SOCIAL MEDIA AND E-LEARNING: HOW TECHNOLOGY IS CONNECTING THE HIV COMMUNITY

Changing technology is facilitating provider and patient as well as peer-to-peer engagement like never before. Social media has the ability to reach people in need of intervention across a wide geographic area and to offer individually tailored interventions in naturally occurring contexts. Social media applications can also provide both connection and anonymity to individuals concerned about revealing their identities — a feature that may be especially important to people with stigmatized diseases such as HIV.

The June of 2011 issue of HRSA CAREAction detailed the rise of social media and common social media terms and platforms, including the ways in which Internet communication and phone applications can enhance patient support, HIV testing, outreach, adherence, and retention programs. These lessons and associated grantee examples remain pertinent today and can be accessed here. Building on that information, this newsletter issue will discuss emerging trends in social media and outline additional lessons learned since 2011 to best support social media use in health care and HIV.

SOCIAL MEDIA AND HEALTH CARE

The ability of people to engage in two-way communication on social media has tremendous applicability in health care. A 2013 study by Pew Research Center found that 72% of Internet users reported looking for health information online in the previous year. What’s more, many survey respondents used the Internet to speak with others who had similar health concerns and to read about their experiences, as well as find reviews and rankings for doctors and medical facilities. The point is that

DID YOU KNOW?

- According to a Google+ study, 57% of people have more conversations online than in person.
- Gay, lesbian, and bisexual individuals sign into social networks more frequently than heterosexuals and are more likely to be plugged into geography-based social phone applications.
- Facebook use by teenagers age 13 to 19 plummeted from 72% to 45% between spring and fall of 2014. Meanwhile, 83% of young adults age 18 to 29 are on Facebook — underscoring the importance of knowing whom you’re targeting and where they’re accessing information.

Sources:
Social media is being used to enhance patient support, HIV testing, outreach, adherence, and retention. In this way, technology is providing an important vehicle in not only meeting patients where they are at, but in moving them along the HIV Care Continuum.

Patients increasingly are turning to the Internet to search for health information and to interact with others about their health. This online dialogue offers an opportunity to improve dissemination of prevention and self-management best practices.

Ryan White HIV/AIDS Program grantees recognize this and are tapping into social media and technology to reinvent the way that they do business. Take, for example, the Boston Health Care for the Homeless Program, featured in this issue of HRSA CARE Action: They are turning to iPads to extend access to electronic medical records while out in the field.

Meanwhile, others are using mobile phone apps and patient portals to empower patients. This includes the federal government. In fact, a myriad of federally funded mobile phone apps were included in a 2014 list of the best HIV apps.

Our dedication as providers, grantees, and federal administrators is to ensure we’re reaching patients and that we’re providing them with the tools they need to build the brightest future possible. Social media technology is one way we’re doing so.

Laura W. Cheever, MD, ScM
Associate Administrator for HIV/AIDS, HRSA

THE CHANGING LANDSCAPE

Social media consists of electronic tools that facilitate real-time communication and collaboration between users to generate and share content. These technologies have shifted the focus from talking at users to talking with them, creating a dynamic social platform that is constantly evolving. Connecting individuals through such online networks enables conversation, community participation, and information sharing.

In recent years, participation in social media (particularly through mobile applications) has steadily increased. Currently, 73% of online adults use some social networking site with 42% using multiple sites. In addition, according to a U.S. Mobile App Report, 2014 is marking a new milestone: More than one-half (52%) of time spent on digital media is occurring on mobile applications. Moreover, the average smartphone user
downloads three apps per month with 57% of smartphone users accessing apps every single day.\textsuperscript{12,13}

Apps are playing an increasing role in public health efforts, and for HIV in particular. For example, a testing and care services locator app like this one from AIDS.gov allows users to search for HIV testing sites, housing assistance, health centers, Ryan White HIV/AIDS Program facilities, mental health services, substance abuse treatment, and family planning programs. It can even be sorted by locations where English or Spanish is spoken.

In fact, HIV-related apps have become so popular that Healthline released a 2014 list of the “Best HIV iPhone and Android Apps of the Year,” found here. It includes:

- \textit{Facing AIDS}, a U.S. Department of Health and Human Services (HHS) app that helps counter stigma;
- The HHS \textit{AIDSinfo} glossary of terms in English and in Spanish;
- \textit{HIV Connect}, which facilitates discussion and support between patients;
- \textit{HIV iChart} that helps identify HIV treatment combinations;
- \textit{iStayHealthy} to track HIV medication, viral load, and CD4 counts;
- \textit{PozTracker} for medication reminders;
- \textit{HIV Risk Calculator} with safe sex and risk reduction tips;
- \textit{inPractice HIV} for medical providers delivering care for HIV patients; and many others.

