



Published in final edited form as:

*Curr Opin Psychol.* 2016 June 1; 9: 56–66. doi:10.1016/j.copsyc.2015.10.024.

## A Review of Social Media Technologies Across the Global HIV Care Continuum

Renee Garrett, MS, LCSW<sup>1</sup>, Justin Smith, MS<sup>2,3</sup>, and Sean D. Young, PhD, MS<sup>2,3</sup>

<sup>1</sup>ElevateU, Los Angeles, CA, USA

<sup>2</sup>University of California Institute for Prediction Technology, Department of Family Medicine, University of California, Los Angeles, Los Angeles, CA, USA

<sup>3</sup>UCLA Center for Digital Behavior, Department of Family Medicine, University of California, Los Angeles, Los Angeles, CA, USA

### Abstract

HIV remains one of the main health global threats of the 21<sup>st</sup> 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 was evenly distributed between outreach 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.

### 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

Address Correspondence to: Sean Young, UC Institute for Prediction Technology, Department of Family Medicine, 10880 Wilshire Blvd, Suite 1800, Los Angeles, CA 90024, Sdyoung@mednet.ucla.edu.

**Publisher's Disclaimer:** This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

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, vs. 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.
10. Forum Based - experts create an online forum where users of SM can access health and sex information.

## RESULTS

After reviewing the articles and classifying the papers, the following information was extracted for all papers (Table 1):

- 1) Title
- 2) First Author/Publication Year
- 3) Platform(s) used in the study (ex: Facebook, Myspace, or Twitter)
- 4) Location
- 5) Target population
- 6) Number of participants
- 7) Focus of the research (e.g., recruitment/outreach, prevention, prediction, and surveillance))

A total of 44 unique studies met inclusion criteria and were reviewed. Based on the first classification method on the type of HIV research, the papers were classified as follows: outreach/recruitment (n=15, 34.1%), prevention/treatment (n=16, 36.4%), and surveillance/observation (n=13, 29.5%). All studies were published between 2011 and 2015, with the majority (n=23, 52.3%) being published in 2014/15. Most studies took place in developed countries, particularly in North America and Europe (n=34, 77.3%).

Looking at the use of SM platforms throughout both tables 1 and 2, 26 studies (59.1%) used Facebook, 3 (6.8%) used MySpace, 10 (22.7%) used geo-social networking sites (GSN), and 13 (29.5%) used several different platforms. From 2011 to 2014, there was a steady increase in the number of studies that were based on Facebook. The most common populations were MSM (n=24, 54.5%) and youth (n=13, 29.5%).

The second framework used in the paper was to classify papers as either intervention or nonintervention (Table 2). For intervention papers, we added the following columns of information:

- 8) Type of Intervention – One of the 10 types of interventions discussed above.
- 9) Length of Study – The period of time subjects were observed.
- 10) If there was a control group–If the study utilized a comparison group.

Out of the 44 papers, a total of 17 were classified as intervention studies. Peer leader based (n=5, 29.1%) and informational posts (n=4, 23.5%) were the most popular forms of intervention. The other eight types of interventions were only witnessed once each. The average length of a study was 7–8 months with 9 studies being 6 months or less (53%). Finally, 9 (52.9%) of the studies did not use a control group, 1 (5.9%) used a non-equivalent control, and 7 (41.2%) used an equivalent control group.

As compared to non-intervention studies, the intervention papers preferred to use Facebook over sexual/geo-social networking sites. In total, 76.5% of intervention studies used Facebook and 5.9% used a GSN, as compared to 48.1% and 33.3% respectively for non-intervention papers. Other platforms include independent websites (n=2, 11.7%), YouTube (n=2, 11.7%), independent blog (n=1, 5.9%), Bebo (n=1, 5.9%), High5 (n=1, 5.9%), Flickr (n=1, 5.9%), and Twitter (n=1, 5.9%).

SM-based interventions included in the review targeted several different sub-populations at high-risk of HIV: MSM (n=9, 52.9%), youth (n=5, 29.4%), and patients of sexual health clinics (n=2, 11.8%). Most studies focused on delivering HIV-related knowledge via social media (n=8, 47%). However, some studies sought to modify HIV testing (n=5, 29.4%), raise online awareness (n=4, 23.6%), and increase condom use (n=3, 17.6%). Of note is that most intervention-focused studies focused on primary prevention with participants that are at-risk of HIV (n=15, 88.2%). Only two studies focused on people living with HIV or AIDS.

