

Demonstration Site Summary

**SMARTEE: Social Media App for Retention, Treatment,
Engagement, and Education**

Howard Brown Health

Chicago, IL

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***

Principal Investigator: Kristin Keglovitz Baker,
kristink@howardbrown.org

Other Contact Person and Information: James Zuniga
jamesz@howardbrown.org

December 2019

This publication was made possible by award number [H97HA28891](#) 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.

SMARTEE

Social Media App for Retention, Treatment, Engagement, and Education

Intervention Summary

Many HIV-positive men who have sex with men (MSM) and transgender women of color (TWOC) struggle with managing their health. Increased individual and systemic barriers like homelessness, unemployment, and stigma can make it difficult for these populations to be retained in care and reach viral suppression.¹ The Social Media App for Retention, Treatment, Engagement and Education (SMARTEE) intervention uses mobile technology to increase engagement in care and adherence to antiretroviral therapy (ART) for these at risk populations.

Using the HIPAA compliant mobile app (Healthvana), clients work with Retention in Care Specialists (RICS) to identify and address barriers to care to improve treatment adherence and retention in healthcare. With the app, clients have access to personal test results and additional health information to increase health literacy, as well as the ability to update their contact information when it changes. The direct messaging feature allows clients and staff to discuss client needs and coordinate care and services in a familiar, convenient method. Over the course of the program, RICS conduct appointment reminders, personal check-ins, and appointment scheduling, in addition to the provision of supportive services needed by each client.

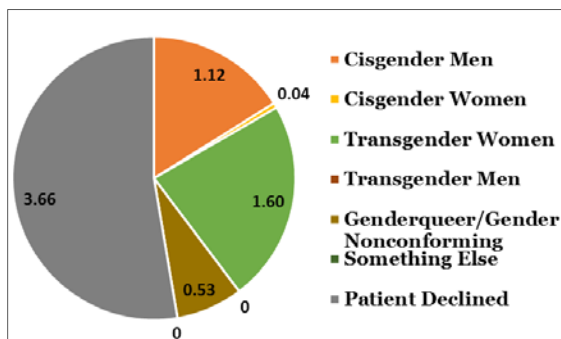
This intervention was designed for agencies, organizations, and clinics that provide HIV primary medical care alongside supportive services following the patient-centered medical home model. Implementation would be most effective in organizations already utilizing electronic health records (EHR) systems in clinical settings or who are interested in expanding their use of technology for client engagement and retention efforts.

Rationale and Need

Chicago is the 3rd largest city in the United States with an estimated population of 2.7 million.² As with other major metropolitan areas, HIV disproportionately affects Chicago. While Chicago represents 21% of Illinois' population, in 2016 it accounted for 61% of the state's new HIV diagnoses.³ Findings from Chicago's 2018 HIV/STI Surveillance Report indicate that in 2017 the city saw 752 new diagnoses, an 11.5% decline from the 839 reported in 2016.⁴ Despite this decline, the incidence among MSM rose for the 6th consecutive year with MSM comprising nearly 75% of all new diagnoses in Chicago.⁴ This trend was greater than the national figures reported by the CDC where MSM accounted for an estimated 66% of new diagnoses in 2017.⁵

Comparatively, new diagnoses among Non-Hispanic Blacks/African Americans are greater in Chicago at 55%, than the national percentage of 43%.^{4,6} Transgender women in particular face the greatest impact of the epidemic, as the CDC estimates upwards of 56% of Black transgender women to be living with HIV.⁷ Similar numbers were seen in 2017 among those screened for HIV at Howard Brown Health. Of patients screened in 2017 (Figure 1), transgender women had a positivity rate of 1.60%, compared to a positivity rate of 1.12% for cisgender men.⁸

Figure 1: HIV Positivity Rate by Gender Identity in 2017



Chicago's HIV trends also mirror the national landscape in regards to age. In 2017, youth ages 13 to 24 accounted for 24% of new incidences in Chicago, compared to the national average of 21%.⁴⁻⁵ While city and local data do not specify the proportion of YMSM ages 13 to 24 that account for new diagnoses, the CDC estimates that in 2017 the percentage was as high as 83%.⁵