Additionally, a variety of physician-specific networks — such as QuantiaMD, doximity, and iMedExchange — have emerged as general online gathering places for doctors to learn from peers, discuss clinical issues and management challenges, and consult regarding specific patient cases.\textsuperscript{14} Similarly, virtual communities, such as the Substance Abuse and Mental Health Services Administration’s (SAMHSA’s) Homelessness Resource Center, offer a place for providers across the country to share case studies, lessons learned, and best practices on engaging homeless populations.

HAB’s Special Projects of National Significance (SPNS) Program will be expanding on social media lessons learned by launching a new intervention to create, test, and evaluate the impact of social media and phone apps on moving HIV-positive patients along the HIV Care Continuum. At the conclusion of the initiative, SPNS will disseminate best practices.

**Social Media and Patient Risk**

People within an individual’s social network have a lot of influence on health behaviors and outcomes. That influence can be positive and facilitate improved health outcomes, but it can encourage risk-taking behaviors too. For example, Twitter often contains significant discussions about prescription drug abuse. Linking to and communicating with others about substance use can connect users to “access points” for illicit consumption; even those individuals not currently abusing prescription drugs are exposed to normalizing messages about risky behaviors.\textsuperscript{15}

While multiple studies have examined this issue, a new analysis in \textit{Preventive Medicine} suggests that through geomapping, mediums such as Twitter can predict sexual risk and drug use behaviors. Researchers create maps of tweets and other messages, and then overlay those maps with data on the geographic distribution
SOCIAL MEDIA TRENDS

- Photo and video sharing are among the fastest-growing social media trends.
- YouTube has become the second largest search engine online, processing more than 3 billion searches a month — second only to Google.
- More Americans are accessing the Internet through apps than personal computers.
- Native advertising — online ads that appear to be part of a site's content — is on the rise. On Facebook, native ads generate a 49-times higher click-through rate and 54% lower cost-per-click than traditional Facebook sidebar placements.
- Of American adults, 58% have smartphones, and 34% of cell phone Internet users go online mostly via their phones. Addressing this trend, responsive websites (i.e., websites that adjust to users' screen sizes) are being used to maximize information receipt and experience.
- Infographics are visual representations intended to present complex information clearly and for quick digestion. This type of data visualization has grown in popularity, with both the Health Resources and Services Administration and the White House embracing the trend.

Sources:

of HIV cases. The resulting analysis can guide HIV prevention efforts.\textsuperscript{16,17} Similarly, over the past three years, the National Institute of Health has funded more than $11 million in research that explores the use of social media to advance scientific understanding, prevention, and treatment of substance use and addiction. Sites such as Facebook and Twitter are becoming valuable sources of public information to identify prevailing attitudes and myths about addictive substances.\textsuperscript{18}

Knowing where target patient populations congregate and how to use those social media platforms for health interventions are key. For example, the rise of online “hook up” sites, particularly those targeting the MSM community, is particularly noteworthy given high HIV infection rates among gay and bisexual men.

Recent research suggests that social networking sites that enable users to connect in real time can be used to facilitate more rapid sexual encounters.\textsuperscript{19} When individuals use social networking sites for sex seeking, they may be at increased risk for HIV and other sexually transmitted infections (STIs).\textsuperscript{20} In a study by the Los Angeles Gay and Lesbian Center, more than 7,000 gay and bisexual men were tested for STIs. Though only 36% of individuals within the study said they use dating apps, these men were 25% more likely to have gonorrhea and 37% more likely to have chlamydia than those who met partners in person.\textsuperscript{21}

Although GPS-enabled apps can be used for sex-seeking, HIV providers can also use these technologies to target at-risk and HIV-infected individuals. For example, outreach workers in Indianapolis are using using a social/dating app to find MSM in their community and subsequently offer them health and safe-sex information. In Tennessee, clinic advertisements, including banner ads, have been put up on MSM-centric apps. In New York, outreach workers are using palm cards with quick response codes (more commonly known as QR codes).\textsuperscript{9} That way, MSM can quickly scan the QR code information on a smartphone without the fear or hassle of taking health-related pamphlets. Meanwhile, in Florida, outreach workers are using another MSM social/dating app to share health messages (e.g., “Ask me about [health message]”) particularly with individuals who may mark “anything goes” in their profiles and are HIV-positive or high-risk HIV-negative individuals. Newer apps such as Fake GPS Location can enable community health workers to

\*QR codes are two-dimensional codes consisting of black dots in a square grid that can be read by a smartphone to deliver an image or message.
engage in online outreach from their offices while appearing to be in high-prevalence neighborhoods or within gay clubs — all in an effort to better encourage MSM to engage with them online. In all cases, however, organizational policies and oversight need to be established for online and social media use.