## DISCUSSION

The use of online SM for HIV prevention/care is as potentially useful as it is new. The growth of papers on this topic is reflective of this, with over 50% of the reviewed papers being published in 2014/2015 alone. The range of interventions reflects both the novelty and the possibilities of this topic. Out of 17 papers which had an intervention, 10 separate types of intervention were identified. The most common types of intervention were peer-leader based and informational posts, but even among these papers the specifics of the intervention and the online platforms used were highly variant. Some studies even attempted several

different interventions at once, such as text-based and internet-based notification for intimate-partners[34\*].

There is an increasing amount of research applying either peer-leader or informational post methods to SM/SNSs. The science behind peer-leader based models in offline settings has been established, and much of the work in the current studies applied this method to an online setting. Many of these studies are thus exploratory, focusing more on the frequency of SM-use among different populations and the challenges with online recruitment[35\*]. Importantly, three out of the four peer-leader interventions found some degree of positive impact, a finding in support of the peer leader model[36\*]. The appeal of the informational post intervention was related to the low cost of using these online platforms to access large populations. However, the results from studies that use informational posts are mixed, with no positive findings in any of the interventions.

The most consistent theme throughout all of the 44 papers was the emphasis on either outreach/recruitment or prevention. Little work was focused on HIV+ populations. In fact, only two of the intervention papers focused on HIV+ populations. The lack of studies on HIV+ populations suggests a significant gap in the research. An additional point of note is that the target population was overwhelmingly focused on MSM or subpopulations of MSM. Few studies were focused on other high-risk populations such as IDUs, sex workers, and women. This finding is consistent with Park et al., 2013, who found minimal research on the use of SNS targeting youth/young adults [37]. It is important to include research on the broader populations affected by HIV, as each subgroup has their own unique cultural and social issues that might respond to programs, platforms, and interventions in different and unexpected ways. This raises issues of external validity with the literature, a concern also found in the fact that 77% (n=34) of the target populations came from either North America or Europe.

Online social platforms and media are constantly and rapidly evolving. Observing the frequency of platforms used throughout the research, over half of the studies (n=26) used Facebook and nearly a quarter (n=10) used one of several geo-social/sexual networking apps. This reflects the popularity of Facebook, given that there are now nearly 1 billion users, and the relevancy of the sexual and geo-social networking apps to the target populations [28]. Evidence in support of the relevancy of the GSNs is found in one interesting study from Phillips, et al. (2014), where it was found that 64% of MSMs use GSNs, and of these 58.9% use the GSNs to find a sexual partner [38\*\*]. However, research might not be keeping up with online developments, as only five studies used Twitter and one used Instagram. One of the studies exemplifying the possibilities of these under-researched websites comes from Young, et al (2014) where over 500 million tweets were used to show the geographic relationship between HIV related Tweets and actual HIV health data [39\*\*]. There is a general need for more formative research to assess whether the platforms involved in this field have been appropriate. There is a lack of research showing the relevancy of these platforms to the target platforms in regards to HIV and sexual health/behavior.

According to Yonker, et al., (2015) who wrote a systematic review of the literature on social media in adolescent and young adult health care, only 12 out of 87 relevant papers (14%) were intervention studies while the remaining were observational studies [40]. Our analysis confirmed this preference for observational studies, but not at such a dramatic rate. Another point of note is the need for more rigorous research methods: only 7 out of the 17 interventions used an equivalent control group (if this were used as an inclusion criteria, then the findings mimic those from Yonker, et al, with only 16% of the 44 papers being an intervention). Additionally, the majority of interventions were 6 months or less, meaning that there is limited measurement of long term effects. This is of note especially considering the Bull, et al. (2012) paper which found that the positive effects shown at 2 months-post intervention to be non-existent at 6 months [41]. A considerable need exists in this field to expand from the exploratory phase and move into rigorous research methods that explore long-term effects.

