfer of sensitive personal health information, the Program must ensure that a valid consent to release of HIV information is always on file for each participant.
- xi. The Program corrects deficiencies failures of the participant to access the service by rescheduling the appointment.
- xii. The Program documents planned navigation and services by means of the optional Comprehensive Care Plan Form and/or electronic medical record.
- b. Health Promotion (Education, Coaching and Medication Adherence)
  - i. The Program would ensure optimal health literacy for all patients by providing health promotion on the biology of HIV, disease management, communication with providers, risk reduction and healthy behavior, and ART adherence.
  - ii. The Program would provide health promotion content that is tailored, personalized and specific to the needs of each participant as identified by the Comprehensive Care Plan and on an on-going basis.
    - 1. Health promotion should be delivered in a way that is suitable to meet patients' education, developmental, language, gender, sexual and cultural needs.
    - 2. The health promotion curriculum consists of 9 topic areas and 29 sessions and may be delivered to the participant to meet their individual, tailored, personalized and specific needs. The health promotion curriculum includes the following:
      - a. General HIV Information
        - i. HIV 101
        - ii. The HIV Life Cycle
        - iii. Deliverinng HIV Results
        - iv. Case Study-driven Learning
      - b. HIV Treatment
        - i. HIV Treatment Cascade
        - ii. Effective Strategies for Improving Adherence
        - iii. ART Simplification Strategies
        - iv. FDA-approved HIV Medicines
      - c. Retention in HIV Care
        - i. Retention in HIV Medical Care: Risk factors, interventions and identifying those in need of support
        - ii. Gender-responsive Practices for Linkage and Retention in Care
        - iii. Creating a Welcoming Environment for Persons Living with HIV/AIDS
      - d. Health Issues for PLWHA

- i. Weight Gain and HIV Care: Too Much or Just Right?
- ii. Lipoatrophy and Wasting
- iii. Lipohypertrophy in HIV
- iv. Dermatologic Manifestations Associated with HIV/AIDS
- v. Pain Management in HIV Patient
- vi. HIV & Mental Health: Managing Drug Interactions
- vii. HIV Drug Resistance: What is it and Types
- viii. Depression in HIV/AIDS
- ix. Approach to Common Complaints among HIV+ Patients: Headaches and Fever
- x. Opportunistic Infections: Prophylaxis
- e. Substance Use and HIV Resources
  - i. Recreational Drugs, HIV and ART
  - ii. HIV and Meth
- f. Screening for Alcohol and Substance Abuse in HIV-Infected Patients
- g. Population-Specific Resources
  - i. Counseling Latino Patients
  - ii. Transgender Women, Hormone Therapy and HIV
- h. Access to Care
  - i. Understanding Patient Health Care Coverage Is
- i. PrEP Resources
  - i. All About PrEP for HIV Prevention
  - ii. PrEP for HIV Prevention: Real World Clinical Case Studies
- 3. The Program will review the health promotion curriculum every two years.
- iii. The Program would ensure that all staff that provide health promotion and all direct or indirect supervisory staff receive ongoing trainings on the curriculum.
- iv. All health promotion sessions with patients are one-on-one, because the intent is to incorporate coaching and counseling content that is individualized to the patient.
- v. Participants will be categorized into low and high acuity status based on their needs identified by the Comprehensive Care Plan and on an on-going basis.
- vi. High acuity participants are defined as individuals who were recently diagnosed with HIV, or are currently homeless, actively using substances or have an undiagnosed mental health issue.
- vii. Low acuity participants will receive at minimum 1 health promotion encounters a week based on their needs identified by the Comprehensive Care Plan and as new needs are identified. High acuity participants will receive at minimum 2-3 health promotion encounters a week based on their needs identified by the Comprehensive Care Plan and as new needs are identified. Health promotion should occur as frequently as needed.

- 1. *For substance users, including injection drug users,* harm reduction techniques including but not limited to non-sharing of injection equipment with fellow injectors.
- 2. *For persons on ART,* medication adherence techniques such as pill counting, and guidance on how to handle ART side effects and difficulties.
- viii. During the six month intervention period, low acuity participants will receive at minimum 24 health promotion encounters and high acuity participants will receive at minimum 48-72 health promotion encounters. Each health promotion encounter should be linked to a goal or goals in the participant's Comprehensive Care Plan.
  - 1. It may take more than one encounter to complete a topic or achieve measurable progress toward goals in one's Comprehensive Care Plan.
  - 2. Topics may be repeated.
  - 3. Health promotion topics and conversations may be conducted in stand-alone encounters focused solely on health promotion or may be incorporated into other service type encounters (e.g. accompaniment).
  - 4. If necessary, a single health promotion topic could be covered over more than one session over the course of a calendar year.
- ix. Health promotion conversations are documented on the Services Tracking Log.
- c. Motivational Interviewing
  - i. Motivational interviewing is a technique in which you become a helper in the change process and express acceptance of your client. It is a way to interact with clients, not merely as an adjunct to other therapeutic approaches, and a style of counseling that can help resolve the ambivalence that prevents clients from realizing personal goals. Motivational interviewing builds on Carl Rogers' optimistic and humanistic theories about people's capabilities for exercising free choice and changing through a process of self-actualization. The therapeutic relationship for both Rogerian and motivational interviewers is a democratic partnership. Your role in motivational interviewing is directive, with a goal of eliciting self-motivational statements and behavioral change from the client in addition to creating client discrepancy to enhance motivation for positive change (Davidson, 1994; Miller and Rollnick, 1991). Motivational interviewing activates the capability for beneficial change that everyone possesses (Rollnick and Miller, 1995). Although some people can continue change on their own, others require more formal treatment and support over the long journey of recovery. Even for clients with low readiness, motivational interviewing serves as a vital prelude to later therapeutic work.
  - ii. All encounters with participants will be rooted in motivational interviewing, especially those pertinent to their Care Coordination Plan,