BEST PRACTICES

Because health behavior is strongly influenced by others, it makes sense to view social networks as more than a way to communicate with patients. They can also be a way to encourage health behavior changes across far-reaching networks of people. To do this successfully, it is important to have clarity within an organization on the ways social media should and should not be used.

To start, establish your goals, and then make a plan to support them. Consider resources and expertise required before deciding which tools to use. Start small and grow your online social media presence from there. Remember that social media is about connection, so regular maintenance, new material, and engagement are all important qualities for a successful online presence. If you or your organization are new to social media or do not have a social media strategy in place, consider outlining target audiences, objectives, measurements, and review the 2011 HRSA CAREAction newsletter and this AIDS.gov “Getting Started” list of recommendations. (See also “Top Social Media Lessons” box.)

As a social media campaign grows, so does the amount of time and resources needed to set up and maintain it. The Centers for Disease Control and Prevention’s (CDC’s) Health Communicator’s Social Media Toolkit addresses this issue and suggests health care organizations “be strategic and follow demographic and user data to make choices based on audience, communications objectives, and key messages.” It is important to assess the level of effort needed for each platform and the specific population it will reach before deciding which social networks to participate in.

SMARTPHONE APP BATTLES SEXUAL ASSAULT AND VIOLENCE

Born out of the “Apps Against Abuse” challenge, a partnership between the Office of the Vice President, HHS, and the White House Office of Science and Technology Policy, the Circle of 6 app seeks to reshape efforts against sexual violence.

Although the app was not developed specifically with HIV in mind, people with HIV experience intimate partner violence (IPV) at two times the national rate and have been sexually abused at five times the national rate. Sexual violence can also place victims at risk for HIV transmission. In addition, individuals who have experienced IPV are more likely to engage in behaviors that place them at risk for HIV.

Circle of 6, once downloaded, enables users to pick six trusted friends to join their “circle.” Then, if faced with an unsafe situation, send one of the pre-written messages immediately to these friends to seek help. Originally developed to counter sexual assaults on college campuses, the phone app — and others like it — have broader appeal for other at-risk populations.

Meico Whitlock of the National Alliance of State & Territorial AIDS Directors (NASTAD) echoes this theme: “We really stress the importance of having a strategy that is tied to concrete health outcomes. Using Facebook or Twitter, or setting up a profile on one of the many dating sites, doesn’t do you any good if it’s not clear why you’re there and if you even should be there. It really depends on who your audience is and what you’re trying to achieve.”

**Privacy and Confidentiality**

The sensitive nature of private health information requires close monitoring of all social media content. Maintaining patient confidentiality by adhering to Health Insurance Portability and Accountability Act (HIPAA) requirements and establishing appropriate patient-physician boundaries is of utmost importance, especially when dealing with stigmatized medical conditions such as HIV. In response to these concerns, the American Medical Association (AMA) has published guidelines on the ethical use of social media in health care. Recommendations include being cognizant of privacy settings, providing accurate information, declaring conflicts of interest, and creating separate personal and professional profiles.

Recent modifications of the privacy settings on many social networking sites have streamlined this process. An excellent illustration of changing functionality is Google+, which allows users to segment their entire social network into smaller “circles” and decide what information to share with each subgroup. This mimics the way information is shared in real life and reflects the important distinction between personal and professional relationships. Facebook has made a similar change by allowing users to group online friends into “lists” and manage which photos, status updates, and information are visible to each group. Patients and health care professionals can now use social networks to cultivate healthy online connections while still protecting private information.

**Maximize Content**

Social media enables health communicators to reach patients how, when, and where they want to be reached. Not only does this influence satisfaction and increase trust, but it also improves the overall availability and efficacy of the messaging. That’s because providing
information on multiple platforms and in multiple formats gives individuals different ways to interact with content, while reinforcing the messages at the same time.

To create effective content, however, the information should be relevant, useful, interesting, and most of all accurate. Because social media platforms typically have limited space for information, word choice is key. Therefore, it is important that information be easy to understand and easy to share. Due to the social nature of social media, a friendly, engaging tone can help foster followers and create a sense of community.

Repurposing existing content is a helpful technique and allows for maximization of reach while still making the best use of time and resources. Messages can be tailored to the appropriate format for each social media site while still retaining key health information, simplifying the creation of a multiplatform communications strategy. Dashboard websites such as Hootsuite or Buffer allow users to manage profiles and post on multiple social networking sites at once.

