What Is Social Media?

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SOCIAL MEDIA AND HIV

It is time that [health] programs embrace Facebook, texting, all the communication means, the new information technology that … people are using. It is not by billboards that we are going to introduce social change and personal behavior change on a large scale.

—Peter Piot, UNAIDS, at the 2008 International AIDS Conference

"Mary" felt isolated and ostracized in her small town. Lack of anonymity and stigma kept her away from medical care for years, and when she finally enrolled in much-needed primary—and specialty—care, she traveled long distances to receive it. Her delays in care were partly because such services were rare in her hometown and partly because Mary has a secret: She has HIV.

Unfortunately, Mary's story is not unique—nor is the fact that Mary's isolation only increased her desire to find like-minded peers in whom she could confide. Yet, her fear kept her from accessing such support.

But that was then. Today, she attends an online support group with other HIV-positive women, uses online technology to remind her to take her medications, and is improving her health literacy by reading communications from trusted health organizations on their social media platforms. A tutorial in social media offerings showed Mary that much of what she wanted was just a click of a mouse away.

DID YOU KNOW?

▸ If Facebook were a country, it would be the third most populated country in the world (more "residents" than the United States and smaller only than China and India).[1]

▸ Twitter went from 5,000 "tweets" per day in 2007 to 50 million in 2010 to 140 million per day as of March 2011.[2]

U.S. Department of Health and Human Services

HRSA
Health Resources and Services Administration

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Just a few short years ago, the communication, education, and health outreach made possible through social media were unimaginable. But today, everyone from community-based organizations to university hospitals has found a way to tap into this technology and revamp the way we deliver health information.

On a Federal level, the Health Resources and Services Administration (HRSA) has posted informational YouTube videos, updated providers on Twitter about forthcoming trainings, engaged constituents in conversations on Facebook, and highlighted our *Living with HIV* video on the AIDS.gov blog.

Ryan White HIV/AIDS Program providers have always met patients where they are—and social media is no different. Grantees are using social media to advertise about HIV testing events, to encourage adherence to antiretrovirals, and to deliver text-message appointment reminders to improve retention in care. They're using webcasts to connect with providers in more remote areas, Facebook and MySpace to conduct online outreach, and instant messaging to respond to patient questions in a user-friendly format.

HRSA and Ryan White HIV/AIDS Program providers' involvement in social media is just one more way we're working to be flexible and culturally competent to meet our patients' needs and to continuously seek out creative ways to keep patients in care.

Deborah Parham Hopson
HRSA Associate Administrator for HIV/AIDS

Although some parts of the country may have slow connections to the Internet, even there, social media—and the promise it can offer for health care—is increasingly available with the rapid growth of mobile broadband.[3]

Technology is opening up possibilities that were considered science fiction or prohibitively expensive barely a generation ago. This issue of *HRSA CAREAction* focuses on how Internet technology is helping providers enhance their patient support, testing, outreach, and adherence and retention programs.

WHAT IS NEW OR SOCIAL MEDIA?

New media consists of computerized, interactive, networked information and communication. It is defined as "media . . . based on the use of digital technologies such as the Internet, digital video, and mobile devices."[4] *Social media,* however, is new media with a social focus, where information is shared with the purpose of networking. Examples include Facebook, MySpace, YouTube, and Twitter.* This rapid media growth has engendered much new terminology; a glossary of common terms is provided on page 4 of this newsletter.

The terms "new media" and "social media" are often used interchangeably. Not all emerging technologies are social, however, and not all social technologies are necessarily new. For example, older technologies being used in new and interactive or social ways (e.g., text messaging) are beginning to fall under the umbrella of "social media."**

With the early World Wide Web (known as Web 1.0), organizations provided information in one direction: out to the consumer. Now, with the onset of social media, information exchange has become interactive. The term "Web 2.0" is used to describe second-generation online tools and applications[5] as well as an Internet that is much more user-generated and easily enables the publishing and sharing of information and user interconnectedness. In fact, Web 2.0 has been called the "People-centric Web"[6] or the "Participatory Web."[7]

* *Note:* Websites and software mentioned in this newsletter are intended to serve as examples of available technologies in social media; mention in this article should not be considered an endorsement by the U.S. Government.

** For simplicity, this article uses the term *social media*.

Social media is part of Web 2.0 because content can be readily generated and published by users.[8] Web 2.0 offers ways of managing and reusing online information into a customized Web experience that was previously unattainable.[9]

Although health care is one of the country's largest industries, it has been slow to embrace such advances in communications. With increased emphasis on electronic medical records and other kinds of health information technologies, the landscape of health care communication is shifting. These changes increasingly include social media platforms that can bring public health information to more people, more quickly, and more directly than at any other time in history.[3, 10] A recent article in *Health Information and Libraries Journal* noted,

> *The potential benefits of Web 2.0 technologies as enablers in health and health care education should not be underestimated, particularly for disadvantaged groups such as disabled and elderly persons. The same applies to patients and professionals based in isolated and remote areas, where finding or establishing face-to-face support/patient groups and communities of practice might be difficult or impossible.[8]*

WHY USE SOCIAL MEDIA?