their readiness for behavior change, and supporting and maintaining healthy behaviors.

- d. Digital Social Support
  - i. There are certain factors that help with Care Coordination. The Program should ensure that patients have maximal access to support from their Digital Navigator. The Digital Navigator will maintain an open, non-judgmental space with participants and provide social support through engaging in active listening, joint problem-solving, and peer counseling on an as needed and ongoing basis during the 6 month intervention period. They may also provide counseling to assist with disclosure where feasible, and/or facilitate referrals to external social support providers (e.g. community based organizations) when appropriate.
  - ii. The Program will maintain formal relationships for referrals with community services agencies that provide center-based services such as:
    - 1. Access to a communal space where PLWHA could gather with peers
    - 2. Structured and unstructured social interaction
    - 3. Peer driven support groups

# Appendix H: Health eNav Phone Agreement

By accepting this mobile phone and enrolling in Health eNav, you agree to the following terms and conditions (please initial next to each paragraph):

- 1. \_\_\_\_\_This is a hand up, not a hand out. Mobile for All is designed to connect you with current mobile technology, quality wireless service and a phone number you can keep. This is so you can connect with your Digital Care Navigator and your medical care team using a smartphone. In exchange, you agree to stay connected, keep us updated and provide feedback.
- 2. \_\_\_\_Eligibility. To participate in Mobile for All, you must be referred by the San Francisco Department of Health and active in the Health eNav project.
- **3.** \_\_\_\_\_**Smartphone + wireless service.** The program includes a phone for your sole use and a 100% subsidized wireless base plan of unlimited text and messages for the duration of the program (12 months). Wireless service is provided by Sparrow. During the program, *you agree not to loan or give your phone to anyone else*.
- 4. \_\_\_\_\_Program duration = 12 months. While you are an active participant, your wireless service base plan is 100% subsidized and you get the service for free. If you choose to add data during the program, you will be responsible for paying for data costs.
- **5.** \_\_\_\_\_Post program service. At the end of the program, you can continue service with Sparrow by signing up for a new plan or port your number to a different carrier. If you continue service with Sparrow, we will help you find a new plan and you can pay it forward by helping someone else in need get connected.
- 6. \_\_\_\_\_Protect and take extra good care of your phone. The supply is limited. You agree that you will not, *under any circumstances,* exchange, give away or sell the Mobile for All phone for the program duration. If you break your Mobile for All phone, you are responsible for the cost of repair or replacement.
- 7. \_\_\_\_Data consent. Information you provide is protected as confidential. The purpose is to understand how the phones are helpful, what features are used, and what could make the program better. Your participation is critical and your privacy is protected.
- 8. \_\_\_\_\_The phone is yours to keep when you complete the program. Upon successful program completion, the phone is yours to keep. You can choose to continue wireless service with Sparrow or you can take the smartphone to any compatible network.

- **9. \_\_\_\_\_Lost or stolen phone.** If your phone is lost or stolen, notify Sparrow *as soon as possible* at **(844) 697-7277 / (844) MY-SPARROW.** You can keep the subsidized wireless service, however you will need to get a replacement phone that is compatible with Sparrow's network, and you are responsible for the cost of the replacement phone. Your line can be put on hold for up to a week while you find a replacement phone.
- 10. \_\_\_\_\_SMS messages. We may send you SMS messages containing surveys, useful information like job fairs, storm alerts, medical services and other local resources. These messages are part of the unlimited text message service provided at no cost to you. If you find the messages helpful or have suggestions, let us know.
- 11. \_\_\_\_\_Program updates & changes. Mobile for All reserves the right to make changes to the program and wireless plan. Changes will be communicated to you via phone, text message or email 14 days before implementation. However some changes will be implemented at the program's discretion as part of piloting the program.
- 12. \_\_\_\_\_Privacy protection. No personally identifiable information (PII) will be publically disclosed without your express consent. You agree to allow Mobile for All to share your data collected through this program with San Francisco Department of Public Health and for San Francisco Department of Public Health to share your relevant data with Mobile for All.
- 13. \_\_\_\_\_ZERO TOLERANCE. You agree not to use the Mobile for All phone or wireless service for illegal purposes or to send, store or post any material or information which (whether lawful or not) is offensive, abusive, threatening, indecent, obscene, defamatory, malicious, racially motivated or menacing, or to harass, inconvenience or cause distress to any person. Mobile for All reserves the right to deny services to ANY PERSON AT ANYTIME.
- 14. \_\_\_\_\_Be a Good Mobile Citizen. This program is for you. Long hours of work and resources are being dedicated to providing you with this phone and service. All we ask from you in return is to participate and follow the program rules.
- 15. \_\_\_\_\_In it to win it. The smartphone is yours to keep, as long as you stay connected and uphold this agreement. If for some reason you are not able to continue, you agree to notify Dillon and return the smartphone so someone else can get this life-changing mobile service.

