Technology Profile: Online Social Media Sites

Overview

Online social media sites allow individuals to connect to health information, share knowledge and experience, provide personal support, and collaborate with other users online. These sites can also provide an environment for learning skills to support self-care. Social media applications can operate through a variety of web-based communication tools including blogs, wikis, podcasts, social networks, instant messaging, and video file-sharing.

A major benefit of online social media and what may explain their popularity is the unique experiences created with virtual networking. Patient-centered knowledge exchange and support make online social media a very powerful healthcare platform that can transform the manner in which patients' access information and can influence the design, development, and delivery of future healthcare services.

Technology	Online Social Media Sites
Applications	Health education and promotion, social support
Comparison Technology	N/A
Vendors	PatientsLikeMe, DiabetesMine, iMedix, WeAre.Us, Starbright World
Drivers	N/A
Barriers	Privacy and security, limited research, non-moderated content
Cost	N/A
Reimbursement	N/A

Applications

Children, and teens in particular, are among the more active users of social media and are attracted by the ease and simplicity by which they can communicate. In many instances, the use of social media is already a central part of teen culture and personal lifestyle. Specific areas of social media where young people are generally active include blogging and social networking sites to communicate and stay in contact with friends (e.g., MySpace, Facebook). Teens, particularly girls, are also active in the creation of content.[1]

Public health services have been quick to adopt social media tools. The US Centers of Disease Control and Prevention (CDC) established the National Center for Health Marketing (www.cdc.gov/healthmarketing) to serve as an outreach strategy to communicate with the public on a broad range of health-related issues. Applications being explored by the Center include social networking, Twitter, and virtual worlds.

Social networking sites provide services that connect patients with other patients as well as to other stakeholders in health care (e.g., clinicians, researchers, health plans, vendors). Patients have used web-based social networking services to exchange knowledge and share experiences on the management of their conditions. Clinicians and researchers have also used social networks to educate and promote preventive health and to respond to their patients' needs.

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[1] Pew Internet & American Life Project "Teens and Social Media." December 19, 2007. Available from: www.pewinternet.org/Reports/2007/Teens-and-Social-Media.aspx

Social Media Sites for Health and Wellbeing

Targeted Need	Social Media Example	Description
Children with life threatening Illnesses	Starbright World www.starlight.org/starbrightworld	A site for seriously ill teens and their teen-aged siblings. Whether from home or the hospital, members are able to get to know other teens from around the world who are going through similar experiences.
Targeted Need	Social Media Example	Description
Families with sick children	Sophia's Garden www.sophiasgarden.org	A site that combines the richness of real-life collaboration with online learning to help families of children with life-threatening and chronic conditions harness the power of community to address all of their needs.
Parenting and prevention	iParent Network www.iparentnetwork.org	A broad based community coalition of parents, professionals and other community members from three small towns. The mission is to equip parents with the tools to be prevention experts so our youth develop in healthy and safe ways.
Patient support groups	PatientsLikeMe www.patientslikeme.com	A more effective way to capture valuable results and share them with patients, healthcare professionals, and industry organizations that are trying to treat the disease.
Storytelling	Center for Digital Storytelling www.storycenter.org	Organization assisting people in using digital media to tell stories from various facets of their lives, such as education, health, and family.
Mental health	Real Mental Health www.realmentalhealth.com	The online community includes individuals, their family members, loved ones and friends who want to easily and interactively obtain knowledge about mental health symptoms and treatments in a supportive community environment.

More recently, virtual worlds have emerged to provide opportunities to interact and participate in specialized communities. Users can engage in a range of activities such as building shared content, obtaining information and playing games. In virtual worlds, people can participate in an immersive environment that allows users to create a virtual persona or avatar that can interact in a variety of virtual experiences that promote and facilitate the in-world practice of healthy behaviors. Evidence to date suggests that such an approach leads to sustainable behavior change in the real physical world. In Second Life (www.secondlife.com) there are currently communities dealing with autism, stroke, and cancer. Persons with disabilities can lead a virtual life they can only dream of in the physical world.

The CDC is currently participating in several virtual worlds as a means to educate and influence healthy behavior. For example, they have targeted health promotion and disease prevention campaigns in Whyville (www.whyville.net) a virtual world popular with children between the ages of 8 and 15. Children can get their avatar virtually vaccinated or practice regular hand washing to prevent the flu. Participants have learned "first-hand" about epidemics when flu was introduced into the virtual community and those

who were not practicing prevention methods became infected. Participants in the virtual world were also used as intermediaries to communicate key public health messages to older family members.

Another emerging online social media platform is Twitter, where users send and receive short text-based updates no longer than 140 characters in length. Twitter works very much like social networking in that updates are posted on a user-profile page and shared with other users who have self-selected to be part of that network. Twitter has been used by government, for profit and nonprofit agencies to provide health, wellness and prevention updates.

Barriers

A technology barrier is the rapid life cycle of consumer technology and limited evidence base to support broad use in health care. Investment in this approach for now is restricted to experimentation rather than more formal broad-based applications. The main barrier preventing rapid development and dissemination of online social media is a concern about patient privacy and confidentiality. Another apprehension is the potential risk of non-moderated content and to reduce this problem some sites have health experts who provide advice and moderate the content.

The Future

These technologies have in common the ability to reach a large number of people in a short period of time. This aligns best with health promotion activities. Therefore, we should expect to see public health departments and national groups use this media to more effectively communicate with youth and change health behaviors. A trend in online social media is the effort to create portals around communities of interest that engage users by consolidating resources, services, and provide applications that support specific health needs. As the current adolescents and young adults move into roles in health care they will create exiting and innovative ways to use this class of technologies to interact and communicate.

To access additional background, forecast, and policy materials, please go to
www.childrenspartnership.org/HITInnovationForChildren