"Shifting to Web 2.0 does not mean abandoning basic Web 1.0 information or technologies," says Circe LeCompte, communications director at the National Minority AIDS Council (NMAC) in Washington, DC. "It does, however, offer an opportunity to reach more people and to deliver information on the platform they most prefer," she explains. And people definitely are turning to the Internet to meet their health information needs: According to a Pew Institute survey, approximately 83 percent of people said they go online to look for health/medical information.[11] A Daemon Group survey found that 67 percent of Internet users engage in social media.[12] As Marta M. Figueroa Santos, project coordinator at Puerto Rico Community Network for Clinical Research on AIDS (PR CoNCRA) in San Juan, Puerto Rico explains, "If this is where our clients are, then this is where we need to be."

The appeal of this technology for many organizations is to expand the reach of their traditional services, increase traffic and search rankings of their website,[13]
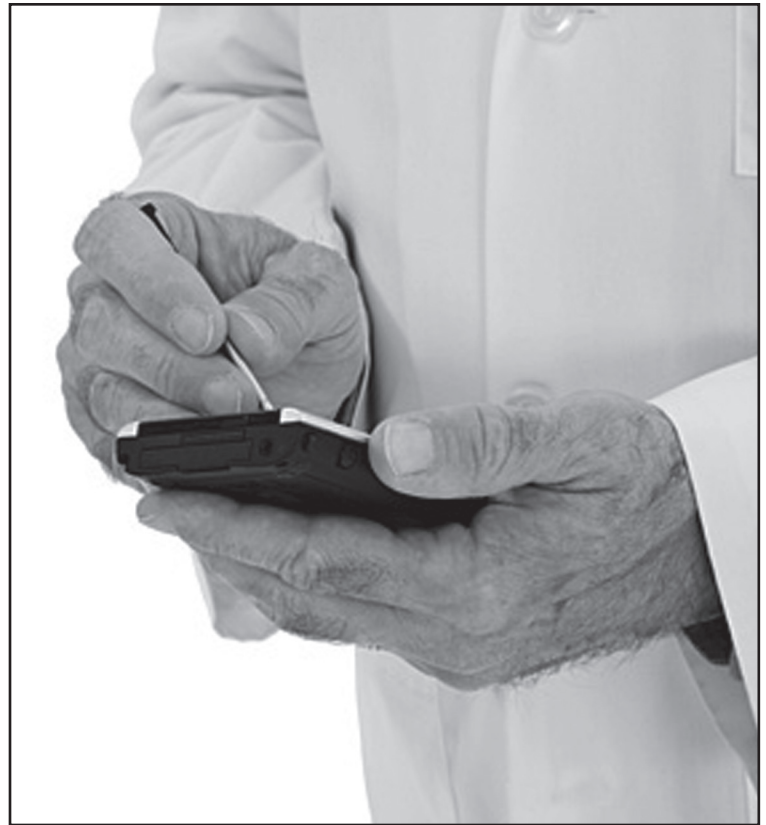
and allow for more targeted interventions. Cell phones, for example, are ubiquitous—88 percent of Americans own one.[14] Most people travel with them at all times, there's little to no "spam," and the average text message is read within 15 minutes.[14] It's no wonder that providers communicating appointment reminders or medication reminders to patients by means of text messaging are seeing improved communication and an uptick in retention and adherence. Other examples of the health care communication exchange made possible through social media are described in the sections that follow.

EVEN WEB 1.0 HAS EVOLVED: SPECIALIZED SEARCH ENGINES ONLINE

▸ Google Scholar:
http://scholar.google.com

▸ Scirus (science-specific search engine):
http://scirus.com

▸ Kosmix (consumer health search engine):
www.kosmix.com

▸ Technorati (specialist blog search engine):
http://technorati.com

Application/App
A program or utility written and designed to perform specific tasks for devices and platforms.

Blog
A combination of the terms "Web" and "log." Blogs are online journals or diaries, usually informal and regularly updated. They bypass the need to program hypertext in HTML and allow easy self-publishing. They often include a combination of text, images, video, and links to other Websites; encourage dialogue between authors and readers; and are published chronologically (e.g., www.blog.AIDS.gov, http://blog.bioethics.net).

Badges/Buttons
A virtual "button," or graphic, embedded into a website, Web page, or blog, typically advertising a short message or resource. Users can click on the badge or button for more information.

Chatrooms/forums
A website where participants can post information in an on-going conversation.

Cloud or cloud computing
Software, data access, and storage services that do not require end-user knowledge of the physical location and configuration of the system that delivers the services (i.e., cloud computing offers an abstract view of services and simplifies details).

E-cards
Electronic greeting cards sent by e-mail. They can be used to invite people to an event (e.g., Evite) or encourage safe behaviors (e.g., World AIDS Day testing e-cards, CDC health e-cards at www2c.cdc.gov/ecards/).

Instant messaging
Online, real-time, text-based communication between at least two users by means of networked computers or cell phones.

Mashups
A combination of various data or tools into a website (e.g., HealthMap).

Newsreader
Client software or Web application (e.g. Google News Reader) that aggregates news headlines, blogs, podcasts etc. to a single location, creating a kind of "personal newspaper."

Personal digital assistant
A mobile, hand-held personal organizing computing device.

Photosharing sites
Websites that allow you to share digital photographs (e.g., Flickr, Picasa, Photobucket). Some HIV/AIDS organizations have used such sites to share photos of people "Facing AIDS" as part of World AIDS Day initiative or to share the events and attendees of an HIV conference.

Podcasts
A blend of the words "iPod" and "broadcast," podcasts are audio or video files that can be downloaded on demand and listened to or watched on computers and portable media devices. Podcast search engines (e.g., http://podcasts.yahoo.com) allow users to search for podcasts on topics of interest.