This study has limitations. One limitation of the current study is that it is not a meta-analysis and the effectiveness of the SM interventions were therefore not statistically evaluated. Additionally, only published papers were included in the study, conference abstracts and presentations were not included due to lack of inclusion in the database search results. It is therefore possible that this study could have missed some studies and other ongoing research. Future research on this topic can include ongoing research papers on this growing topic.

## Conclusion

Social Media is immensely popular and is increasingly being used a tool in HIV research. The potential benefits from research on SM in this field are important for both the target populations and for the research community. Even with the increased number of research studies in this area, the use of SM to address issues along the HIV care continuum remains an under-researched topic, especially in regards to the various different combinations of SM platforms and interventions. There is an even greater need for statistically rigorous studies on efficacy, effectiveness, and long term effects. Finally, there are numerous subpopulations, both in the US and around the world that have not been accounted for or studied in this research. Of considerable importance is the lack of research into HIV+ community. Future research can help to address this need and improve the body of research in this rapidly growing field.

## Acknowledgments

The authors wish to thank Jason Chiu and Mika Wang for feedback and assistance on previous versions of this manuscript. The authors thank the NIMH for funding this study.

## References

1. [accessed July 31, 2015] The US Government & Global Emerging Infectious Disease Preparedness and Response. n.d. <http://kff.org/global-health-policy/fact-sheet/the-u-s-government-global-emerging-infectious-disease-preparedness-and-response/>
2. [accessed July 31, 2015] Global Health Observatory (GHO) Data - HIV/AIDS, WHO. n.d. <http://www.who.int/gho/hiv/en/>

3. [accessed July 31, 2015] UNAIDS Global Statistics HIV. n.d. <http://www.unaids.org/en/resources/campaigns/2014/2014gapreport/factsheet>
4. Baral S, Sifakis F, Cleghorn F, Beyrer C. Elevated Risk for HIV Infection among Men Who Have Sex with Men in Low- and Middle-Income Countries 2000–2006: A Systematic Review. *PLOS Med.* 2007; 4:e339.10.1371/journal.pmed.0040339 [PubMed: 18052602]
5. Mathers BM, Degenhardt L, Phillips B, Wiessing L, Hickman M, Strathdee SA, et al. Global epidemiology of injecting drug use and HIV among people who inject drugs: a systematic review. *Lancet Lond Engl.* 2008; 372:1733–1745.10.1016/S0140-6736(08)61311-2
6. UNAIDS Factsheet: Women, Girls, Gender Equality, and HIV. 2010. [http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/factsheet/2012/20120217\\_FS\\_WomenGirls\\_en.pdf](http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/factsheet/2012/20120217_FS_WomenGirls_en.pdf)
7. [accessed July 31, 2015] The Global HIV/AIDS Epidemic, Henry J Kais Fam Found. n.d. <http://kff.org/global-health-policy/fact-sheet/the-global-hiv-aids-epidemic/>
8. Baral S, Beyrer C, Muessig K, Poteat T, Wirtz AL, Decker MR, et al. Burden of HIV among female sex workers in low-income and middle-income countries: a systematic review and meta-analysis. *Lancet Infect Dis.* 2012; 12:538–549.10.1016/S1473-3099(12)70066-X [PubMed: 22424777]
9. Doherty T, Chopra M, Nkonki L, Jackson D, Greiner T. Effect of the HIV epidemic on infant feeding in South Africa: “When they see me coming with the tins they laugh at me”. *Bull World Health Organ.* 2006; 84:90–96.10.1590/S0042-96862006000200008 [PubMed: 16501725]
10. Kalichman SC, Simbayi LC. HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sex Transm Infect.* 2003; 79:442–447.10.1136/sti.79.6.442 [PubMed: 14663117]
11. Campbell, C.; Maimane, S.; Sibiyi, Z. Understanding and Challenging HIV/AIDS Stigma. 2005.
12. Nyblade, Laura; Field-Nguer, Mary Lyn. [accessed July 31, 2015] Women, Communities, and the Prevention of Mother-to-Child Transmission of HIV: Issues and Findings from Community Research in Botswana and Zambia. 2001. <http://www.icrw.org/publications/women-communities-and-prevention-mother-child-transmission-hiv-issues-and-findings-comm>
13. Bond V, Chase E, Aggleton P. Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia. *Eval Program Plann.* 2002; 25:347–356.10.1016/S0149-7189(02)00046-0
14. Alder SC, Simonsen SE, Duncan M, Shaver J, DeWitt J, Crookston B. Perspectives on Efforts to Address HIV/AIDS of Religious Clergy Serving African American and Hispanic Communities in Utah. *Open AIDS J.* 2007; 1:1–4.10.2174/1874613600701010001 [PubMed: 18923690]
15. DiClemente RJ, Sales JM, Borek N. Barriers to Adolescents’ Participation in HIV Biomedical Prevention Research. *J Acquir Immune Defic Syndr* 1999. 2010; 54:S12–S17.10.1097/QAI.0b013e3181e1e2c0
16. Chakrapani V, Newman PA, Shunmugam M, Kurian AK, Dubrow R. Barriers to Free Antiretroviral Treatment Access for Female Sex Workers in Chennai, India. *AIDS Patient Care STDs.* 2009; 23:973–980.10.1089/apc.2009.0035 [PubMed: 19821725]
17. Feng Y, Wu Z, Detels R. Evolution of MSM community and experienced stigma among MSM in Chengdu, China. *J Acquir Immune Defic Syndr* 1999. 2010; 53:S98–103.10.1097/QAI.0b013e3181c7df71
18. Weiss MG, Ramakrishna J, Somma D. Health-related stigma: Rethinking concepts and interventions. *Psychol Health Med.* 2006; 11:277–287.10.1080/13548500600595053 [PubMed: 17130065]
19. Ogden, J.; Nyblade, L. Common at its core: HIV and AIDS-related stigma across contexts. n.d.
20. Levine D, Madsen A, Wright E, Barar RE, Santelli J, Bull S. Formative Research on MySpace: Online Methods to Engage Hard-to-Reach Populations. *J Health Commun.* 2011; 16:448–454.10.1080/10810730.2010.546486 [PubMed: 21391040]
21. Ramo DE, Prochaska JJ. Broad Reach and Targeted Recruitment Using Facebook for an Online Survey of Young Adult Substance Use. *J Med Internet Res.* 2012; 14:e28.10.2196/jmir.1878 [PubMed: 22360969]
22. LeGrand S, Muessig KE, Pike EC, Baltierra N, Hightow-Weidman LB. If you build it will they come? Addressing social isolation within a technology-based HIV intervention for young black men who have sex with men. *AIDS Care.* 2014; 26:1194–1200. Several focus group discussions



