

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) Program Initiative

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

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December 2019

This publication was made possible by award number [H97HA28895](#) from the U. S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau's Special Projects of National Significance Program. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. government.

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Intervention 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 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, out-of-care and not virally suppressed youth and young adults living with HIV need support most.

Rationale and Need

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.¹ 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 Latino MSM.² Similar to young racial/ethnic minority MSM, young racial/ethnic minority trans women also bear a huge burden of HIV infections in the US.³ In San Francisco, trans women have the highest HIV prevalence of any risk population (35.5% vs. 22.7% among MSM).⁴ Evidence suggests that racial/ethnic minority trans women are at even higher HIV risk compared to their white counterparts.⁵ In San Francisco, 34% of trans women diagnosed with HIV infection were between the ages of 13-29

¹ 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.

² Ibid.

³ 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.

⁴ SFDPH. HIV/AIDS Epidemiology Annual Report, 2008. San Francisco: San Francisco Department of Public Health (SFDPH); 2008.

⁵ 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.

compared to 21% of all other cases in the same time period.^{6,7} Of AIDS cases among trans women in San Francisco, individuals were more likely to be non-white and younger.⁸

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.⁹ At the time of developing this manual, data from CDC indicated that racial/ethnic minority and younger individuals fare worse along the treatment cascade.¹⁰ 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.¹¹ 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 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.¹² 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.¹³ Young trans women are also disproportionately impacted by HIV. Data collected with young trans women in San Francisco found a 7% HIV

⁶ SFDPH. HIV/AIDS Epidemiology Annual Report, 2008. San Francisco: San Francisco Department of Public Health (SFDPH); 2008.

⁷ 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.

⁸ SFDPH. HIV/AIDS Epidemiology Annual Report, 2008. San Francisco: San Francisco Department of Public Health (SFDPH); 2008.

⁹ Ibid.

¹⁰ 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*, 2013;173(14):1337-44.

¹¹ Unpublished data. San Francisco Department of Public Health (SFDPH); 2013.

¹² Unpublished data. Transfemales Empowered to Advance Community Health (TEACH). San Francisco Department of Public Health. 2009.

¹³ 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.

prevalence,¹⁴ which is in contrast to the estimated local HIV prevalence among adult trans women of 42.4%.¹⁵ 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. 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.¹⁶ 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.¹⁷

Theoretical Basis / Conceptual Model

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 eNav is designed to improve health outcomes through a proactive, patient centered, service oriented, accessible, and cost effective PCMH Model.¹⁸ 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;

¹⁴ 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.

¹⁵ 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*, 2013;173(14):1337-44.

¹⁶ 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.

¹⁷ 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.

¹⁸ Jackson GL, Powers BJ, Chatterjee R, et al. The patient-centered medical home. A systematic review. *Ann Intern Med*. 2013;158:169–178.

and increased efficiency and quality of care. 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.^{19, 20} 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 with people that require more intensive, ongoing support.²¹ 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.²²

Intervention Description

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, out of care or not virally suppressed. Health eNav is comprised of three digital innovations: (1) digital HIV care navigation using social media platforms, (2) digital care circles using a secure text messaging platform, and (3) 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 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

¹⁹ Wagner, E. H., Austin, B. T., & Von Korff, M. (1995). Improving outcomes in chronic illness. *Managed care quarterly*, 4(2), 12-25.

²⁰ 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>

²¹ 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.

²² 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.

Navigator and 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.

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 are delivered 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.^{23, 24} Motivational interviewing activates the capability for beneficial change that everyone possesses.²⁵ 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.

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.

²³ Davidson, R. (1996). Motivational issues in the treatment of addictive behaviour. *Psychotherapy, Psychological Treatments and the Addictions*, 173-188.

²⁴ Miller, W. R., & Rollnick, S. (2012). *Motivational interviewing: Helping people change*. Guilford press.

²⁵ Rollnick, S., & Miller, W. R. (1995). What is motivational interviewing?. *Behavioural and cognitive Psychotherapy*, 23(4), 325-334.

Intervention Typology

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

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 city-wide 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 in 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 super user of digital technology, text messaging and social media. In addition to the Digital HIV Care Navigator, the Data Manager is also 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 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. However, there was a training focus on the health promotion curriculum that consisted of 9 topic areas and in motivational interviewing.

Resources

Publications

1. Turner CM, Arayasirikul S, Trujillo D, Lê V, Wilson EC. Social Inequity and Structural Barriers to Completion of Ecological Momentary Assessments for Young Men Who Have Sex With Men and Trans Women Living With HIV in San Francisco. *JMIR Mhealth Uhealth*. 2019 May 8;7(5):e13241. doi: 10.2196/13241. [PMID: 31066714]