RSS feeds
Real simple syndication (RSS) feeds are a way for a website to notify subscribers when new content has been posted and enable the free flow of content between applications and websites (e.g., HIV/AIDS prevention resources at www.cdc.gov/hiv/rss/hiv.xml).

Social bookmarking
A way to save websites and searches by "bookmarking" them; the information may be organized with user-defined keywords or tags. Social bookmarking may be shared with colleagues, made public, or kept private. Sharing social bookmarks allows users to see the collective list of resources from people with a common interest as well as locate people with related interests. These collaborative lists could be made into Web resource guides for patients.

Social/professional networking sites
Online communities that allow users to connect with people sharing a common interest (e.g., Facebook, My Space, LinkedIn, Meetup, Academia.Edu). Users first create an individual or organizational profile and then invite others to join as "friends" or "fans." Facebook is the fastest-growing social networking site. Unlike chat rooms, social networking focuses on connecting and strengthening existing relationships.

Social search engines
A search engine designed to search social media (e.g., Technorati). In many cases, searches can be saved not only on social search engines but, increasingly, on more traditional sites, such as PubMed, where users are given the option to convert their queries to an RSS feed via Hubmed.

Text messaging
Information sent to and from cell phones or personal digital assistants. One text message is 160 characters in length or less. Text messaging is also known as "short message service" (SMS).

Twitter
A "micro-blog" allowing short messages, or "tweets," limited to 140 characters. Tweets are broadcast to a list of people who sign up to "follow" you. You can also sign up to follow individual Twitter users and organizations. Other Twitter terms are as follows:

> **Hashtags:** A key word or phrase used to search for individuals, events, or conversations on Twitter (e.g., #WAD09 indicates tweets related to World AIDS Day 2009). Users add a hashtag to a tweet to make it searchable.

> **Direct Message (DM):** A private tweet that can be viewed only by the sender and receiver.

> **@<username>:** A way to indicate a reply to a specific Twitter user.

> **RT:** "Retweet," or sharing someone else's tweet with one's followers.

Video-sharing sites
A website to share and store videos (e.g., YouTube). HRSA has its own YouTube channel, where it posts videos on HIV and other health information (www.youtube.com/user/HRSAtube).

Video/computer games
Interactive games played on game devices (e.g., Xbox, Playstation, Wii) or over the Internet. Health-related video-games include the Kaiser Family Foundation's "Pos or Not" game (www.posornot.com) and Games for Health (www.gamesforhealth.org).

Virtual world
An online simulated environment (e.g., Second Life) where participants create "avatars" (digital selves) and interact with others to socialize and share information. Virtual worlds are increasingly used for teaching and training.

Vodcasting
The video equivalent to podcasting.

Web conferencing
Participants use their own computers to connect online and participate in a virtual conference; usually, users must download software (e.g., WebEx) to participate.

Webinars/webcasts
A Web-based seminar or event to share information, typically one-way communication where information is shown on a screen as a presenter speaks.

Widget/gadget
A small application that provides an icon embedded in a website, blog, or social network (e.g., a clock counting down the time until World AIDS Day).

Wiki
A Web page that allows editing and collaboration by different users; it may be public or limited to users within a specific organization or network. Examples include an online community calendar of HIV-related events or an internal document with multiple contributors (e.g., Wiki Surgery, at www.wikisurgery.com; Healtheva, at www.healtheva.com). Perhaps the best known wiki is Wikipedia (www.wikipedia.com). The word wiki comes from the Hawaiian word for "fast" or "hurry."

Sources: Adapted in part from Blog.AIDS.gov. *New media toolkit.* n.d. Available at: http://blog.aids.gov/glossary.html. Accessed March 16, 2011.

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FACEBOOK GROUP PAGE VERSUS FAN PAGE: WHAT IS RIGHT FOR YOU?

GROUP PAGE	FAN PAGE
Functions the same as a personal page but listed by name of organization	Can formally register your organization and services with Facebook
Smaller scale (max 5,000 friends)	No limit on number of fans
People send you a "friend request," which you can accept or reject, and vice versa.	Anyone can sign up to be a fan.
Cannot add applications	Can add applications
Limited data tracking capabilities	Numerous data tracking capabilities
Can send private messages to friends' in-boxes	No private messages; information is broadcast from the "wall" (i.e., home page)
Event function can be used to invite followers to an event	Event function can be used to invite followers to an event

Support

Patients like Mary are going online to connect with others and find support. The Internet offers 24-hour access, requires no transportation or child care coordination, and provides a level of anonymity that may be especially appealing to people with HIV or other stigmatizing health issues, such as mental health disorders and sexually transmitted diseases (STDs). Support meetings may take place in chat rooms, on specific social networking sites created by members (e.g., MySpace Cure Diabetes Group), or in virtual worlds like Second Life.

Justin Goforth, director of medical adherence at the Whitman-Walker Clinic (WWC) in Washington, DC, explains that many of the clinic's clients have had success using a website called "PatientsLikeMe" (not affiliated with WWC). People who are HIV positive can track their CD4 counts, lab work, and antiretroviral (ARV) medication use and express challenges they are experiencing. Patients can share stories with one another and provide encouragement. Not only do online networks like Patients Like Me increase patient support, but websites and Web services such as CarePages (www.carepages.com) allow patient family members and friends to share or view updates about a patient and their care experience.

