

Demonstration Site Summary

weCare

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In the Ryan White HIV/AIDS Program (RWHAP), Part F: Special Projects of
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***Use of Social Media to Improve Engagement, Retention,
and Health Outcomes along the HIV Care Continuum***

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Intervention Summary

Estimates suggest that only about 30% of all individuals living with HIV in the US have achieved viral suppression. Gay, bisexual, and other men who have sex with men (collectively referred to as MSM) and transgender women, particularly racial/ethnic minority young MSM (YMSM) and young transgender (YTG) women, are at increased risk for HIV infection. HIV testing rates among YMSM and YTG women are low and, when tested, racial/ethnic minority YMSM and YTG women have disproportionately lower rates of retention in care and viral suppression compared to other subgroups.

weCare is a social media-based intervention designed to improve care engagement and health outcomes among racially and ethnically diverse YMSM and YTG women, ages 16-34, living with HIV.

The intervention harnesses established social media that YMSM and YTG women between these ages commonly use, including Facebook, texting, and established GPS-based mobile applications (apps).

Community-based participatory research (CBPR) was used to develop and implement weCare, enhancing the quality and validity of the intervention by equitably involving community members, organization representatives, healthcare providers, clinic staff, and academic researchers.

This intervention is intended for clinics or community-based organizations (CBOs) that provide services for YMSM and YTG living with HIV.

To effectively implement the intervention, a CBO would need to be connected to or have a close working relationship with a clinic that treats individuals living with HIV.

Rationale and Need

An estimated 21% of HIV infections occur among youth and young adults ages 13-29.¹ It is estimated that less than half of youth ages 13-24 with HIV know their status, one quarter are in care, and only 6% achieve viral suppression.^{2,3} The greatest number of infections among youth and young adults occur among racial and ethnic minority YMSM and YTG women.

MSM and transgender women of all races/ethnicities and age groups continue to be disproportionately affected by HIV, accounting for nearly two-thirds of all new infections in the US.^{4,5}

Although the overall annual HIV diagnosis rate decreased by 33.2% from 2002 to 2011, the number of new HIV infections among MSM has continued to increase. In addition, the rate of new HIV diagnoses among MSM is 44 times that of other men and 40 times that of women.^{6,7}

Among all MSM, African American/black and Latino MSM carry a disproportionate burden of HIV, resulting in profound HIV-related health disparities. These national trends hold true in the US South, which is now referred to as the new HIV epicenter in the US. For example, in North Carolina, MSM accounted for 77% of all the new HIV cases in adult/adolescent males. African American/black and Latino MSM had rates nearly eight times and three times, respectively, the rate for white men, with racial and ethnic minority youth also disproportionately affected.⁸

Despite advances in HIV diagnostics, treatment, and behavioral interventions to increase medication adherence, youth and young adults continue to have low rates of care engagement. A profound need exists for innovative interventions to improve outcomes among YMSM and YTG women and to achieve the objectives of the National HIV/AIDS Strategy.

Theoretical Basis / Conceptual Model

The weCare intervention is delivered over 12 months by a trained Cyber Health Educator (CHE). The Cyber Health Educator uses social media to communicate with each participant individually using theory-based messages specific to each participant's place on the Continuum. In addition to working with participants one-on-one via social media, the Cyber Health Educator also manages an optional Facebook secret group for participants.

Social media communications between the CHE and participants are based on social cognitive theory,⁹ the theory of empowerment education,^{10,11} and natural helping.¹²

Social cognitive theory emphasizes information; mastery of skills and development of self-efficacy; enhancement of proficiency; and social support for behavior changes and positive action.

Accordingly, the CHE identifies and fills knowledge gaps, (e.g., what to expect when attending one's first clinical appointment after an HIV diagnosis). A participant may express discomfort so the CHE will help increase self-efficacy by identifying and then reducing perceived barriers (e.g., perceptions that one will be judged by clinic staff). The CHE also may role-play, via social media, with a participant by having the participant practice asking questions they may have of their provider, support incremental steps (e.g., filling an ART prescription), and reinforce HIV care behaviors (e.g., taking ART as prescribed).