were undertaken with 22 young black MSMs (22–30 years old). Discussions focused on social isolation and lack of support from both racism and homophobia. Study participants were receptive to the use of SNS to reduce social isolation and build a community.  
10.1080/09540121.2014.894608 [PubMed: 24617609]

23. Hightow-Weidman LB, Muessig KE, Pike EC, LeGrand S, Baltierra N, Rucker AJ, et al. HealthMpowerment.org: Building Community Through a Mobile-Optimized, Online Health Promotion Intervention. *Health Educ Behav Off Publ Soc Public Health Educ.* 2015  
HealthMpowerment is a mobile app/online intervention meant to build communities and supportive relationships within young black MSMs and young black transgender woman (YBMSM/TW). Study was a 1-month trial with 15 participants. Significant improvement was evidenced in social support, social isolation, and depression. 10.1177/1090198114562043
24. Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of Social Media. *Bus Horiz.* 2010; 53:59–68.10.1016/j.bushor.2009.09.003
25. Duggan, M.; Ellison, NB. [accessed July 31, 2015] Cliff Lampe, a Lenhart, Social Media Update 2014. Pew Res Cent Internet Sci Tech. n.d. <http://www.pewinternet.org/2015/01/09/social-media-update-2014/>
26. [accessed July 31, 2015] Teens Fact Sheet. Pew Res Cent Internet Sci Tech. n.d. <http://www.pewinternet.org/fact-sheets/teens-fact-sheet/>
27. [accessed July 31, 2015] Online Activities in Emerging and Developing Nations. Pew Res Cent Glob Attitudes Proj. n.d. <http://www.pewglobal.org/2015/03/19/2-online-activities-in-emerging-and-developing-nations/>
28. [accessed July 31, 2015] Company Info | Facebook Newsroom. n.d. <http://newsroom.fb.com/company-info/>
29. Muessig KE, Nekkanti M, Bauermeister J, Bull S, Hightow-Weidman LB. A Systematic Review of Recent Smartphone, Internet and Web 2.0 Interventions to Address the HIV Continuum of Care. *Curr HIV/AIDS Rep.* 2015; 12:173–190.10.1007/s11904-014-0239-3 [PubMed: 25626718]
30. Ventola CL. Social Media and Health Care Professionals: Benefits, Risks, and Best Practices. *Pharm Ther.* 2014; 39:491–520.
31. The Health Communicator's Social Media Toolkit. 2011
32. Lim MS, Vella A, Sacks-Davis R, Hellard ME. Young people's comfort receiving sexual health information via social media and other sources. *Int J STD AIDS.* 2014; 25:1003–1008. Authors conducted a survey with 620 young people (16–29 years old) about social media and their comfort with receiving sexual health information via social media. Most participants reported being comfortable or very comfortable accessing sexual health information from websites (85%), followed by a doctor (81%), school (73%), and the mainstream media (67%). Fewer reported being comfortable getting information from social media: Facebook (52%), apps (51%), SMS (44%), and Twitter (36%). 10.1177/0956462414527264 [PubMed: 24616114]
33. Mugavero MJ, Norton WE, Saag MS. Health Care System and Policy Factors Influencing Engagement in HIV Medical Care: Piecing Together the Fragments of a Fractured Health Care Delivery System. *Clin Infect Dis Off Publ Infect Dis Soc Am.* 2011; 52:S238–S246.10.1093/cid/ciq048
34. Udeagu C-CN, Bocour A, Shah S, Ramos Y, Gutierrez R, Shepard CW. Bringing HIV partner services into the age of social media and mobile connectivity. *Sex Transm Dis.* 2014; 41:631–636. Authors compared three different forms of notification to partners of patients who recently tested positive for STI: traditional notification, text-based notification, and internet notification. Contact rate most successful with Text (77%), followed by traditional (69%) and internet (41%). Higher likelihood that people contacted over internet and text were notified as compared to traditional. However, traditionally notified partners were most likely to ultimately test for HIV (69%) as compared to text (45%) and internet (34%). 10% of those who were contacted over the internet and underwent an HIV test were positive for HIV. [PubMed: 25211262]
35. Hernandez-Romieu AC, Sullivan PS, Sanchez TH, Kelley CF, Peterson JL, del Rio C, et al. The Comparability of Men Who Have Sex With Men Recruited From Venue-Time-Space Sampling and Facebook: A Cohort Study. *JMIR Res Protoc.* 2014; 3 The authors compared MSM recruited through venue-based, time-space sampling (VBTS) with Facebook-based recruitment. Facebook recruits were older, had more sexual partners, engaged in more frequent unprotected anal

intercourse, and had similar retention pattern after 24 months between the two groups. 10.2196/resprot.3342