By signing this agreement, you acknowledge having read and accepted these terms and conditions.

I, \_\_\_\_\_\_ (print name), fully understand the terms and conditions of the Mobile for All program as set forth in this agreement and I am over the age of 18 years and competent to sign on my own behalf.

Signature:	Date:
Alt phone:	Current Zip code:

Email: \_\_\_\_\_ Organization you are associated with: \_\_\_\_\_

\_\_\_\_\_

# **Appendix I: Ecological Momentary Assessment Instrument**

### **Depression, Anxiety and Mood**

In the past 24 hours, have you experienced feeling nervous, anxious or on edge?

1 – Yes

0 – No

In the past 24 hours, have you experienced not being able to stop or control worrying?

1 – Yes 0 – No

In the past 24 hours, have you experienced little interest or pleasure in doing things?

1 – Yes 0 – No

In the past 24 hours, have you experienced feeling down, depressed, or hopeless?

1 – Yes 0 – No

On a scale from 0 to 10, how do you feel right now? With 0 being "happy" and 10 being "sad."

# <u>Sexual Risk</u>

In the past 24 hours, did you have sex? 1- Yes With how many people? (Numeric value) What kind of sex? 1- I bottomed (their penis in my anus) Did your partner(s) use a condom?

- 0- No
- 1- Yes
- 2- Sometimes
- 2- I topped (my penis in their anus or vagina)
  - Did you use a condom with your partner(s)?
    - 0- No
    - 1- Yes
    - 2- Sometimes
- 3- Both

Did you or your partner(s) use a condom?

- 0- No
- 1- Yes
- 2- Sometimes

4- Other

0- No

# Alcohol and Substance Use

In the past 24 hours, how much alcohol did you drink?

1- None 2- 1-2 drinks Did you have sex while drinking alcohol? 1- Yes 0- No 3-3-4 drinks Did you have sex while drinking alcohol? 1- Yes 0- No 4: 5 or more drinks Did you have sex while drinking alcohol? 1- Yes 0- No In the past 24 hours, did you smoke marijuana (not prescribed to you)? 1-Yes Did you have sex while smoking marijuana? 1- Yes 0- No 0- No In the past 24 hours, did you use any other substance(s)?

1- Yes

In the past 24 hours, did you use heroin (e.g. mud, tar)?

1-Yes Did you have sex while using heroin? 1-Yes 0- No 0- No In the past 24 hours, did you use methamphetamine (e.g. speed, crystal, tina)? 1- Yes Did you have sex while using methamphetamine? 1-Yes 0- No 0- No In the past 24 hours, did you use crack/cocaine (e.g. rock)? 1- Yes Did you have sex while using crack/cocaine? 1-Yes 0- No 0- No In the past 24 hours, did you use poppers (or amyl nitrates)? 1- Yes Did you have sex while using poppers? 1-Yes 0- No 0- No 0- No

## **Treatment Adherence**

In the past 24 hours, did you take your ART meds?

1- Yes

0- No

Would you like to receive daily reminders to take your meds?

- 1-Yes
- 0- No

What was the biggest challenge that prevented you from taking your meds? Open-ended response

# <u>Social Support</u>

In the past 24 hours, did you spend time with someone you care about, like a loved one, relative or a friend?

Yes

How did that make you feel? Open-ended response

No

# **Closing**

Thank you for completing your daily survey! Just a reminder – to protect you, please delete these text messages as soon as possible.

# Appendix J: Qualitative Baseline Interview Guide

First, I'd like to learn about you as an individual.

- 1. Tell me a little about yourself. How do you identify in terms of your sexuality (or gender identity, if applicable)?
  - a. When did you come out? What was that process like for you?
  - b. To what extent do people know about your identity?

Next, we're going to switch gears and I'd like you to think about the time when you were diagnosed with HIV.

- 2. Can you tell me what was going on in your life at that time?
  - a. When were you diagnosed with HIV?
  - b. What made you want to get tested?
  - c. Could you describe the events that let up to your HIV diagnosis?
    - i. Intention: Identify the factors that might have influenced HIV infection (e.g. mental health, substance use, sexual partners, homelessness, social support, etc.)
- 3. Tell me about your thoughts and feelings when you learned about your HIV diagnosis.
- 4. What did you do next? Can you tell me more about that?
  - a. Intention: Identify the step-by-step process of disclosure and information- and social support-seeking.
- 5. What important people in your life, if any, supported you once you learned about your HIV diagnosis?
  - a. How did they support you?
  - b. Was this typical of the types of reactions you received? Can you tell me more about that?
  - c. Probe for friends, family, organizations, staff, sexual partners.
- 6. How did you decide who to tell or who not to tell?
  - a. What types of things did you take into consideration?