Of course, patients going online carries dangers, especially on social platforms, because sharing information and reading studies intended for researchers could result in self-medication (which can create other health problems) or self-diagnosis (which can lead to needless anxiety). In the case of PatientsLikeMe, it has also led to new research findings related to the sharing of peer-to-peer information. In short, patients feel empowered by the ease with which they can access and share information online. Thus, the health community can benefit in many ways by creating authoritative online sources to ensure accurate health information and to direct patients to sites one's organization has already vetted.

HIV Testing

The Internet is a great resource for information on HIV testing, whether a user is looking for a testing site or wants to find out more about the testing process and the meaning of test results. HIV prevention and testing information has been disseminated through the Health Resources and Services Administration (HRSA) and AIDS.Gov YouTube channels as well as the Centers for Disease Control and Prevention (CDC) "Act Against AIDS Campaign Voices of Experience" series. On National HIV Testing Day in 2009, the White House released a video of President Obama receiving an HIV test in hopes of increasing awareness and decreasing stigma. Similarly, E-cards have been used to send reminders about HIV testing and health practices, and photo-sharing sites have been used to increase awareness (e.g., participants upload pictures of themselves with HIV ribbons or with

HIV messages, as in the AIDS.gov "Facing AIDS for World AIDS Day" online photosharing initiative.)

Some applications enable a person to locate the nearest HIV testing center by typing in a zip code or sending a text message. For the Kaiser Family Foundation "Know It" campaign, for example, all people had to do was send a text to the number 566948 to locate a testing center; the processs was made possible through geo-demographic technology. More recently, AIDS.gov has created a cross-government HIV prevention and services online locator and widget (http://aids.gov/locator/) that pulls data from HRSA, CDC, U.S. Department of Housing and Urban Development, the Substance Abuse and Mental Health Services Administration, and the Office of Population Affairs websites.

Finally, Ryan White HIV/AIDS Program providers such as the Sixteenth Street Community Health Center in Milwaukee, WI, and PR CoNCRA are using Facebook to invite their "friends" to community events where testing and HIV education are taking place.

Adherence and Retention

Text messaging has been used successfully to remind patients about appointments and to foster medication adherence. Some Web-based software enables medication reminders to be sent to patients via secure Web accounts; patients can use this same technology to schedule and track their appointments. Such software works with an organization's existing client management system, and most software companies can provide assistance with setup. Some software systems provide one-way communication that simply sends a reminder to patients, whereas others allow two-way messaging, whereby patients can confirm or reschedule appointments using their cell phones.[15] Similarly, daily medication reminders and medication refill reminders can be sent to phones.[15] (To learn more about available software programs, see http://blog.aids.gov/2009/02/text-messaging-for-hiv-appointment-and-medication-reminders-part-ii.html.)

Many people prefer text message appointment reminders to reminders by other means (e.g., voicemail or e-mail).[16] WWC has found text messages to reduce no-show rates. Although case managers could send text messages to patients rather than use software systems, the task can become costly and time consuming.

Regardless of which mechanism an organization chooses, patients should be asked to "opt-in" for the service, and any cell phone costs related to text messaging should be discussed. Note that Health Insurance Portability and Accountability Act (HIPAA) requirements still apply, so messages are coded using a phrase patients have selected or created themselves (e.g., "Do your thing") and never mention health or test information.

A more rudimentary, though cost-effective, approach some HIV clinical pharmacists are taking is to create medication reminders directly on patients' cell phones. When the pharmacist meets the patient to discuss any medication interactions, expired drugs, etc., he or she also programs the patient's phone alarm to sound at a specific time (chosen by the patient). When the alarm goes off, the patient knows what he or she needs to do. Similarly, cell phone calendars can be used to note appointment dates so that a notice appears on the patient's phone when it's time to come back to the clinic.

Teaching

Web 2.0 encourages more interaction between users, thereby leading to "collective intelligence." It has been shown to encourage active learning engagement, feedback, and a sense of community.[8] Many new collaborative opportunities for clinical practice and education are available.[17]

Webinars, webcasts, podcasts, and vodcasts are particularly relevant to teaching[7]; they can help fill communication gaps and engage the audience in conversation.[18] Webinars and webcasts take place in real time, but they can be archived and reviewed at a later date. Nursing or public health professors can conduct their classroom sessions with online participation; create a podcast from the lecture; and make the lecture, slides, and handouts available online for students or other interested parties.[7]

Technology changes; trends change. [R]ecognize that there is a time commitment to not only establishing a social media presence but keeping up with it too.

—Kathleen Donovan, Sixteenth Street Community Health Center

Podcasts, webcasts, and webinars have been particularly useful in Ryan White HIV/AIDS Program technical assistance trainings offered at the Technical Assistance Resources, Guidance, Education, and Training (TARGET) Center website (www.careacttarget.org). Characteristics that make podcasts especially popular are their cost-effectiveness for reaching a large audience; the ease with which a topic of interest can be easily identified and downloaded to a computer or portable media player; and the capacity to provide learning in a user-controlled context—that is, any time, any place.