36. Young SD, Cumberland WG, Lee S-J, Jaganath D, Szekeres G, Coates T. Social networking technologies as an emerging tool for HIV prevention: a cluster randomized trial. *Ann Intern Med.* 2013; 159:318–324. Authors investigated whether SNS communities could increase HIV testing among African American and Latino MSM. This randomized control trial (RCT) consisted of 112 MSM randomized across 16 peer leaders within online, Facebook groups over a 12-week period. 95% of treatment and 73% of control used the online platform. 44% of treatment (n=25) requested an HIV test kit, with 36% (n=9) of those ultimately mailing the test kit for a test. This was compared to 20% (n=11) of the control requesting a kit, and 18% (n=2) ultimately mailing the kit. 10.7326/0003-4819-159-5-201309030-00005 [PubMed: 24026317]
37. Park BK, Calamaro C. A Systematic Review of Social Networking Sites: Innovative Platforms for Health Research Targeting Adolescents and Young Adults. *J Nurs Scholarsh.* 2013; 45:256–264.10.1111/jnu.12032 [PubMed: 23676115]
38. Phillips G, Magnus M, Kuo I, Rawls A, Peterson J, Jia Y, et al. Use of geosocial networking (GSN) mobile phone applications to find men for sex by men who have sex with men (MSM) in Washington, DC. *AIDS Behav.* 2014; 18:1630–1637. This was the first study to compare GSN use and sex-seeking behaviors. 63.6% of MSM in study have used GSN to find other men in the last year, of this group 58.9% have looked for sexual partners. Users of GSN are more likely to identify as homosexual, undergo HIV testing, have depressive symptoms, and belief that their last sexual partner was engaging in concurrent partnerships. 10.1007/s10461-014-0760-9 [PubMed: 24682866]
39. Young SD, Rivers C, Lewis B. Methods of using real-time social media technologies for detection and remote monitoring of HIV outcomes. *Prev Med.* 2014; 63:112–115. Over 550 million tweets filtered based on HIV keywords, 9800 geo-located tweets extracted. Significant relationship established between HIV-related tweets and HIV cases. 10.1016/j.ypmed.2014.01.024 [PubMed: 24513169]
40. Yonker L, Zan S, Scirica C, Jethwani K, Kinane TB. “Friending” teens: systematic review of social media in adolescent and young adult health care. *J Med Internet Res.* 2014; 17(1):e4–e4. [PubMed: 25560751]
41. Bull SS, Levine DK, Black SR, Schmiede SJ, Santelli J. Social Media–Delivered Sexual Health Intervention: A Cluster Randomized Controlled Trial. *Am J Prev Med.* 2012; 43:467–474.10.1016/j.amepre.2012.07.022 [PubMed: 23079168]

### Highlights

- Most studies in this area were observational.
- The focus areas of the studies was evenly distributed between outreach outreach/recruitment (n=15, 34.1%), surveillance/observation (n=13, 29.5%) and prevention/treatment (n=16, 36.4%).
- Researchers used 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 men who have sex with men (MSM) (n=24, 54.5%) and youth (n=13, 29.5%) with little research focused on HIV+ populations (n=5, 11.4%).

Table 1

## Non-Intervention Social Media/HIV Studies, 2011–2015.

Title	First Author/Year	Platform	Location	Target	Number of participants	Focus of Research
Drama and danger: the opportunities and challenges of promoting youth sexual health through online social networks.	Venot, 2011	Focus groups - NOT online	USA	Youth	94	Outreach/Recruitment, and Surveillance/Observation