To compound this disparity, surveillance data also indicate significant regression at each step of the HIV Care Continuum after diagnosis.⁴ Of people who were living with HIV in 2017, only 63% accessed medical care at least once during the year, and fewer than 36% were considered retained in care.⁵ In 2016, Howard Brown's retention in medical care rates for clients ages 13 to 24 was 44% and an even lower 38% for clients ages 25-34. These figures corroborate the CDC's findings that YMSM of color and TWOC experience lower rates of viral suppression and retention in care, and demonstrate the critical need for novel approaches to improve engagement.⁹

According to the World Health Organization, improving the health disparities of these vulnerable populations begins by addressing structural and intermediary determinants of health that may prevent improved health outcomes.¹⁰ Technology and mobile apps may hold the key to addressing both structural and intermediary determinants of health while increasing access to care. Findings from a study conducted by Pew suggest that nearly 94% of people ages 18 to 29 have access to a smartphone with internet access.¹¹ Furthermore, while communities of color have lower rates of laptop/computer ownership, Black and Latinx communities rely more heavily on mobile devices for managing their healthcare compared to their white counterparts.¹¹ While relatively new, interventions utilizing mobile technology to deliver auxiliary services, encourage engagement, and improve retention in care, may prove to be instrumental in helping underserved populations overcome the barriers faced along the HIV Care Continuum.

Theoretical Basis

The SMART-EE intervention is grounded in client-centered frameworks. Coordinating medical care for enrolled clients follows the Patient-Centered Medical Home (PCMH) model. The PCMH model centralizes patient care by having a primary care provider lead a multidisciplinary team that coordinates care based on a patient's needs.¹² When working with clients or coordinating patient care, staff utilize a variety of frameworks with an emphasis on trauma-informed care, and practices centered on harm reduction and cultural humility.

Trauma-informed care is the practice of recognizing and validating the impact of trauma on individuals and communities, and responding in ways that reduce the systemic processes that cause further trauma.¹³ A trauma-informed approach allows staff and clients to build rapport that can lead to greater engagement and

retention in care. **Harm reduction** is the strategic approach to reducing the harm that results from certain behaviors.¹⁴ In addition to building rapport, harm reduction strategies help clients address harmful behaviors, such as non-adherence, in stages that feel manageable for the client. **Cultural humility** is the process of reflecting on one's personal identity, beliefs and values in relation to understanding another's lived experiences.¹⁵ Cultural humility enables staff and clients to work in greater partnership as staff can learn how various dynamics and experiences across all social levels can impact client health. Cultural humility also empowers clients to voice and prioritize their medical needs when working with staff.

Intervention Components and Activities

The SMART-EE intervention focuses on engaging and retaining clients in HIV primary medical care and providing support for those struggling with medication adherence. Clients ages 13 to 34 receiving HIV care on site and not enrolled in medical case management are eligible to participate if they meet one of the following:

1. Newly diagnosed (defined as diagnosed for the first time in the last 12 months)
2. Have not attended an HIV medical appointment within the last 6 months
3. Have a viral load equal to or greater than 200

Intervention components at the **organization-level** focus on supporting and enabling staff to provide patient centered care while developing their professional skills, abilities and goals. Key activities at the **organization-level** include:

- Coordinating with multidisciplinary teams to identify eligible clients
- Working with clinical staff to prioritize and address client needs
- Overseeing administrative tasks
 - Assigning clients to a suitable Retention in Care Specialist (RICS)
 - Scheduling individual and team supervision meetings
 - Facilitating communication with the app platform company and other internal teams (e.g., IT)
 - Creating reports to monitor client progress, program effectiveness, and staff performance

Client-level activities are based on supporting clients with improving health literacy, navigating healthcare systems, and remaining engaged in care. RICS work with clients for up to 18 months to improve treatment adherence and ability to self-manage their medical care using the app as the main method of contact. Clients in need of ongoing support are then linked to long-term case management services and programs.

Key activities at the **client-level** include:

- Conducting outreach to eligible clients
 - Scheduling return medical appointments for clients, in addition to project enrollment
- Working with clients to identify barriers to medical care and assessing needed resources regarding:
 - Identification cards, food, shelter, financial, legal, clothing, and transportation
 - Mental health
 - Substance use
 - Social support
- Developing relevant medical goals with clients
- Increasing access to care by assisting with:
 - Enrolling in health insurance and medication assistance programs
 - Liaising client needs to healthcare providers (medication refills, referrals, insurance navigation)
 - Providing access to transportation services for medical appointments
 - Conducting personal check-ins and reminders for medical needs via the app
- Increasing health literacy
 - Providing access to lab results in the health app and addressing client messages

Staffing Requirements

The **Project Manager** is responsible for:

- Supervising implementation and development of the project
- Overseeing project operations, including assignment of duties to appropriate staff members to fulfill protocol requirements
- Providing clinical and administrative supervision and consultation for staff as needed
- Reviewing data, reports and manuscripts and overseeing analysis planning

The **Program Coordinator** manages communication and implementation of all aspects of the intervention, in addition to managing a small caseload of clients who have fallen out of care.