Social media has also helped professionals who are in remote areas by helping them connect to urban clinical centers through vodcast trainings and Web conferencing.[8] For example, the University of New Mexico's Project Extension for Community Healthcare Outcomes (Project ECHO) has created an innovative health care program for addressing chronic and complex diseases, including HIV. The project uses video distance-learning technology to bridge the gap between health care specialists and providers in underserved and often rural settings in the State to share best practice protocols and case-based learning. Part of the Mountain Plains AIDS Education and Training Center (AETC), Project ECHO won the United States Distance Learning Association's 2010 International "21st Century Award for Best Practices in Distance Learning" for this work. Project ECHO's model of video conferencing and distance learning is being replicated by the University of South Florida for technical assistance and evaluation work as part of HRSA's Special Projects of National Significance Hepatitis C Treatment Expansion Initiative. (To learn more, visit http://echo.unm.edu/index.shtml.)

More than 100 hospitals have created YouTube channels and Twitter accounts linking users to educational materials, news stories, and blogs.[19] Some hospitals are even using Twitter to raise awareness and teach surgical techniques to followers. For example, Children's Medical Center in Dallas, Texas, tweeted during a kidney transplant[19]; other health organizations have tweeted updates during medical conferences. Note that for Twitter surgeries, patients and their families are consulted, consent forms are obtained, and the patient is never identified by name to ensure confidentiality.[19]

Training

Virtual worlds are increasingly being used to facilitate team building, skills building, and training.[8] Virtual reality applications have been used in surgical training and health education.[20] In Second Life, for example, pharmacy students can log on and play the role of patients and pharmacists interacting with one another online.[7] Virtual health conferences, in which avatars discuss new research, show videos and PowerPoint presentations, and respond to questions, can take place. For example, on World AIDS Day 2009, AIDS.gov gave a presentation in Second Life about the state of HIV/AIDS in the United States. For emergency preparedness, avatars can practice working together to evacuate a virtual hospital and patient population in the aftermath of a simulated natural disaster.

Knowledge Sharing

Social media can enhance professional networking and information sharing. For example, the National Institutes of Health spent $12.1 million to create a "Facebook for scientists." The network allows researchers to readily search and share information and streamline lists of their published articles, academic publishers, institutional repositories, and other information.[21]

Social media technologies can also facilitate the sharing of documents. A shared calendar or online collaboration to track changes in documents or spreadsheets may help increase provider coordination. As explained in a recent *Health Information and Libraries Journal* article,

The collaborative concepts underpinning these Web 2.0 applications are very similar to the notion of [W]eb-based, shareable and distributed electronic health/patient records. Patients and clinicians can securely and simultaneously access these records across multiple institutions and places, facilitating speedy information exchange, communication and collaboration among clinicians to potentially improve clinical outcomes and cost reduction.[8]

Marketing

Many of HRSA's AETCs are using Twitter as a marketing tool to keep providers updated on upcoming trainings and other pertinent events. Although tweeting can take some time and coordination, most people have found Twitter to be more cost-effective than investing in traditional mail products, and it avoids e-mail spam filters.

Facebook has been particularly useful in the health arena for marketing purposes because its ad system provides instant feedback on metrics (e.g., the number of times people click on an ad)[22] and allows marketers to do targeted recruitment using Facebook member profile demographics and identified preferences.[22] For example, if researchers were recruiting participants for a study on men who have sex with men (MSM) in Boston, Massachusetts, they could buy ad space on Facebook; to cut down costs and increase efficiency, the ads would only go out to Facebook members who, according to their interests and demographic information, live in Boston, have self-identified as MSM, and fit other characteristics of interest to the study recruiters.

WHAT DO SOCIAL MEDIA INITIATIVES LOOK LIKE?

Sixteenth Street Community Health Center

The Sixteenth Street Community Health Center is tapping into social networking sites to spread the word about local events. The center has program profiles on MySpace and Facebook, although, according to Katheen Donovan, director of HIV services, the organization has had much more success on Facebook. In short, the center has a Facebook page where it posts information about events,

testing, and HIV and health. It also uses the Facebook event feature to invite people who are fans of the center. "We don't use 'HIV' when advertising events. We call them things like 'Latino Night,'" explains Donovan. "But what's a social event for them is a prevention event for us."

In addition to an organization page, Donovan has created a personal page for the same purposes. "We've found that people are more likely to respond to a face than a logo. If they see my personal page and can associate a face to our Center's service offerings, then they're more likely to look into them," she explains. "Also, people are more apt to accept my friend request as an individual than as

a health center." Because community members may not necessarily know to look for Donovan on Facebook, the Center maintains its organization page, too.

"We also use MSM networking sites such as Manhunt, Gay.com, and Adam for Adam," explains Donovan. "They're not as interactive, but we can create profiles on these sites and include information about public events and testing. We'll also have someone go into a chat room, say who we are, and include testing information. Sometimes people will see this and privately send us questions," says Donovan. "I'll personally reach back out to that person, and if the question seems to be one that many people might have, then I'll also post the answer on my page for others to see." (To learn more about this technique, see box, "Hooking Up Online," pp. 12–13.)

To increase its online outreach efficacy, the Sixteenth Street Community Health Center now issues social media–related questionnaires when patients come in. The purpose is to ensure that the center is not over- or underestimating how much its patient population uses computers, has computer access, and wants to be reached online. Thus far, MSM and young MSM (YMSM) are the patients using networking sites the most. In addition, the center is looking online for patients who have been lost to traditional follow-up and who, perhaps, are still Facebook friends with Donovan or the organization and may be reached through that medium.