Sometimes people living with HIV tell us that there are good and bad things that have occurred as a result of having this disease. Next, I would like for you to think about what has changed or not changed in your life because of HIV/AIDS.

- 7. How, if at all, has your view of your self changed since your HIV diagnosis?
  - a. Probe for a sense of before and after
  - b. Probe for an understanding of why Intention: To gain a deep understanding of the impact an HIV diagnosis on the self.
- 8. How, if at all, has your social life changed since your HIV diagnosis?
  - a. Probe for a sense of before and after
  - b. Probe for an understanding of why
  - c. Intention: To gain a deep understanding of the impact an HIV diagnosis on one's social life.

- 9. How, if at all, has your dating and sex changed since your HIV diagnosis?
  - a. How has looking for sexual partners changed, if at all?
  - b. How have discussions about sex with other people changed, if at all?
  - c. How have sexual behaviors changed, if at all?
  - d. Probe for a sense of before and after
  - e. Probe for an understanding of why Intention: To gain a deep understanding of the impact an HIV diagnosis on sexual behavior.

We are almost at the end of our interview. I'd like to ask you a few questions about mobile technology and your care.

# 10. Tell me about the relationship you have with your mobile phone?

- a. When do you use it?
- b. How often do you use it in a day?
- c. What do you use it for?
- d. Do you use it for HIV-related things at all? Can you tell me more about that?
- 11. What impact has your mobile phone had on your life?
  - a. What would life look like if you didn't have your mobile phone?
- 12. When do you think about your health and well-being?
  - a. Think about the last time you advocated for your health and wellbeing. What did you do? What steps did you take?
    - i. Intention: Identify the step-by-step process of health information-seeking.
- 13. In general, when you see your care provider, what do you do, if anything, to prepare?
  - a. How about after you visit your provider or in between visits?
  - b. Can you talk me through an example?
- 14. How do you think having direct access to a digital navigator impact your HIV care experience?

Thank you so much for your time and sharing your experiences with me. We have come to the end of the interview. We will conduct a similar interview in a year from now. I thank you for your participation.

# **Appendix K: Brief Intake Assessment**

# Health eNav Brief Intake – Assessment

CLIENT ID #		Intake Date _	
Referral Date	Referred by:		
Last Name	_First Name		M.I
Does client prefer to be referred to by any other nan	ne?		
Street/Apt. Number	City		
State California ZIP County		_	
Phone ( Cell pho	one (	_	
Emergency Contact Number ()	_Name/Relationship		
Is Emergency Contact aware of client's HIV status?	?Yes	_No	
Client can be contacted (check all that apply)	At Home	By Mail	_By Phone
Is discretion required?			

### PRESENTING PROBLEM/IMMEDIATE CASE MANAGEMENT SERVICE NEEDS:

### NON-MEDICAL SERVICE PROVIDERS:

(i.e. Advocacy, Intensive Case Management, Housing, Food, Support Groups)

Agency	Contact Person	Phone	Service

Are case management services provided through another agency?  $\Box$  Yes  $\Box$  No

o 10 . . . . . . .

Date of Birth:Age:	
GENDER: D Female D Transgender-ID as Femal	□ Male le □ Transgender-ID as Male
Ethnicity: Hispanic?  □ Yes, specify:	🗆 No
Race:□Asian□Black or African An□White□American Indian or	nerican □ Native Hawaiian/Pacific Islander Alaska Native □ Other:
Relationship Status: □ Single □ Singl □ Separated □ Wido	e-living w/partner □ Married □ Divorced wed
Person describes self as:  Heterosexual	□ Homosexual □ Bisexual □ Other:
Primary language spoken:	
<b>English: Read</b> ? □ Yes □ No Write?	□ Yes □ No
Other Language:Read?	□ Yes □ No Write? □ Yes □ No
Does the client have difficulty Does the client have difficulty using English to nav	yunderstanding English? □ Yes □ No vigate the health and social service systems? □ Yes □ No
Citizenship/Immigration Status:	
Is the client an undocum Does the client have pendin	ented U.S. resident?  Yes  No ng immigration issues?  Yes  No
Living Situation:	sitional
Living Arrangement: Relations/Friends	
Does the client have temporary, unsa	afe, and/or inadequate housing? 🗆 Yes 🗆 No

### HOUSEHOLD COMPOSITION

### Number of people in household (including client): \_\_\_\_\_

### Adults

Name	Relationship	Age	Aware of Client's HIV+ Status? (Y/N/NA)

### SOCIAL NETWORK (partners, other close supports)

Name	Relationship	HIV Status (+ , - or unknown)	Age	Aware of Client's HIV+ Status (Y/N)	IRL or Online?