The Program Coordinator is responsible for:

- Submitting reports required to obtain/maintain funding with support from Program Manager
- Facilitating communication between the IT application company, the clinical site, and other organizations as needed
- Assisting in creating and managing participant tracking orders and data collection tools that capture service utilization, patient contact, and intervention progress
- Ensuring accurate reporting of progress towards project outcomes by collaborating with key staff to determine intervention measures and modify data tools
- Preparing abstracts and presenting findings at local, state, and national conferences
- Coordinating and attending weekly team meetings with project staff; including creating the agendas, recording meeting minutes, and assigning tasks as needed
- Providing individual supervision to program staff, including delivering performance appraisals and counseling for staff experiencing performance issues
- Working with a multidisciplinary team of medical providers, case managers, and linkage to care staff to ensure access to care for intervention users

The **Retention in Care Specialist** engages clients who have fallen out of care or who struggle with medication adherence by providing short-term medical case management.

The Retention in Care Specialist is responsible for:

- Working with a multidisciplinary team to identify patients who have been or are at-risk of being lost to care
- Conducting active outreach to contact and re-engage identified patients. Outreach includes, phone calls, letters, text messages, emails, use of health apps, etc.
- Linking patients back into primary medical care
- Supporting patients' re-engagement into care by providing short-term case management
- Transitioning patients into appropriate aftercare services upon program completion
- Confirming patients' linkage to medical services and engagement in care by adhering to program follow-up procedures
- Providing referrals for internal and external supplemental resources as needed
- Supporting access to treatment by enrolling clients into health insurance through Medicaid, the ACA, the Ryan White B Program, or other assistance programs
- Developing, producing and distributing outreach and marketing materials as needed
- Assisting in managing the health apps used by the clinic to ensure clients care

The **Data Manager** is responsible for:

- Assisting staff with providing summary reports to project team as necessary
- Providing data analysis support to PI, Program Coordinator and evaluators
- Participating in other recruitment/retention activities as needed
- Attending trainings, staff meetings, and in-services as required

Ideal characteristics of staff in all roles include having a thorough understanding of the strengths, as well as the needs and challenges experienced by communities impacted by HIV.

Staff must have:

- Knowledge of transgender and gender nonconforming identities and communities and the specific risks and challenges these communities face in accessing healthcare.
- Strong understanding and application of trauma informed care and harm reduction principals and methods.
- A deep comprehension of cultural humility and the ability to respect, acknowledge and affirm individual identities and expressions of identity.
- Understanding of the importance of using technology in healthcare settings.
- Proficiency in creating and following systems of management to assist clients.
- Willingness to be adaptive to a client's needs to help navigate healthcare.
- The aptitude to efficiently communicate with other teams and organizations and successfully compromise to create alternative solutions when necessary.

Programmatic Requirements

The following should be addressed prior to implementation in order to be successful:

- Complete a systems integration to allow test results to flow from EHR to the health app platform
- Specify the ideal process for a client to obtain and use the health app in a step-by-step flow
 - Identify which staff members will need to be trained on using the health app platform
 - Purchase necessary equipment for implementation (laptops, stands, routers, etc.)
- Maintain ongoing communication with app developer
- Collaborate with interdepartmental teams to develop protocols for identifying and reporting errors
- Establish how the program integrates alongside existing departments
 - Identify gaps or possible improvements in existing services for the target population
 - Determine programmatic services and methods of delivery
 - Develop methods for identifying the target population
 - Define staff roles and responsibilities
 - Create internal processes for referrals and the coordination of patient care
- Develop and define programmatic services
 - Hire and train staff on existing protocols and procedures
 - Create outreach and enrollment procedures and methods
 - Develop protocols and procedures for monitoring services, activities, platforms and caseloads
 - Identify needed reports and measures to monitor progress toward program outcomes
- ❖ *If modifying the app*, collaborate with the app developer to negotiate possible features and functions
 - ✧ Form an advisory board/focus group to garner feedback on the new features and functions
 - ✧ If applicable, tailor the language within the app with the direction of advisory board/focus group
 - ✧ Create marketing materials with input and feedback from the advisory board/focus group
 - ✧ Test pilot and launch new features one at a time