Thus far, the center has had success tapping into social media, but there were growing pains to get the organization where it is today. For instance, accessing sites such as Facebook or Manhunt required working with the center's IT department to allow particular staff to access those sites because they were being blocked for security purposes. The center also recognized that even though Twitter is a great resource, most people using that technology are not, in fact, the population the center is trying to reach. Donovan's advice to organizations getting started with social media is to learn what sites their audience is using and how they are using them. "Be flexible, and continually reevaluate for effectiveness," says Donovan. "Technology changes; trends change. Also recognize that there is a time commitment to not only establishing a social media presence but keeping up with it too."

Dallas Family Access Network/Youth Angle
In Texas, Dallas Family Access Network (FAN)/Youth Angle has taken a new twist on technology to improve patient

retention among adolescents transitioning to adult care. "Kids didn't want to stay in the adult clinic and were having trouble transitioning from adolescent care," says Betty Cabrera, executive director. "One of our social workers suggested we use restaurant-style pagers to give to young adult patients while they waited. This way, they could leave the adult waiting room, where they felt uncomfortable, but still know when it's time for their appointment by being paged anonymously," Cabrera explains. The strategy has helped improve appointment retention among Dallas FAN/Youth Angle's youth population.

Using the pagers has led the organization to investigate other ways of improving communication. "Young people don't want calls on their parents' home phone, so we looked to text messaging, Facebook, and MySpace to send reminders about appointments or reach out to those who have missed appointments and bring them back into care," says Cabrera. The organization also encourages youth to text a Dallas FAN/Youth Angle peer employee if they need someone to meet them at an appointment, a feature they have found particularly helpful in retaining patients during the months immediately after diagnosis.

Many of the staff members who are overseeing implementation of these technologies are young themselves. As such, Dallas FAN/Youth Angle documents all conversations to ensure that employees are abiding by HIPAA as well as their own internal consent regulations. Cabrera stresses that youth have to accept a friend request on Facebook to allow a staff member to send them a message and that staff know to send private messages and not post on a patient's public "wall." She emphasizes, "Using this technology allows youth to have a professional relationship with this peer, while the peer can relay to the care team what concerns or health questions have arisen. For instance, over the weekend we had a client who broke out in a rash and contacted our peer member rather than a clinical staff member, as that's who they were most comfortable with. The peer followed up with clinical staff and was able to address the client's concern in a way that included all team members."

Dallas FAN/Youth Angle has seen an increase in these kinds of inquiries from youth and is working toward using the instant messaging (IM) feature on Facebook to enable virtual chats with a doctor or other clinical care team member. The organization is still working out the details, but the likely scenario is a weekly time during which a care team member would be online and

available for questions. "We're trying to utilize technology that youth use. We also recognize that when youth are newly diagnosed, it's a very tentative time for them and they need a way to reach you that is noninvasive as well as comfortable and familiar to them," says Cabrera.

Cabrera warns organizations that are considering delving into social media that although they have much to gain, they need to be cognizant that whenever something new is put in place, a learning curve is involved. She offers the following advice:

▸ Avoid making social media involvement mandatory. Instead, enroll people in your social media efforts who are excited to be involved.

▸ Get buy-in from decision makers within your organization—and from clients!

▸ Don't make assumptions: Conduct lots of surveys about what technologies clients are really using.

▸ Add a "preferred method of contact" field to intake forms that allows clients to select social media platforms.

▸ Start small, potentially as a pilot program, to work through implementation difficulties.

▸ Respond to client needs using the social media platform with which they are comfortable.

▸ Realize that your social media strategy will continue to evolve as your clients' needs change.

▸ Recognize the possibilities—and limitations—of the technologies you are using.

▸ Look for opportunities to learn from local partners about what they are doing in social media, and share lessons learned.

▸ Contact social media sites and review their terms of service before launching your online presence, because some sites have specific guidelines regarding how public health information and entities can be integrated onto social media platforms.

PR CoNCRA
PR CoNCRA is focusing on reaching youth through online outreach efforts and is turning to its young employees to help do so. "Many of the 'peers' [employees] are used to these social media Internet platforms in their personal

ONLINE RESOURCES

Faces of Ryan White online feature
http://careacttarget.org/uploads/uploadform.asp

HRSA Facebook page
www.facebook.com/pages/Rockville-MD/Health-Resources-and-Services-Administration-HRSA/199893476843

HRSA YouTube channel
www.youtube.com/watch?v=SdLn7QIfdlw)

Postexposure Prophylaxis (PEP) Widget
www.ceiwidget.com/online/

Text4Baby, free text messaging to promote healthy birth outcomes
www.text4baby.org

TECHNICAL ASSISTANCE

101 Things to Do With a Mobile Phone in Healthcare
www.themobilehealthcrowd.com/?q=node/39

AIDS.Gov e-learning
www.aids.gov

Health Communicator's Social Media Kit
www.cdc.gov/healthcommunication/ToolsTemplates/SocialMediaToolkit_BM.pdf

HRSA TARGET Center Online Antistigma Campaign
www.careacttarget.org/feature_stigma.asp

Improving Your Web Presence
www.careacttarget.org/feature_web_presence.asp

New Media Toolkit
http://blog.aids.gov/new-media-resources.html

Ryan White Community National Online Networking for Grantees
www.careacttarget.org/community.asp

U.S. Department of Health and Human Services Center for New Media
www.newmedia.hhs.gov

Using New Media
www.aids.gov/using-new-media/

Using the Web to Search for HIV Care Services
www.careacttarget.org/feature/going_online_looking_for_hiv_care.asp

Increasingly, people are turning to the Internet to establish sexual, often anonymous, relationships. This practice is particularly popular among MSM and poses many challenges to HIV outreach and partner notification. In fact, online sexual hookups have become so popular among MSM that they have been called "gay takeout."[1]

According to a report by the Pew Institute and American Life Project, people who use the Internet to meet sexual partners are more likely to engage in riskier behaviors, have more sexual partners, and are more likely to have an STD.[2] In some areas of the country the trend of online hookups has sounded an alarm: In San Diego County, for example, 40 percent of reported syphilis cases in 2003 were from men who met their partners online.[3] This trend has only continued to increase over the years.