Understanding Social Media Analytics
It is likely that digital media’s influence in the health sector will continue to grow. Consequently, more thorough and consistent methods for measuring success need to be developed. Most forms of social media were not designed to include evaluation metrics, and existing analytics (e.g., number of site hits, time spent on a page, audience location) are not always the most appropriate evaluation tools. Though it is difficult to attribute specific effects to social media as it is typically one of a set of tools used in a health intervention, it is crucial to evaluate efforts in order to improve communication and gauge success.

In addition, monitoring trends on social networking sites serves as a valuable way to identify current interests and levels of knowledge about a particular health topic. This feedback loop is the crux of social media. Examining responses and reactions to outreach efforts, as well as social listening around trending topics, allows health communicators to tweak specific messages and adjust overall strategy as needed.

Good strategies when considering analytics:
- Understand what you want to track.
- Set goals.

- Make sure data is accurate.
- Look at analytics across all of your organization’s platforms.
- If possible, use a social media plugin to streamline and layer with Google analytics (or whichever analytics platform is being used for your organization’s website)
- After you analyze data, make recommendations for improvements.

E-LEARNING
With face-to-face conferences, meetings, and trainings becoming less frequent, the need for e-learning best practices is rising. Internet-based education provides a unique opportunity to disseminate new research findings and ultimately improve health outcomes, even in a resource-limited setting. Virtual engagements consist of the use of online technology to facilitate any type of training or information transfer, and they have a number of benefits. These include time and location flexibility, lower training costs and time commitment, ability for participants to self-direct and self-pace, and potential for a collaborative learning environment.

Regarding Web-based e-learning, Michael Hager of the National Quality Center explains: “You really need to go the extra mile to grab people’s attention. Injection of fun, of course, is one of the best ways. So a joke here or there or an anecdote to make the information more relatable, especially when you can have supporting pictures in the background that are interesting and thought provoking, can be very effective.”

The AIDS Education and Training Centers (AETC) Program provides guidelines for a number of e-learning technologies in their Technologies for Training Toolkit. Best practices for distance learning sessions stress the importance of planning ahead. This means assessing the goals of the training to identify the best technology, understanding what time commitments the audience may have, and what the audience’s training needs are. They recommend uploading all slides, files, and handouts to the virtual learning space and testing interactive features before the training begins, as well as providing faculty and trainees with a checklist of what they’ll need to participate.

Hybrid events are possible too. These are instances when live face-to-face events are occurring but not all participants can be there in person. Hybrid events
typically include live streaming of events accompanied with PowerPoint slides, interactive participation, and all launched via an online platform.

If hybrid events are being recorded, let participants know where they’ll be able to access the recording and slide sets. Once posted, the e-learning sessions can be promoted on social media platforms via tweets and status updates. Video recordings also can be uploaded to YouTube as well as repurposed for multimedia press releases.

Podcasts, or audio files that can be listened to on-the-go from an iPod, mobile device, or other portable music player, are another way to virtually share educational knowledge. Podcasts also provide an opportunity to repurpose audio files from previous presentations, ensuring maximization of content across platforms. Delivering information in this convenient and enjoyable format is becoming increasingly common as more people own devices with digital audio capability.

**HOW TECHNOLOGY IS EXTENDING CLINIC CARE AND PATIENT SUPPORT**

**Boston Health Care for the Homeless Program**

Boston Health Care for the Homeless Program provides quality health care for some of the hardest-to-reach, highest-needs patients in the greater Boston, Massachusetts area. The program includes multidisciplinary care teams who provide primary medical and mental health care to currently street homeless or formerly street homeless men and women.

As Dr. David Munson, staff physician for Boston Health Care for the Homeless Program summarizes:

“We practice in a unique setting. We’re either on the street or in people’s homes. For me it’s always about recreating a ‘typical’ clinical encounter in those different settings. As technology becomes more and more important in office-based practice, we needed to figure out how to make it part of non-office based practices too. There are...
always going to be folks who are not going to come into offices, so we want to make sure that they receive the same standard and amount of care available.

Enter iPad Charting: HIV street outreach workers now have iPads that are connected to the Program’s Web-based electronic medical record (EMR) system. Outreach workers turn their cell phones into Internet hotspots, thus enabling them to connect their iPads to the Internet so they can go online and look up medical information and prescriptions, as well as any other data in the clinic EMR. In short, it’s giving providers access to the same information they’d have in the clinic for a patient visit — only this visit is taking place on the street.