As empowerment education posits that individuals move beyond learning and critically reflect to "get to" action, the CHE uses conversation "triggers" to promote critical consciousness. For example, using app-based instant messaging the CHE might applaud a participant who reports getting an ART prescription after diagnosis, and also ask him/her how he/she plans to get the prescription filled.

As norms and expectations contribute to risk, raising consciousness is best facilitated by community insiders such as the CHE through social media platforms that the participants are

already using. Trained community insiders, who are natural helpers, can be highly effective to promote health and health outcomes by:

- Providing support as a peer who is socio-economically and experientially similar;
- Possessing an intimate understanding of social networks, strengths, health needs and priorities;
- Understanding what is meaningful to those like themselves;
- Communicating in a similar style and language; and
- Recognizing and incorporating identities (including both racial/ethnic and sexual minority cultures and identities).

Thus, the CHE uses social media-based communication to:

- “Demystify” the HIV treatment process;
- Help to link and engage newly diagnosed young MSM to care;
- Offer social support and resources to deal with stigma and fears of rejection;
- Provide guidance for navigating clinics; and
- Support contingency plans for overcoming barriers.

weCare is founded on the HHS Common HIV Indicators for Use in HIV Care Continuum: linkage to HIV medical care, retention in HIV medical care, ART prescription, ART adherence among persons in HIV medical care, and viral load suppression among persons in HIV medical care.

Intervention Description

Target Population

The weCare social media-based intervention is designed to improve care engagement and health outcomes (e.g., viral load suppression), among underserved, underinsured, and hard-to-reach racially and ethnically diverse YMSM and YTG women between the ages of 16 and 34, living with HIV. weCare is tailored to the social media preferences of each participant and personalized to each participant’s needs and context.

Intervention Functions

weCare is comprised of the following intervention functions:

Communication.

The CHE creates profiles on Facebook and commonly used apps, such as A4A/Radar, badoo, Grindr, Jack’d, and SCRUFF, which he uses for two-way communication with intervention participants about HIV care engagement once enrolled in the intervention. These profiles are designed to spark interest among participants, provide information about the intervention, and represent the CHE’s roles. All profiles are bilingual (English and Spanish).

weCare's secret Facebook group is interactive and bilingual and is optional to intervention participants. All aspects of this secret group are invisible to those who are not members, and only participants who are enrolled in the weCare intervention are invited to join and admitted in to the group if they choose.

To communicate with each participant, the CHE uses:

- A combination of Facebook messenger, texting, and app-based instant messages based on their preferences.
- Theory-based messages tailored to the specific context of the individual participant (e.g., age, time since diagnosis, and/or specific challenges with care) to assist in addressing their unique needs (e.g., communicating with providers, challenges with family, navigating healthcare coverage, and other sexual health education such as PrEP information for participants' sexual partners), as well as challenges and successes.

The CHE meets in person with the participants at delivery of their HIV diagnosis or during their clinic visit and enrolls them in the intervention. Even if the face-to-face interactions are limited, these initial interactions help with relationship development and trust building and lay the foundation for effective communication via social media.

Interpersonal connections are valuable for participant recruitment and retention and assist with improving health indicators. The participant knows who is on the other side of the social media communications and feels "connected".

Information.

The Cyber Health Educator provides information to participants about living with HIV and resources they can access.

The posts displayed in the secret Facebook group contain information related to sexual health, including:

- HIV care engagement (for example, graphics that illustrate the rates of MSM and TG women who are linked and retained in care and have suppressed viral loads);
- Brief facts about HIV, including short videos; and
- Low literacy articles and guides about living with HIV.

To avoid "fatigue" posts on other topics are included, such as those related to nutrition, physical exercise, finance management and others. Posts should be in English and Spanish to ensure that the intervention reaches Spanish-speaking Latino YMSM and YTG women.

Education.

Intervention participants sometimes have little knowledge of medical jargon related to HIV, and they may turn to the CHE for clarification. Examples include questions regarding the meaning of “CD4 count”, how the billing/insurance system works, and what to expect when attending one’s first clinical appointment after an HIV diagnosis. Also, the posts displayed in the secret Facebook group contain engaging and accessible information designed to educate and create awareness about the importance of staying in care.