Finding Teens in TheirSpace: Using Social Networking Sites to Connect Youth to Sexual Health Services	Ralph, 2011	MySpace	USA (CA)	Youth	993	Outreach/Recruitment
Adolescents' Views Regarding Uses of Social Networking Websites and Text Messaging for Adolescent Sexual Health Education	Selkie, 2011	Offline recruitment	USA (MN)	Youth	29	Outreach/Recruitment
Twisting about testing: do low-income, parenting adolescents and young adults use new media technologies to communicate about sexual health?	Divecha, 2012	Facebook LinkedIn, MySpace, Twitter, multiple GSNs.	USA (CT)	Youth	94	Outreach/Recruitment
Use of the Location-Based Social Networking Application GRINDR as a Recruitment Tool in Rectal Microbicide Development Research	Burrell, 2012	Grindr	USA (CA)	MSM	137	Outreach/Recruitment
Epidemiology, Sexual Risk Behavior, and HIV Prevention Practices of Men who Have Sex with Men Using GRINDR in Los Angeles, California	Landovitz, 2012	Grindr	USA (LA)	Youth, MSM	375	Outreach/Recruitment
Never testing for HIV* among men who have sex with men recruited from a sexual networking website, United States.	Margolis, 2012	Sexual networking sites	USA	MSM	8,040	Surveillance/Observation
Technology use and reasons to participate in social networking health websites among people living with HIV in the US.	Horvath, 2012	Facebook, LinkedIn, Bebo, TheBody, MySpace, Poz, Xanga	USA (MN)	HIV-positive	312 surveys, 22 focus group members	Outreach/Recruitment
Putting prevention in their pockets: developing mobile phone-based HIV interventions for black men who have sex with men.	Muessig, 2013	Social media (online journals) and focus groups	USA (CT)	Black MSM	22	Surveillance and Outreach/Recruitment
Young people's comfort receiving sexual health information via social media and other sources.	Lim, 2014	Comparison of social networks vs. doctor vs. other	USA	Youth	620	Outreach/Recruitment
Still is Hard to Reach Population? Using Social Media to Recruit Latino Gay Couples for an HIV Intervention Adaptation Study	Martinez, 2014	Craigslist, Facebook, Jack'd, Grindr, Twitter, Instagram, SCRUFF	USA (NYC)	MSM	14 couples (28 individuals)	Outreach/Recruitment
The comparability of men who have sex with men recruited from venue-time-space sampling and facebook: a cohort study	Hernandez-Romieu, 2014	Facebook	USA (GA)	MSM	110 from Facebook, 693 from offline	Outreach/Recruitment
Using Online Social Media for Recruitment of Human Immunodeficiency Virus-Positive Participants: A Cross-Sectional Survey	Yuan, 2014	Facebook, Twitter, LinkedIn, Craigslist, and Tumblr	USA (CA)	HIV-positive	1221	Outreach/Recruitment
If you build it will they come? Addressing social isolation within a technology-based HIV intervention for young black men who have sex with men.	LeGrand, 2014	Focus groups - NOT online	USA (NC)	Young black MSM	22	Outreach/Recruitment
Use of Geosocial Networking (GSN) Mobile Phone Applications to Find Men for Sex by Men Who Have Sex with Men (MSM) in Washington, DC	Phillips II, 2014	Geo-social networking apps (Grindr/Encounter)	USA (DC)	MSM	379	Outreach/Recruitment
Sexual risk behavior, alcohol use, and social media use among secondary school students in informal settlements in Cape Town and Port Elizabeth, South Africa	Kaufman, 2014	Offline recruitment	South Africa	Youth	4,485 secondary school students	Outreach/Recruitment
Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering	Mo, 2014	Online bulletin board	Hong Kong	HIV-positive	115	Prevention/Treatment