Do household members or close supports have needs that impact client's ability to access or maintain treatment or care? □ Yes □ No Are there disclosure issues that can be assisted by case management? □ Yes □ No Does the client have a functioning support system? □ Yes □ No

#### PRIMARY INSURANCE

Indicate all that apply:
$\Box$ Medicaid: Number with Sequence # ( )
Is there an exception $-35$ ? $\Box$ Yes $\Box$ No
Is there a spend-down? $\Box$ Yes, in the amount of $\Box$ No
□ MedicaidManaged Care □ Medicare □ Private Insurance □ HMO/Managed Care
□ ADAP PLUS □ Self Pay □ Military □ Other:

### <u>SECONDARY INSURANCE</u> <u>D</u>None or <u>D</u>Yes, (checkbelow)

□ Medicaid Managed Care □ Medicare □ Private Insurance □ HMO/Managed Care □ ADAP PLUS □ Self Pay □ Military □ Other: \_\_\_\_\_

Effective Date of Secondary Insurance: \_\_\_\_\_

Does the client need assistance with insurance for medical care? 

Yes No

#### HIV STATUS

When was client diagnosed with HIV?

Where can proof of HIV status be obtained?

Does client know how he/she was infected?

### MEDICAL

#### A. Primary Medical Care

Provider Name:				
Address:				
City:	_State:	_Zip:	_Main Phone:	
Case Manager/Social	Worker:			Phone:
Primary Physician:				Phone:
Recent Hospitalizatio	ns:			
Last time saw doctor:			_CD4 Count:	Viral load:

### B. <u>TB Status</u>

Last PPD:	_Result: $\Box$ (+) Pos $\Box$ Pos (under Tx) $\Box$ (-) Neg $\Box$ Unknown
If PPD (+), date of last chest x-ray:	Chest x-ray results:
Has client ever been told they have	active TB disease?   Yes  No
If yes, when?	By whom?
Has client ever been on TB medica	tion? □ Yes □ No If yes, when?
Is client currently taking TB meds?	'□Yes □No
If yes, any problems taking meds?	
Do client's partners or members of	their household need TB testing? $\Box$ Yes $\Box$ No
Comments:	
C. <u>Other Medical Conditions</u>	

### D. <u>Pharmacv (Specify)</u>:

Client restricted to us of a specific pharmacy? D Yes D No

E. <u>Medications</u> (List all taken currently, e.g., HIV, TB, HCV, Psychotropics, etc.):

 Does the client have difficulty keeping appointments or problems taking medications?
 □ Yes
 □ No

 Does the client need other services related to accessing HIV treatment and care?
 □ Yes
 □ No

 Are there unmet needs for other medical or health conditions (including pregnancy)?
 □ Yes
 □ No

 Are there debilitating symptoms requiring assistance (i.e., homecare, home delivered meals)?
 □ Yes
 □ No

### TOTAL MONTHLY HOUSEHOLD INCOME SOURCE & BENEFITS

Employment		HIV/AIDS Service Administration	
Social Security		Short Term Disability	
SSI		Survivor Benefits	
SSD		Rent Supplement	
Child Support		Veteran's Assistance	
<b>Public Assistance</b>		Pension	
Disability Ins. Inc.		Long Term Disability	
Alimony		Unemployment Insurance	
Workman's Compensation		Food Stamps	
Other:			
		Total Personal Monthly Income:	
Additional monthly in	come from household mem	ibers:	
Total monthly househ	old income:	Annual household income (for URS) : (M	Ionthly income x12)
Does the	Does the client have a r oes client have difficulty the client linked to income client need assistance/a	egular source of income?  Yes  No meeting monthly expenses?  Yes  Ves sources they are eligible for?  Yes dvocacy in accessing entitlements?  Y	No No es □ No

### **HISTORY OF INCARCERATION**

Has client been released from a correctional facility in the last 12 months?

□ Yes, when	_□ No	
How long incarcerated?	_days/weeks/months/years	
Is client currently on parole/probatio	n? □ Yes □ No	
If yes, name of Parole/Probation Off	icer:	phone: ()
Reason for incarceration:		
Comments:		

If recently incarcerated, does client need to be reconnected to health or human services?  $\Box$  Yes  $\Box$  No  $\Box$  NA Are there continuing legal needs to be addressed before client is ready for services?  $\Box$  Yes  $\Box$  No  $\Box$  NA

### MENTAL HEALTH

Phone: □ Yes □ No
□ Yes □ No
🗆 Yes 🗆 No
re?
□ Yes □ No
eeds:
s 🗆 No – If yes, explain
es 🗆 No - If no, explain:
r would resort to force when

#### SUBSTANCE USE

Does client have a history of drug/alcohol use? □ Yes □ No Is client currently using? □ Yes □ No If Yes, how long?days/weeks/months/years Drug(s) of choice:
Frequency of use:
Program Name:
Contact Person: Phone:
If not in treatment, is client interested in SU treatment, syringe exchange, other supports? $\square$ Yes $\square$ No
Does client want assistance to quit smoking? □ Yes □ No
Is the client experiencing problems as a result of alcohol or drug use? □ Yes □ No Is the client seeking treatment for alcohol or drug use? □ Yes □ No
BASIC HIV EDUCATION/HARM REDUCTION

### Does client know how HIV is transmitted and prevention techniques? □ Yes □ No

Assess level of knowledge regarding: 
Basic HIV transmission Safer Sex/Use of Latex
Needle/Works Sharing Drug/Alcohol

Use Referral to Prevention Services needed? □ Yes □ No

Comments:

### **OTHER NEEDS**

Does the client need assistance obtaining Nutritious food? □ Yes □ No Appropriate clothing? □ Yes □ No Transportation? □ Yes □ No Legal services? □ Yes □ No Education/training/employment? □ Yes □ No

# SUMMARY PAGE

Summarize client status, presenting needs, and assessed needs. Elaborate on any questions in the shaded boxes indicating unmet needs.