As Carole Hohl, director of HIV services, describes, “We asked to be able to do this because patients may not know what medications they’re on or when their next appointment is … so an outreach worker could be finding someone under a bridge but able to get the information they need to connect [the person] back to care.” For Boston Health Care for the Homeless Program patients, that means connecting them not only to HIV care but also to mental health care services and substance abuse facilities. Security measures, including password-protected logins, are programmed into the iPad system.

iPads are also used for home visits with newly housed individuals. “iPads have changed home visits tremendously,” says Dr. Munson. “We can open up their chart and compare what they’re prescribed against what they say they’re taking. It allows us to do medication reconciliation.”

The Program has also found the iPad-enabled charting to be a timesaver. Whether out on the street or within a person’s home, providers are able to immediately update EMR records. Doing so keeps files updated in real time and has reduced overall administrative burden so that staff can spend more of their time with patients and less time on paperwork.

For more than 10 years, the Boston Health Care for the Homeless Program has also run a weekly clinic at Massachusetts General Hospital to address their patients’ more intensive needs. Using a Massachusetts General Hospital mobile app, Boston Health Care for the Homeless Program providers can additionally access their patients’ hospitalization information in the Massachusetts General Hospital EMR.

In totality, this multidisciplinary team with their multipronged technological approach are delivering the highest quality care to patients and meeting them where they are at — literally wherever that may be.

Empowering Patients
A number of patient-support sites, such as Patients Like Me and Cure Together, have emerged as venues for patients to exchange information on treatment options and discuss symptoms. These social networks are believed to improve emotional health and assist with chronic disease self-management. They are particularly helpful for patients who are too sick, removed, or fearful of stigma to participate in in-person support group meetings.

Patients have also found technologies such as patient portals (where patients can access a snapshot of their health information and communicate with their providers) to be particularly useful in advancing their health literacy and improving their engagement in care. Take Ryan White HIV/AIDS Program client Darlene, for example, who benefitted from patient portal technology developed under a HRSA SPNS initiative. Like many aging individuals with HIV, Darlene has a myriad of health care needs and thus her care was fragmented. Her patient portal, however, enabled a dispersed team of care providers to access her medical records. It also allowed Darlene to keep track of her care, encouraging her to participate more fully in her own health care management. As Dr. Peter Gordon at New York-Presbyterian Hospital and Darlene’s HIV physician explains:

“What we found was that people were eager to be trained and, many times, for some individuals it was the first time they had ever sat down at a computer terminal and opened up a browser, and were quite liberated, not just by learning how to access their medical record, but how to take that access and use it to promote a sort of self-efficacy and understanding [of the] chronic illnesses they had been diagnosed with or medications. “

The next phase of the patient portal recently added mobile phone capabilities for patients to have on-the-go and increased capacity for patient-provider communication.

Other ways patients are feeling empowered is through carved-out, patient-centric forums within broader campaigns and clinics. Although the concept of patient involvement in HIV is nothing new, where these individuals are connecting — and what they’re talking about — is. For example, the in+care Campaign
is an HIV retention-in-care campaign funded by HRSA and managed by the National Quality Center. Although the Campaign initially focused on engaging providers, a separate consumer group was formed. In particular, the consumer group formed a private Facebook group to enable participants to connect with other HIV-positive individuals around the country and share news and encouragement. Increasingly, conversations are focused on new media: what’s new; what apps assist with medication adherence; clinic advertisements with QR codes that link up to patient portals; and other new health technologies. What they’re looking for are free, easy-to-access ways to be engaged in their care in a way that blends seamlessly with their social media and technology-rich lives.

CONCLUSION
Ryan White HIV/AIDS Program providers and grantees are constantly evolving to better engage patient populations, and provider use of social media and other technologies is no different.

Although challenges — such as obtaining approval of content, securing buy-in from leadership, understanding how to use and measure social media tools, and maintaining relationships with communications and IT personnel once on a platform — persist, these challenges also can be readily overcome. As grantee examples within this newsletter illustrate, HIV organizations can, and are, successfully reaching target populations and improving their care receipt and health literacy through social media.

Social media is important; NASTAD’s Meico Whitlock underscores, however, that “it is just one component of an entire ecosystem of communications.” When organizations think critically about their entire communications operations, including social media’s role within it, it can make for a more robust and comprehensive approach than ever before: one based on foresight, planning, and strategic execution.
Horvath KJ, Danilenko GP, Williams ML, et al. Technology use and reasons to participate in social networking health websites among people Living with HIV in the US. *AIDS Behavior.* Published online February 16, 2012.


*comScore,* 2014.

Bahgat, 2014.