Reminders.

The CHE is trained in and provided access to the electronic medical record system used by the clinic, in order to be able to remind participants about upcoming appointments and follow up after participants miss a scheduled appointment and assist with rescheduling. Example reminder messages include:

- *“Good morning Mark, how are U? R U enjoying the summer? Don’t forget ur appointment tomorrow.”*
- *“Hi Jim, I heard u missed ur appointment today. Are u ok? Please call the clinic to reschedule at ###-###-####, let me know ☺”*

If participants successfully attend their appointment, the CHE will also follow up and acknowledge them for making it to their appointment.

Participants are also reminded to ask their providers questions or clarify medical concerns and are encouraged to bring their questions ready to their appointment.

The CHE also reminds participants to fill their prescriptions for ART and to take it correctly and consistently. Example prescription reminder messages include: *“Good morning Mark, how are U? Don’t forget 2 pick-up ur prescription at the pharmacy, its ready today”*.

All reminder messages from the CHE are “live”, not automated.

Skills Building.

Lacking experience with clinics and healthcare providers may further complicate the ability of YMSM and YTG women to navigate the healthcare system, making their access and retention in HIV care challenging.

Youth and young adults may lack the skills necessary to negotiate clinical policies and procedures (e.g., appointment scheduling, payment, insurance, and residency/immigration documentation), especially within clinics without bilingual and bicultural services. Examples of messages to build these skills include:

- Participant: “Hey Eli, can u give me the number of the ADAP lady?” (ADAP=AIDS Drug Assistance Program).
- CHE: “Hi Mark, sure this is the ###-###-####. Please let me know if you can’t reach her.”
- Participant: “Hi Eli, can u give me clinic’s phone number? I need to reschedule my appointment”
- CHE: “Hi Mark, sure this is the number ###-###-####.”

Social support/networking.

Through their participation in the secret Facebook group, participants:

- Are provided a tool to connect, interact, and provide each other with social support;
- Ask the CHE questions related to their health; and
- Share posts about their lived experiences with HIV care and offer social support.

The CHE also:

- Posts informal and welcoming pictures and videos of clinic staff to increase the self-efficacy of participants to attend appointments and
- Offers participants support and resources to deal with stigma and fears of rejection, emphasizing to them that clinics are places where they can feel secure and not judged.

“Check-ins”.

The CHE often sends messages to participants to “check in” and offers support and resources using scripted theory-based messages that are adapted to meet participants’ needs and context.

Also, to be friendly, build further trust, and support retention, the CHE sends greetings on participants’ birthdays and on holidays such as New Year’s Eve and Thanksgiving.

Technology Platforms/Channels

Participants decide how they want to be contacted by the CHE for one-on-one interactions; they can choose one or multiple social media platforms and they can change how they want to be contacted over time.

The CHE, using all these social media platforms, responds to participant needs in a normal, non-judgmental fashion; his/her role is to listen and offer information and advice.

The CHE’s social media profiles should:

- Be created in collaboration with a steering committee that oversees and guides the intervention;
- Be designed to spark interest among intervention participants;

- Provide information about the intervention;
- Accurately represent the CHE's roles, including their affiliation with the intervention and purpose within Facebook;
- Have a "neutral" picture of the CHE, which must not be sexually suggestive.

Social media.

The CHE uses Facebook messenger to communicate with participants about HIV care engagement once enrolled in the intervention.

The CHE posts standardized theory-based conversation triggers on the intervention Facebook profile and changes these triggers 2-3 times a week.

Text messaging ("texting").

In addition to using Facebook and app-based instant messages to communicate with participants, the CHE also uses texting, including mobile phone-based messaging as well as texting apps such as Kik and Whatsapp. Texting, unlike Facebook and app platforms, does not allow for profiles, but it is a popular platform chosen by participants, probably because of its accessibility and quickness.

Social networking sites/apps.

weCare harnesses established GPS-based mobile apps that YMSM and YTG women commonly use for social and sexual networking. The Cyber Health Educator uses a variety of apps (e.g., A4A/Radar, badoo, Grindr, Jack'd, and SCRUFF) to communicate with participants. Apps should be selected from those commonly used in the catchment area. This is critical because different apps are preferred by users of different socio-demographic backgrounds and races/ethnicities, and the popularity of these social media platforms changes over time.