### CASE DISPOSITION

Client ID#:	Client Name:
Case management recomme	ended?  vert Yes  vert No
Acuity Level?	ow Acuity 🗆 High Acuity
(Explain recommended mod	lel to client)
Case Management accepted	? $\Box$ Yes $\Box$ Declined
If declined, where will client b	be referred?
IMMEDIATE DEEEDDAI	LS MADEL (include contact name)
INIVIEDIA LE REFERRA	<b>IS MADE:</b> (include contact name)
	-

Hospital/Clinic:	For:
Agency:	For:
Agency:	For:
Internal:	For:
Internal:	For:
Intake/Assessment Completed by:	Date:
Reviewed by:	Date:

Appendix L: Case Notes Template

		Date:	
	CASE NOTES		
 			_
 	· · · · · · · · · · · · · · · · · · ·		

Initials:

# **Appendix M: Enrollment Check List**

Date:	Subject ID:

□ Eligibility Screening Form

□ Signed Informed Consent

□ UCSF HIPPA Consent

□ Medical Release Forms

□ ARIES Consent Form

□ Residential Status

□ Letter of Diagnosis

 $\Box$  Income Assessment

 $\Box$  Comprehensive Locator Form

□ Completed Comprehensive Assessment

□ Completed and Signed Service Plan

□ Receipt

NOTES:	
--------	--

Staff Signature \_\_\_\_\_

Staff Initials \_\_\_\_\_

# Appendix N: Case Closure Form

Case	Health eNav e Closure Summary
Name:	Record #:
Case Opening Date:	Case Closing Date:
Summarize services rendered to the client and toward goals in the service plan. Where neces contact persons.	I reasons why case is being closed. Comment on the progress made ssary, include provisions for continued services, listing agencies and
Reasons for Closure:	
Services Provided and Progress Toward Go	bals:
If applicable, is client aware of case closure	? 🗆 Yes 🗆 No 🗆 N/A
If yes, how was client notified?	
Transfer, discharge, or follow up plans:	
Digital Navigator Signatu <u>re:</u>	Date:
Supervisor Signature:	Date:

	Health eNav Brief	Service Pla	u	
Client Name:			B	#:
Need	Action	Person Responsible	Target Date	Outcome
Client Signature:			Date:	
Service Plan Developed By:			Date:	
Supervisor Signature:			Date:	

# Appendix O: Service Plan Template

# **Appendix P: Locator Form**

### Health eNav Locator Form

Study ID		
Preferred name		
Legal name		
Other name(s)		
you go by?		
Address	Address:	
	<i>Apt.</i> #:	
	City:	
	State:	
	Zip:	
	□ OK to send mail to address?	
Phone #(s)		
	OK to leave message?	
Mahila appa for	U OK to text?	
direct messaging		□ Line
direct messaging	□ WhatsApp:	□ Other:
	□ Skype:	Other:
Email address		
Alternative		
email address		
Alternative		
email address		
F 1 1		
Facebook		
account		
Social Media	Twitter:	Grindr:
Accounts	□ Instagram:	BBRT:
(include user	Snapenat:     Tumble:	$\square$ Jack'd:
name and/or		Other:
email used for	□ OkCupid:	Other:
log-in)		

### **Contact Information**

Please list 2 people who will be able to contact you in the event that we are unable to reach you.

	Contact 1			Contact 2		
Name						
Relation						
Address	Address/Apt. #:			Address/Apt. #:		
	City:			City:		
	State:	Zip:		State:	Zip:	
Phone #		0 O	k to leave a		0 O	k to leave a
		voic	e message?		voic	e message?
Email address						
Social media						
Ask for:						
Call ourselves:	Health eNav oOther:	o SFDPH	o Staff name	Health eNav oOther:	o SFDPH	o Staff name
Comments						

### **Provider Information**

Please list 2 agencies or providers (case manager, social worker, probation/parole officer, shelter, community center, etc.) who will be able to contact you in the event that we are unable to reach you.