Title	First Author/Year	Platform	Location	Target	Number of participants	Focus of Research
processes of participation within HIV/AIDS-related online support groups						
Epidemiology of sexual health in the virtual environment: A multinational online survey of Spanish- and Portuguese-speaking men who use an internet sexual networking site.	Bello, 2014	Sexual networking sites	Latin America, Spain, Portugal	Spanish and Portuguese speaking MSM from latin America	36,063	Surveillance/Observation
Methods of using real-time social media technologies for detection and remote monitoring of HIV outcomes	Young, 2014	Twitter	USA	General public	553,186,061 tweets	Surveillance/Observation
Sexual risk and HIV prevention behaviors among African-American and Latino MSM social networking users.	Chiu, 2014				118 Participants	
A social-media based HIV prevention intervention using peer leaders.					15 Peer Leaders	
Stimulant use among African American and Latino MSM social networking users.					118 Participants	Surveillance/Observation
The relationship between online social networking and sexual risk behaviors among men who have sex with men (MSM).	Young, 2013	Offline/Online Recruitment	USA(LA)	MSM	118 Participants	
Sexual risk and HIV prevention behaviors among African-American and Latino MSM social networking users.					118 Participants	
Social media technologies for HIV prevention study retention among minority men who have sex with men (MSM).	Young, 2014	Offline/Online Recruitment	USA(LA)	MSM	118 Participants	Surveillance/Observation
Methods for measuring diffusion of a social media-based health intervention.	Young, 2015					
Feasibility of Recruiting Peer Educators to Promote HIV Testing Using Facebook Among Men Who have Sex with Men in Peru	Mancho, 2015	Recruitment on Facebook	Peru	MSM	34 Peer Leaders	Surveillance/Observation

Table 2

Social Media/HIV Studies by Intervention Description, 2011–2015.