The following are programmatic requirements that should be addressed throughout implementation:

➤ **Administrative needs**

- **Schedule monthly team meetings and bi-weekly individual supervision sessions for staff**
- **Monthly calls with the app developer**
- **Monthly reports for funders and internal supervisors as needed**

References

1. Colasanti, J., Stahl, N., Farber, E., Rio, C. d., & Armstrong, W. (2017, February 01). An Exploratory Study to Assess Individual and Structural Level Barriers Associated With Poor Retention and Re-engagement in Care Among Persons Living With HIV/AIDS. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. Retrieved February 26, 2019, from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6140317/>
2. *World Population Review*. (2018, December 27). Retrieved February 25, 2019, from Chicago, Illinois Population 2019: <http://worldpopulationreview.com/us-cities/chicago-population/>
3. *AIDSVu*. (2019, February 25). Retrieved February 25, 2019, from Local Data: Chicago: <https://aidsvu.org/state/illinois/chicago/>
4. Chicago Department of Public Health. (2018). *HIV/STI Surveillance Report 2018*. Chicago: Chicago Department of Public Health. Retrieved February 25, 2019, from https://www.chicago.gov/content/dam/city/depts/cdph/infectious_disease/STI_HIV_AIDS/HIVSTI_surveillance_report_2018_1272018.pdf
5. Centers for Disease Control and Prevention (CDC). (2018, November 19). *HIV/AIDS Basic Statistics*. Retrieved 25 February, 2019, from Centers for Disease Control and Prevention: <https://www.cdc.gov/hiv/basics/statistics.html>
6. Centers for Disease Control and Prevention (CDC). (2019, February 4). *HIV and African Americans*. Retrieved February 25, 2019, from Centers for Disease Control and Prevention (CDC): <https://www.cdc.gov/hiv/group/raciaethnic/africanamericans/index.html>
7. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. (2018, April). *HIV and Transgender People*. Retrieved February 25, 2019, from Centers for Disease Control and Prevention: <https://www.cdc.gov/hiv/pdf/group/gender/transgender/cdc-hiv-transgenderfactsheet.pdf>
8. Thompson, L., & Rusie, L. (2018). Howard Brown Health 2018 Epidemiology Report. Chicago. Retrieved February 25, 2019, from https://howardbrown.org/wp-content/uploads/2018/11/HHB_EpiReport18-FINAL_lr.pdf
9. Centers for Disease Control and Prevention. (2013, November 22). *CDC Health Disparities and Inequalities Report —United States, 2013 Morbidity and Mortality Weekly Report*. Retrieved February 25, 2019, from Centers for Disease Control and Prevention: <https://www.cdc.gov/mmwr/pdf/other/su6203.pdf>
10. Centers for Disease Control and Prevention. (2010, October). *Establishing a Holistic Framework to Reduce Inequities in HIV, Viral Hepatitis, STDs, and Tuberculosis in the United States*. Retrieved February 25, 2019, from <https://www.cdc.gov/socialdeterminants/docs/SDH-White-Paper-2010.pdf>
11. Aderson, M., & Jiang, J. (2018, May 31). *Teens, Social Media & Technology 2018*. Retrieved February 25, 2019, from Pew Research Center Internet & Technology: <http://www.pewinternet.org/2018/05/31/teens-social-media-technology-2018/>
12. Agency for Healthcare Research and Quality. (n.d.). *Defining the PCMH*. Retrieved February 27, 2019, from Patient Centered Medical Home Resource Center: <https://pcmh.ahrq.gov/page/defining-pcmh>
13. Substance Abuse and Mental Health Services Administration. (2014). Trauma-Informed Care in Behavioral Health Services. *Treatment Improvement Protocol (TIP) Series 57*. Retrieved February 26, 2019, from <https://store.smhsa.gov/system/files/sma14-4816.pdf>
14. Paediatr Child Health. (2008). Harm reduction: An approach to reducing risky health behaviours in adolescents. *Paediatr Child Health*, 53-56. Retrieved February 27, 2019, from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2528824/>
15. Yeager, K. a., & Bauer-Wu, S. (2013). Cultural humility: Essential foundation for clinical researchers. *Applied Nursing Research*, 251-256. doi:<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3834043/>