	Provider 1	Provider 2
Agency		
Contact		
Relation		
Address	Address/Apt. #:	Address/Apt. #:
	City:	City:
	State: Zip:	State: Zip:
	□ OK to send mail? o OK to visit?	□ OK to send mail? o OK to visit?
Phone #	o Ok to leave a voice	o Ok to leave a voice
	message?	message?
Email		
Ask for:		
Call ourselves:	□ Healthy eNav o SFDPH	□ Health eNav o SFDPH
	□ Staff name oOther:	□ Staff name oOther:
Comments		

#### **Location Information**

If we lost contact with you, where would we typically be able to locate you? (Routine activities; work location; usual areas/neighborhoods/community locations and times of day)

Do you prefer we identify ourselves as:

□ Health eNav o SFDPH o Staff name oOther:

### **Contact Preference**

What are your preferred ways and times to be contacted?

Phone call

□ Text\_

Email

Mail

Social Media

Friends/Family \_\_\_\_\_\_

Provider/Community agency

Community location

### Comments

# Appendix Q: Field Incident Report Template

Name of Person Filing Report:
Position (check all that apply): Digital Navigator Project Director Other (Specify):
Location of Incident (name and address):
Date of Incident (mm/dd/yy)://
Time of Incident: / am pm (circle one)
Description of Incident and Actions Taken:
Incident Reported Locally to (check all that apply):
Supervisor Date:/ Time:/ am pm (circle one)
Police Date: / / Time: / am pm (circle one)
Comments (other information relevant to the incident):
Signature of Person Filing Report:Date://

# Health eNav Field Incident Report

### **Appendix R: Medical Release Form**

### San Francisco Department of Public Health Center for Public Health Research Health eNavigation (Health eNav): Digital HIV Care Navigation (415) 554-9032

### AUTHORIZATION FOR RELEASE OF MEDICAL INFORMATION

By this written authorization I permit Health eNav, a program at the San Francisco Department of Public Health, Center for Public Health Research, to obtain information regarding my:

() Medical Information Record

() Psychiatric Health Record

() Chemical/Alcohol Treatment Record

() HIV Records

Patient Name (Please Print):	
Date of Birth:	
Address:	
Telephone Number:	

Information is being requested from:

Name of Physician, Health Care Facility or Provider:
Address:
Phone Number:
Fax Number:

This authorization is effective from the date following my signature and shall terminate two years from that date. I understand that I have a right to receive a copy of this authorization. I wish a copy of this authorization: () Yes () No

Printed Name of Patient

Signature of Patient

Date

Printed Name of Witness

Signature of Witness

Date

# Appendix S: Qualitative Feasibility and Acceptability Interview

Thank you for taking the time to speak with me today. Now that the Health eNav intervention is over, I want to ask you a couple of questions about your experience with the project. Please feel free to tell me exactly how it was for you – the good, the bad, the ugly. This will help us make the project better! First, let's go to the very beginning. You enrolled in the study on: (Enrollment date: \_\_\_/\_\_\_) ...

- What first interested you in the study?
  - What were some of the reasons why you wanted to participate in Health eNav?
- What were your <u>FIRST</u> impressions about the being in the study? Can you tell me more about that?
  - Was there any part that you were looking forward to or curious about?

There were two main pieces to the study that you participated in: 1) the daily, text message surveys that you received every day for 90 days – let's call this the DAILY SURVEYS – and 2) the one-on-one text messaging about your care and support that lasted 6 months – let's call this DIGITAL NAVIGATION. For these next few questions, let's first talk about the DAILY SURVEYS.

- Tell me about your experience with the DAILY SURVEYS. What was it like? Can you tell me more about that?
  - What did you like <u>most</u> about DAILY SURVEYS?
  - What did you like <u>least</u> about DAILY SURVEYS?
- You received DAILY SURVEYS for a period of 3 months. What did you think about that length of time? Can you tell me more about that?
  - Did you want it for longer or shorter? Why?
- How did the DAILY SURVEYS help you, if at all?
  - What did you gain from it?
- How did the DAILY SURVEYS impact your life, if at all?
- How did the DAILY SURVEYS impact your medical care, if at all?

Now, let's first talk about the one-on-one text messaging about your care and support that lasted 6 months or DIGITAL NAVIGATION.

- Tell me about your experience like with DIGITAL NAVIGATION. What was it like? Can you tell me more about that?
  - What did you like <u>most</u> about DIGITAL NAVIGATION?
  - What did you like <u>least</u> about DIGITAL NAVIGATION?
- Think about a conversation during DIGITAL NAVIGATION that you stood out to you or that you can remember and tell me about that.

- What was the conversation about?
- Why did it stand out to you?
- Were you concerned, if at all, about talking about sensitive subjects over text message?
- You received DIGITAL NAVIGATION for a period of 6 months. What did you think about that length of time? Can you tell me more about that?
  - Did you want it for longer or shorter? Why?
- How did the DIGITAL NAVIGATION help you, if at all?
   What did you gain from it?
- How did the DIGITAL NAVIGATION impact your life, if at all?
- How did the DIGITAL NAVIGATION impact your medical care, if at all?

Thank you so much for your time and sharing your experiences with me. We have come to the end of the interview. I thank you for your participation in Health eNav.

