

# A review of social media technologies across the global HIV care continuum

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HIV remains one of the main health global threats of the 21st century. There is a great need to reach HIV at-risk and HIV+ populations across the HIV care continuum to improve HIV prevention, testing, and treatment. New technologies, such as social media (SM) and social networking sites (SNS) have shown early promise in HIV research studies. To assess the state of research on the use of SM/SNSs across the HIV continuum, we conducted a systematic literature review on HIV-related research using SM during the last 10 years. A total of 44 papers were identified, of which 17 (38.6%) were classified as intervention studies and 19 (61.3%) as observational. The focus areas of the studies were evenly distributed between outreach/recruitment ( $n = 15$ , 34.1%), surveillance/observation ( $n = 13$ , 29.5%) and prevention/treatment ( $n = 16$ , 36.4%). Researchers engaged the community through Facebook ( $n = 26$ , 59.1%), multiple-platforms ( $n = 13$ , 29.5%), or one of several geo-social networking sites ( $n = 10$ , 22.7%). Studies primarily targeted MSM ( $n = 24$ , 54.5%) and youth ( $n = 13$ , 29.5%) with little research focused on HIV+ populations ( $n = 5$ , 11.4%). The current state of the field, trends, and limitations of this work are discussed.

## Addresses

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## Introduction

Well into its fourth decade, the HIV epidemic remains a major global public health challenge. To date, HIV has impacted more than 78 million people [1]. In 2013, it was estimated that 2.1 million people were newly infected

with HIV [2], and 35 million people were living with HIV worldwide [3]. Many countries are now struggling with concentrated HIV epidemics among several subpopulations. Some of the most affected sub-populations include men who have sex with men (MSM), male and female sex workers, injecting drug users, youth (aged 15–24), and women [4–8].

One of the key barriers in HIV prevention, treatment, care, and support is HIV-related stigma [9–13]. HIV related stigma is characterized by negative attitudes and behaviors that discourage people from accessing HIV-related information and services. This leads to individuals who are unaware of their HIV status, not in treatment, and continuing to engage in high-risk behaviors that sustain the epidemic. This is particularly salient among the subpopulations at high-risk of HIV as they are often ostracized by society [14–17]. For example, homosexuality remains criminalized in many countries, and public health programs often have difficulties reaching MSM under homophobia and HIV-related stigma and discrimination. One method to increase the chance of success for an intervention is to adapt and modify the intervention to meet the local environment [18,19]. Innovative strategies and technologies that can bypass traditional social structures to reach populations at high-risk of HIV are also needed.

## Social media and public health

Social media (SM)/social networking sites (SNS) use has increased tremendously in the past decade, and these technologies have emerged as potential platforms to access hard-to-reach populations [20,21,22\*,23\*]. Social media refers to social networking sites that offer different functionalities, such as private messaging and multimedia content sharing among many others [24]. SM is characterized by its user-generated content and many-to-many communication style. Users create a profile that often includes a list of identifying information, such as their personal names, photographs, birthday, religion, political views, and hobbies. Unlike traditional websites, users can then create and share information and multimedia content with their friends or be connected with others with similar background and interests.

SM use is extremely popular, with an estimated that 73% and 80% of the US adult and teen internet users using some form of SM [25,26]. Additionally, a recent trend

shift has occurred such that many emerging countries have a greater percentage of SM users compared to developed countries [27]. Facebook is the most popular SNS worldwide, with approximately 968 million computer users and 844 million mobile users [28]. With the popularity and the convenience of accessing social media, these sites offer the potential for public health to reach a large number of individuals at-risk of and living with HIV/AIDS.

A number of public health researchers and practitioners have started exploring the potential of using online social networks and online communities to deliver health information and services [29–31]. An important discovery from this work is that SM is especially suited for disseminating information on sensitive topics (e.g. sexual risk) and stigmatized diseases such as HIV/AIDS. The freedom to access information and services at any time/location, along with a degree of anonymity, allows some of the stigma and discrimination associated with the disease to be avoided. However, there is some concern that a preference still exists to obtain sexual health information in-person with a doctor or from a website, versus from SM [32\*]. In addition, social influence is a primary facilitator in behavioral change, and researchers have been able to use SM to establish online communities rapidly and facilitate communication about sexual health and HIV prevention behavior with high-risk populations.

The potential implications of using SM in combating the global HIV pandemic are tremendous, especially given the ability for SM to address the global HIV care continuum (prevention, testing, care, adherence, retention, and treatment) [33]. However, to date, only a small number of studies have examined the cross section between online social networks and HIV. Therefore, in this paper, we seek to review the current state of how SM has been used to improve the global HIV care continuum.

## Methods

### Selection criteria and data

We searched PubMed, PsycInfo, and Google Scholar with the following combination of keywords HIV, AIDS, social media, and social networking sites. Due to the large number of results, we reviewed the first 500 listed articles in the 10 years leading up to July 1, 2015. For this review, SM-based HIV research was defined as studies that explore how to use SM/SNS as the primary or sole medium to deliver HIV-related intervention content. We included studies that utilized existing SNSs (e.g. Facebook, Twitter, and YouTube) and studies that created their own websites with social networking components. We excluded text-based studies and Internet-delivered or smart phone-based studies that did not have any social networking features.

Inclusion criteria for this review included studies that:

- (1) Reported progress, pilot/feasibility testing, or randomized controlled trials (RCT) results for HIV-related programs across the HIV continuum.
- (2) Published in peer-reviewed journals.
- (3) Published in previous 10 years.
- (4) Published in English.

Because of the breadth of the types of studies conducted, papers were broken down according to two different frameworks. One method broke studies down by three different types of HIV-related research: studies on recruitment/outreach, prevention/treatment, or surveillance/observation. Recruitment/outreach studies either investigated the feasibility of using SM or SNSs to recruit target populations or actually recruited participants using SM or SNSs. Prevention/treatment studies investigated methods to encourage and promote safer sex/HIV prevention behavior or different methods of care for HIV+ populations. Surveillance/observational studies reported HIV rates, sexual risk behaviors, or substance use among participants recruited from social media. Studies were able to be classified as more than one topic, if applicable.

The second classification method distinguished between intervention and nonintervention (i.e. observational) studies. An intervention was defined as one of the above papers that introduced some form of online treatment on a subject group over a period of time. After a paper was identified as an intervention, it was then categorized according to the components used in the intervention itself. The following is a list of the 10 different types of interventions in the literature:

- (1) Peer-leader — interventions that utilized peer leaders to disseminate information.
- (2) Informational posts — study teams update and post information/messages to SM profiles periodically.
- (3) Blog-based — interventions that deliver information through a blog format website.
- (4) Webisodes — study teams develop a series of informational videos and distribute them online.
- (5) Partner notification — study teams contact sexual partners of individuals who have tested HIV positive via SM.
- (6) Live chat — study teams communicate with participants solely using chat/message function on SNSs.
- (7) Expert-led — medical experts created SM profiles to engage participants.
- (8) Passive recruitment — study staff creates SM profile for a health worker and leaves it up to the users to initiate contact.
- (9) Online support group — researchers create SM support groups for participants.

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