Online strategies were applied in HRSA's Special Projects of National Significance Program "Outreach, Care, and Prevention to Engage HIV Seropositive Young MSM of Color." Findings from the project presented at the National STD Prevention Conference found that

[t]o effectively reach high-risk MSM who use the Internet, skilled cyber health educators must be indigenous to the population served and must instill an emotionally supportive online atmosphere. Many men reported isolation and loneliness and were seeking "virtual" fraternity with gay/bisexual men. Therefore, this activity reaches sexually active men who may not be reached through traditional prevention services, providing a pseudo-anonymous environment in which to discuss sexual behaviors.[4] (To read more, visit http://hab.hrsa.gov/special/ocp_index.htm.)

In addition to outreach, organizations have also taken to Internet-based partner notification, defined by the Washington, DC, Department of Health as, "[an] investigative and case management tool that utilizes Internet locating information (e.g., e-mail and/or website screen names) in the process of notifying partners of individuals who have been diagnosed

with an STD."[5] According to a large U.S. study in *Sexually Transmitted Diseases*, more than 90 percent of gay men using the Internet to seek sexual partners are supportive of online partner notification.[6]

Several strategies and technologies are being used to increase testing and health care access. Online company Internet Sexuality Information Services has created inSPOT, an online partner notification system allowing users to send a postcard by e-mail to alert a sexual partner that he or she may have been exposed to an STD and invite them to be tested.[7] The card may be sent anonymously, or the infected person may disclose their identity.

Manhunt, the leading online dating website for gay men, is the first social networking site to address STDs.[8] Their public health website, Manhunt Cares, works with State health departments and community-based organizations. Newly STD-infected men share screen names of others possibly exposed. The trained public health professional then sends a confidential, private message to the screen name with help from Manhunt.

Manhunt differs from inSPOT in that the message originates from the public health official rather than the infected person and because screen names can be used, rather than e-mail. David S. Novak, former national syphilis elimination coordinator at CDC and current senior health strategist at Online Buddies, Inc., and managing director of the Online Buddies Research Institute, explains that Manhunt may be able to reach a larger number of people with its approach, because partners may not exchange e-mail before a hookup and e-mail may not be listed on a person's profile. Adhering to strict privacy policies, Manhunt Cares does not reveal the name of the infected person. In fact, in a *Sexually Transmitted Diseases* journal article, it was reported that this kind of partner notification (i.e., on a site like Manhunt) was found to be particularly effective.[9]

"It feels like this is really important work we're doing here," says Novak. "Though I'm in private industry now, I still have my public health and social work hats on. We approach our work from a public health standpoint, and as marketers, we ensure our message and design resonate with our audience."

City health departments across the country (e.g., Boston; Chicago; San Francisco; Washington, DC; and others) have been participating in epidemiologic assessments of this trend, establishing protocols, and performing their own Internet partner notification strategies.[5] On Manhunt alone there are 48 city health departments and counting. As with other social media approaches, Internet partner notification is evolving.

Health departments, of course, have a vested interest in case finding, bringing people in for testing, and enrolling them in long-term HIV care. To that end, many health departments have created organizational profiles on MSM-oriented social networking sites so that users can send them questions.[7, 10]

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lives," says Figueroa Santos. "They 'speak' the language, and the clients seem to be more comfortable communicating with them online," she says.

In addition, these young employees are more willing to go online at night during off-peak work hours. Figueroa Santos explains that in Puerto Rico, stigma surrounding HIV and MSM forces many people, especially YMSM, online to meet potential partners. "Not only do you have to go where your target population is, but you need to go online when they [go online], which for us means 8 to 10 p.m.," she explains. (See box, "Hooking Up Online.") The time PR CoNCRA staff go online is pertinent to their specific efforts because, unlike Facebook or Twitter, their online outreach happens in "real time," in chat rooms or by IM. (Note that national guidelines encourage full disclosure that an outreach worker is part of a health organization.)

Figueroa Santos says, "Everywhere there is a free service that links us to our clients, we're going to use it." She does caution, however, "Be careful with the person you're putting behind the computer to represent your organization, and ensure that person has high work ethic and values, because it can be tempting, especially for peers, to use these chat rooms for their own romantic relationships."

According to Figueroa Santos, quality assurance is essential: "Our supervisor goes online once a month to talk to clients who were reached online about information they received and checks every message that was sent out from the peer," she says. Remember, however, that supervisors are there to oversee, not "control" the exact messaging sent out; the communication needs to feel authentic, and that is something peers can offer.

In addition to using chat rooms and IM, PR CoNCRA advertises upcoming events on Facebook, similar to what Dallas FAN/Youth Angle does. One evaluation component PR CoNCRA is establishing is to ask participants where they learned about each event. This feedback can assist in determining whether the online outreach is effectively driving clients to the clinic and community outings.