Implementation

Pre-Implementation Activities

Steering committee.

Implementation of this intervention should be guided by a steering committee that oversees the intervention in terms of:

- Using the most culturally congruent approach to delivery;
- Helping to create targeted and meaningful messages; and
- Creatively solving problems.

The steering committee should be comprised of:

- Members from the local catchment community, ethnically/racially diverse YMSM and YTG women (some of whom should be HIV positive);
- Representatives from different agencies that provide HIV testing or other HIV-related services; and
- Members of the project team.

Steering committee members can be identified through word-of-mouth and agencies that provide HIV services. The steering committee should meet with the intervention staff monthly for about two hours for the first 6 months and quarterly after that.

Facebook and app profiles.

Profiles for the CHE should be:

- Created in collaboration with the steering committee and provide information about the intervention and the CHE's roles.
- Created on Facebook and other app platforms that MSM and TG women commonly use.
- Used to communicate with participants about HIV care linkage and retention once enrolled in the intervention.
- Used to create and update the bilingual secret Facebook group where both the CHE and willing participants can post helpful information related to health outcomes and other topics relevant to MSM and transgender communities.

Logo.

An intervention logo should be developed in partnership with the steering committee. A recognizable logo to brand the intervention is key to participant recruitment and retention.

Recruitment and implementation space, office supplies, and tools.

The CHE should have:

- Office space in the clinic where they recruit participants during their visits and implement the social media intervention;
- A cell phone and/or tablet that supports Facebook, texting, and GPS-based mobile app use; and
- A computer with ready access to electronic medical records to prescreen to determine whether patients coming in for clinic visits meet eligibility criteria.

Marketing/social marketing.

The intervention should be marketed using:

- A brief colorful flyer with a description of the intervention and eligibility criteria and pictures of the CHE should be prepared and placed in places (e.g., health departments, LGBT centers, HIV service agencies, and testing sites).
- An adaptation of the project flyer should be developed and used as a sponsored post (ad) on Facebook. To make this type of post, an intervention-specific Facebook page must be created.
- Another version of the flyer can be published:
 - In the Volunteer sections of local Craigslist pages
 - In local LGBTQ newspapers

Outreach and recruitment.

Outreach and recruitment strategies should include:

- Collaboration with agencies that provide HIV services, such as Disease Intervention Specialists personnel who follow-up with persons with or exposed to HIV, can be useful in getting the word out about the intervention and recruiting participants.
- In order to reach participants throughout the catchment area, intervention staff may choose to advertise the intervention on the GPS-based mobile apps used in the intervention and encourage potential participants to communicate with the Cyber Health Educator.
- To recruit participants during their clinic visits, the CHE Educator prescreens patients coming in for clinic visits.
- When a patient who meets eligibility criteria (potential participant) arrives for their medical appointment, a nurse or patient navigator briefly introduces the project to them and asks them if they would like to speak with the Cyber Health Educator to get more details.
- To be contacted, the participant may choose one or more of social media platforms; this tailoring allows the CHE to meet the participants where they are.

Implementation Activities

Core Elements

The core elements of the intervention that should not be modified are:

1. Targets MSM and transgender women with HIV
2. Is implemented by a Cyber Health Educator who reflects the target population on at least one of these characteristics: age, sexual orientation/gender identity, and/or race ethnicity.
3. Allows participants to choose the social media platform they prefer (“tailoring”).
4. Is implemented in partnership with a clinic or community-based organization that provides services for people with HIV.
5. Uses personalized -not automated- approach.
6. Harnesses established apps that are commonly used by MSM and transgender women (rather than creating a new one).

Key Characteristics

The key characteristics of the intervention that can be adapted or modified are:

1. Targets MSM and transgender women ages 16-34.
2. Delivered in English and Spanish.
3. Uses a secret Facebook group to provide information about living with HIV.
4. Combines Facebook messenger, texting, and app-based instant messaging.
5. Uses face-to-face interactions between Cyber Health Educator and participants to establish rapport.