# Appendix T: Job Descriptions for Key Personnel

# JOB DESCRIPTION: SPNS DIGITAL NAVIGATOR

# Position Overview

Public Health Foundation Enterprises, Inc. (PHFE) invites applications for the position of Digital Navigator within the Linkage Integration Navigation and Comprehensive Services (LINCS) team of the San Francisco Department of Public Health (SFDPH). There is one position available. This is a temporary position as the funding is based on grants we receive. The position is an important service designed for HIV positive persons experiencing the greatest challenges to remaining in medical care. The Digital Navigator will use digital and social media strategies to reach out to clients who are newly diagnosed with HIV as well as those that have dropped out of HIV care, to assist them with setting up medical appointments, partner elicitation and notification, treatment adherence and linkage to social support services. Employment is provided by PHFE.

# **Roles and Responsibilities**

- Work closely with other LINCS staff to identify HIV positive clients and monitor their linkage and engagement in medical care
- Utilize various forms of digital and social media to engage and retain participants for follow-up
- Demonstrating accurate and comprehensive knowledge of HIV
- Work with patients to ensure that they have received adequate treatment
- Interviewing patients diagnosed with HIV per established protocols. This includes creating case write-ups and data entry into various databases.
- Counseling and motivating patients to seek and notify partners, either directly or with Health Department assistance so that partners can be tested/treated with the goal of preventing and uncovering new HIV infections. This also involves offering/providing current bio-medical interventions such as PEP and PrEP
- Seek out clients by phone, digital and social media or in person in the field to offer LINCS services
- Identify barriers clients experience in accessing HIV care and services, and use a strengths-based approach to overcome them
- Reinforce treatment goals that clients develop with medical care providers

## **Requirements**

## Education/Experience

- Possession of a Baccalaureate degree from an accredited college or university with major course work in the social or health sciences; relevant experience within the last five (5) years can be substituted on a year-for-year basis for the educational requirements
- One year of verifiable experience, gained within the past five (5) years, working with gay/bisexual men and/or trans people providing health or

social services such as counseling, health education, outreach or referral or in a field relevant to the job duties described

- Minimum of 2 years working with clients in public health, community services or medical settings.
- Experience working with people living with chronic illness, substance users, and persons with mental health diagnoses.
- Experience working with a culturally and economically diverse populations, including people of color and gay/bisexual/transgender populations.

# Certificates/Licenses/Clearances

- Required to attend and successfully complete the Passport to Partner Services or ISTDI training
- Certification as an HIV test counselor is highly desirable

# Other Skills, Knowledge, and Abilities

- Ability to speak Spanish desired
- Familiarity with SFDPH clinics and HIV resources in San Francisco desired
- Familiarity with public health program implementation and evaluation desired
- Experience with motivational interviewing and strengths-based case management desired
- Experience with MS Access desired

# JOB DESCRIPTION: SPNS DATA MANAGER

# Position Overview

Public Health Foundation Enterprises, Inc. (PHFE) invites applications for the position of Data Manager within the Center for Public Health Research (CPHR) at the San Francisco Department of Public Health (SFDPH). There is one position available. This is a temporary position as the funding is based on grants we receive. The position will support an important intervention study examining the efficacy of a digital navigation model, using digital and social media strategies to reach out to clients who are newly diagnosed with HIV as well as those that have dropped out of HIV care, to assist them with setting up medical appointments, partner elicitation and notification, treatment adherence and linkage to social support services. Employment is provided by PHFE.

# **Roles and Responsibilities**

# Data Management

- Support a multi-site evaluation activities under the supervision of the Program Evaluator;
- Complete and file all necessary grant reporting;
- Serve as the point of contact for any necessary HRSA communication;
- Knowledge of and previous experience using relevant clinical data management and reporting systems: eHARS, RSR, ARIES, etc.; and
- Experience effectively utilizing electronic medical records for clinical data abstraction.

## Administrative Responsibilities

- Use computer to maintain updated participant information and perform clinical data abstraction for reporting purposes;
- Participate in meetings and quality control activities;
- Assist with planning and executing participant retention planning and events; and
- Perform other duties as required.

## <u>Requirements</u>

*Education/Experience* 

- Possession of a Master's level degree from an accredited college or university in public health, social sciences or other relevant field of study;
- One year of verifiable experience, gained within the past five (5) years, working with gay/bisexual men and/or trans people providing research, health or social services such as counseling, health education, outreach or referral or in a field relevant to the job duties described;
- Minimum of 2 years working with clients in public health, community services or medical settings;
- Experience working with people living with chronic illness, substance users, and persons with mental health diagnoses; and
- Experience working with a culturally and economically diverse populations, including people of color and gay/bisexual/transgender populations.
- Experience with intensive longitudinal analysis is not required but preferred.

## Other Skills, Knowledge, and Abilities

- Bilingual in Spanish and English a plus, but not required.
- Experience working with protected health information and maintaining patient confidentiality preferred.
- Experience interviewing patients with structured questionnaires for research purposes preferred.
- Experience using a PC.
- Knowledge of Microsoft Office (especially Word, Excel and Access).
- Ability to enter data accurately with minimal supervision.
- Meticulous attention to detail.
- Good communication and interpersonal skills.
- Capacity to work independently or in a team environment.
- Knowledge of SAS, STATA, R or SPSS is required.