National Minority AIDS Council

NMAC has found ways to repurpose its communications products and ensure that various social media platforms communicate with one another to get "the most miles" out of each product NMAC creates. For example, NMAC regularly distributes e-newsletters to its members and e-press releases to media outlets. Using Facebook, NMAC can redistribute these official messages. Facebook postings also drive traffic back to the organization's website and other social networking channels. For instance, Facebook followers are notified when a new NMAC video is available on YouTube. NMAC also sends personal messages to followers alerting them to testing events, congressional hearings, and opportunities to sign on to advocacy letters to members of Congress about AIDS and health-related legislation.

According to LeCompte, in addition to NMAC's Facebook page, "many employees have official pages that our constituents 'friend.' . . . Our virtual relationships help strengthen NMAC's standing in the AIDS community and beyond—and make the agency seem less remote and unapproachable to our constituents." For instance, submitting an e-mail to or telephoning an organization may seem formal and may therefore deter many people from reaching out. In contrast, posting a comment on a Facebook page—where this kind of interaction is encouraged—helps forge a stronger connection and allows members to understand what an organization is doing on their behalf. In turn, the organization can better understand the wants and needs of its constituents. Or, as Michelle Samplin-Salgado of AIDS.gov explains, "New media allows you to create a bridge between online communication and real life; it's a way to continue the conversation."

For the U.S. Conference on AIDS, NMAC used a photo-sharing site to allow conference participants to post their pictures and people who could not attend to see what was going on. In this way, NMAC staff created the foundation for "buzz," which constituents perpetuated.

NMAC has also been active on Twitter. LeCompte explains, "Twitter is a much less personal venue than Facebook, which has the essence of an online diary or scrapbook. [On Twitter], we update folks on stories and provide them with links to our website and other media channels for more information. We also 'retweet' other trusted AIDS Twitter sites….This helps position us within the AIDS community online, giving us greater credibility among those who use Twitter to find health and AIDS information." The organization has even tapped into Skype, an online phone system that enables simultaneous video transmission, to communicate in a more cost-effective way with constituents in Puerto Rico.

SETTING UP A SOCIAL MEDIA STRATEGY

The first step to establishing a social media strategy is to determine what type of media is best for your organization and is most accessible to—and most frequented by—your clients. Determine whether your organization is prepared for the online exchange that social media may bring. Be careful not to overextend yourself: Do not try all social media technologies at once, and recognize that social media in and of itself is not a strategy but a set of tools providers can use to extend their ongoing work and communication. LeCompte's advice to organizations considering social media is to tap into the available trainings on AIDS.gov and elsewhere and to learn from others who have successfully harnessed the promise of this new technology.

Involvement in social media requires familiarity with technology and time investment. Asking pointed questions about your organization's objectives and target audience, achieving buy-in, integrating social media with other organizational outreach or communication strategies, and ensuring capacity to execute social media, among other questions, is imperative to building the foundation of your social media endeavors. A strategy map, like that provided by AIDS.gov (http://blog.aids.gov/downloads/new-media-strategy-map.pdf)* offers many questions to consider before initiating social media or fine-tuning the organization's current approach.

Providers need to also think through legal questions, such as adherence to HIPAA requirements, as well as stylistic questions, such as what voice (e.g., formal or informal) they plan to use online and what kinds of items are appropriate for the site. If organizations choose an approach like that of NMAC and the Sixteenth Street Community Health Center, which involves both personal and organizational pages, then staff should discuss how the two types of pages will work together. And once Facebook pages and other social media are created, providers should inform not only patients but also key influencers (e.g., affiliated organizations, local reporters) who can help drive traffic to the site.

As with any approach, consistency is necessary to achieve success, and results won't happen overnight. If you aren't active or responsive, then people will quickly lose interest in your site. Providers must be realistic about the time commitment required to establish and maintain their social media endeavors. One way to ensure consistency is to designate a person in the office to take over in the event the key staff member is unavailable (whether because of sick leave, competing projects, or staff turnover) and to create internal guidelines so that messaging remains on point and approved topics of discussion are already outlined.

As the work of PR CoNCRA and Dallas FAN/Youth Angle highlights, peers (especially youth) may have greater familiarity with social media technology and require little technical training. At the same time, young people require more oversight; the reverse, however, may be true for veteran staff (although older staff and patients, in general, may be less attuned to social media and its everyday use).

Regardless of who spearheads your social media efforts, data collection strategies should be implemented. These could take place by using the tracking capabilities on Facebook (see the "Marketing" section) or the methods discussed throughout this article. In addition, alerts (e.g., Google alerts, at www.google.com/alert) or social media searches (e.g., www.socialmention.com) can be set up so that organizations are informed whenever someone mentions them. In addition, following your followers on Twitter and other platforms will help you hear what they are saying about you.

CONCLUSION

Tapping into social media is just one more way in which HRSA and Ryan White HIV/AIDS Program providers are engaging and retaining hard-to-reach populations. The approaches are evolving as technology permits, and providers are adapting their social media use to better address the needs of their patients and constituents.

Consistent with other Ryan White HIV/AIDS Program initiatives, the providers highlighted in this newsletter enlisted peers to help them identify effective strategies and use word of mouth to promote their social media initiatives once they went "live." As with all technology, providers are having the most success when they ensure buy-in up front, establish some kind of quality assurance capabilities, start small, and evolve as capacity increases and client needs shift.

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