Title	First Author/Year	Platform	Location	Target	Sample	Focus of Research	Intervention Description	Length of Study	Control Group
Evaluation of the use of a social networking site in sexual health care	Hedge, 2011	Myspace, Facebook, Bebo, and High 5	UK	Patients	78	Prevention/Treatment	Forum-Based	22 months	No
Social Media-Delivered Sexual Health Intervention: A Cluster Randomized Controlled Trial	Bull, 2012	Facebook	USA	Youth	1,578	Prevention/Treatment	Informational Posts	2 and 6 months	Yes
Mobilizing homeless youth for HIV prevention: a social network analysis of the acceptability of a face-to-face and online social networking intervention.	Rice, 2012	Facebook and Myspace	USA	Youth	7, 52, and 103	Prevention/Treatment	Peer-Leader	11 weeks	No
Effects of Internet Popular Opinion Leaders (iPOL) Among Internet-Using Men Who Have Sex With Men	Ko, 2013	Facebook	Taiwan	MSM	1,692	Prevention/Treatment	Peer Leader	6 months	Non-equivalent
Queer as F***: Reaching and Engaging Gay Men in Sexual Health Promotion through Social Networking Sites	Pedrana, 2013	Facebook, and Youtube	Australia	MSM	2,929 fans	Prevention/Treatment	Webisodes	1 year	No
Sexual Health Promotion on Social Networking Sites: A Process Evaluation of the FaceSpace Project	Nguyen, 2013	Facebook, Youtube, Flickr, Twitter, and Myspace	Australia	Youth	900 fans	Surveillance/Observation	Informational Posts	6 months	No
An Internet-Based Intervention (Condom-Him) to Increase Condom Use Among HIV-Positive Men Who Have Sex With Men: Protocol for a Randomized Controlled Trial.	Miranda, 2013	Indepen. website	USA	HIV+, MSM	60	Prevention/Treatment	Informational Posts	Unknown	Yes
Let's Blog about Health! Exploring the Persuasiveness of a Personal HIV Blog compared to an Institutional HIV Website	Neubauer, 2014	Blog ( <a href="http://www.sosciurvey.de">www.sosciurvey.de</a> )	Germany	Gen. public	261	Prevention/Treatment	Blog-Based	Instantaneous	Yes
HIV education and counselling using Facebook: A possible new approach.	Rosotti, 2014	Facebook	Italy	Gen. public	open to public	Prevention/Treatment	Expert Led	6 months	No
Social Networking Technologies as an Emerging Tool for HIV Prevention: A Cluster Randomized Trial	Young, 2013.	Facebook	USA (LA)	MSM (African American and Latino)	112	Prevention/Treatment	Peer-Leader	3 months/1-Year	Yes
Project HOPE: online social network changes in an HIV prevention randomized controlled trial for African American and Latino men who have sex with men.	Young, 2014	Facebook	USA (LA)	MSM	556 participants–34 Peer Leaders	Prevention/Treatment	Peer-Leader	9 months	Yes
The HOPE social media intervention for global HIV prevention in Peru: a cluster randomized controlled trial	Young, 2015	Facebook	Peru	MSM		Prevention/Treatment	Peer-Leader	9 months	Yes
Feasibility, acceptability, and preliminary efficacy of a live-chat social media intervention to reduce hiv risk among young men who have sex with men.	Lelutiu-Weinberger, 2014	Facebook	USA (NYC)	MSM, Youth	41	Prevention/Treatment	Live Chat	3 Months	No

Title	First Author/Year	Platform	Location	Target	Sample	Focus of Research	Intervention Description	Length of Study	Control Group
"My YAP Family": Analysis of a Facebook Group for Young Adults Living with HIV.	Gaysynsky, 2014	Facebook	USA (NYC)	Youth, HIV+	43	Surveillance/Observation	Online Support Group	4 months	No
Bringing HIV Partner Services into the Age of Social Media and mobile connectivity	Udeagu, 2014	Facebook and other sexual networking sites (A4A)	USA (NYC)	Sexual partners	275 partners	Prevention/Treatment	Partner Notification	22 months and 10 months	Yes
Acceptability and Feasibility of Using Established Geosocial and Social Networking Mobile Applications to Promote HIV and STD Testing Among Men Who Have Sex with Men.	Sum, 2014	Geosocial and sexual networking apps (A4A Radar, Grindr, Jack'd, and Scruff)	USA	MSM	457 participants	Prevention/Treatment	Passive Recruitment	7 months	No
HealthMpowement.org: Building Community Through a Mobile-Optimized, Online Health Promotion Intervention	Hightow-Weidman, 2015	Indepen. website	USA	MSM, TG	15	Prevention/Treatment	Informational Posts	1 month	No