Enrollment Procedures/Protocol

- The CHE meets the potential participant, explains the project, and, if the potential participant agrees to participate, enrolls them.

- The CHE completes an enrollment form for each participant to record the participant’s demographic and contact information and the social media platform(s) that the participant selects to use as a mode of communication.
- An Intervention Exposure Form is used to record the interactions between the CHE and each participant, which includes the type of interaction (e.g. reminder to reschedule their appointment they canceled) and the number of messages exchanged with the CHE.

Role and Responsibilities of the Cyber Health Educator

Summarized, the roles and responsibilities of the Cyber Health Educator include:

- To interact with participants within the social media platforms;
- To establish rapport and start building trust with participants in-person and through social media;
- To be supportive to participants but not intrusive;
- To send messages to check in with participants to maintain contact; further build rapport; and assess and address potential barriers to linkage, retention and viral suppression (see example below);
- To offer support and resources to deal with stigma and fears of rejection;
- To remind participants to bring questions for their providers to their appointments
- To remind participants of upcoming appointments; and
- To follow-up immediately with participants who do not attend a scheduled clinical appointment (to check on them and encourage them) as well as with those who do attend their appointments (to acknowledge them for taking care of their health).

Some participants may not feel comfortable receiving messages that include words such as “clinic” or “medication”. The CHE should ask the participants at enrollment what word(s), if any, they would like not be included within the message(s) they send.

If the participant shares with the CHE an issue or a situation that the CHE perceives is urgent, the CHE should encourage the participant to call their provider. In the case that the participant shares a situation that is alarming or critical, the CHE should encourage the participant to contact the Emergency Room or dial 911 for help.

The CHE does not supplant the existing roles of those within the clinic, but complements the clinic’s staff work to bolster facilitators of linkage to and retention in care.

Partners

A CBPR approach was used to develop the weCare intervention to ensure that it was developed to be the most relevant, culturally congruent, and promising intervention, with the potential for sustainability for racially and ethnically diverse YMSM and YTG women, ages 16-34, living with HIV.¹³

The weCare team established partnerships comprised of:

- Community members representing racially and ethnically diverse YMSM and YTG women;
- Community-based organization representatives;

- Medical providers
- Clinic staff, including patient navigators; and
- Health department representatives.

These partners help to ensure that the weCare intervention is based in ongoing service delivery and the real-world lived experiences of community members.

The CHE should work closely with the clinic medical providers and staff to thoroughly understand the process of accessing HIV care clinical services within the clinic and the potential barriers faced by racially and ethnically diverse YMSM and YTG women.

Staffing Roles

Project Director: Responsible for all aspects of the project, including intervention implementation and evaluation; budget and fiscal oversight; and recruitment and retention benchmarks.

Evaluator: Responsible for implementation of evaluation activities for the project, including development of data collection instruments and systems, and coordination of analysis and interpretation of process and outcome data.

Cyber Health Educator: Responsible for identifying and recruiting participants, and implementing the intervention according to the protocol.

Data Manager: Responsible for training data collectors, managing and reporting data, and coordinating the cleaning and storage of evaluation data.

Data Analyst: Responsible for planning and executing statistical analyses, providing statistical guidance on recruitment and data collection processes, and writing up and reporting results of statistical analyses.

Key Staff Attributes

Project Director: Experience in HIV prevention and care interventions conducted in partnership with vulnerable populations, including self-identified gay and bisexual men and other MSM; transgender persons; African American/black and Latino communities; and persons living with HIV.

Evaluator: Experience in public health evaluation; program management; social media technology; and data collection (using mixed methods), analysis, and interpretation.

Cyber Health Educator: Experience in health education related to HIV prevention and care with racial and ethnic minority communities including African American/black and Latino, and MSM and transgender communities.

Data Manager: Experience in community-based data collection, data cleaning, and dataset preparation.

Data Analyst: Experience in public health evaluation and statistical analysis, including longitudinal, behavioral, and intervention research.

Resources

[HRSA: Social Media and E-Learning](#)

[Grindr](#)

[Scruff](#)

[adam4adam](#)

[badoo](#)

[Jack'D](#)

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