Using Social Media to Build an Online Community: Learning By Doing

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Abstract and Objectives

37% of American adults access user-generated online health information[1]*. Using social media, consumers build online support communities. In this workshop, participants use social media to build an online community before the Congress and then at the Congress discuss both that experience and research findings regarding (1) potential benefits for underserved populations, (2) privacy risks, (3) ethical considerations, and (4) evaluation of online communities. The workshop online community and online consumer support groups are compared and contrasted.*

The particular social media used are an e-mail list, a blog, a Facebook group, and Twitter. Blog posts are about the workshop, the Congress, consumer health informatics, and social media. Presenters of other programs are also invited to post. Online group dynamics are highlighted. Tweeting and displaying a live Twitter stream during the session at the Congress enables those who do not attend to continue to participate.

After the workshop, participants should be able to use different social media to build an online community; give examples of potential benefits for underserved populations, privacy risks, and ethical considerations; and evaluate online communities.

Keywords

social networks, support groups, Internet, medically underserved areas, privacy, clinical ethics, group process.

Workshop description

This workshop starts before the Congress with an experiential component during which participants use social media to build an online community. That firsthand experience together then informs the session at the Congress, which focuses on the potential benefits of social media for underserved populations, privacy risks and ethical considerations in the use of social media, and the evaluation of online communities. A team of instructors with different areas of expertise facilitates the use of the different social media before the Congress and the discussion at the Congress.

Potential benefits for underserved populations (Wetter)

Consumer health informatics has targeted populations defined by medical condition, education, location etc. In parallel, utilization of the Internet and mobile phones has surged, especially in populations and regions with restricted—if any—access to medical services. Therefore, consumer health informatics may have a specific potential to assist many such underserved populations. Social media may turn out to be enabling technologies because their broad and easy utilization lowers barriers to seeking information and giving and receiving advice. On the other hand, such populations may be more vulnerable because they are typically also deprived of other basic resources. In this workshop, we assemble the state of the art of consumer health informatics for underserved populations and identify

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Fox S, Jones S. The Social Life of Health Information. 11 Jun 2009. http://www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx its opportunities and risks.

Privacy risks (Adams and Grandison)

Privacy in social media is a young field in which there is growing interest. One risk to privacy is the increasing revelation of personal (health) information in health-related blogs. It is especially interesting to consider this in light of two discussions: one within medical informatics about patient privacy and the use of other technologies, such as electronic patient and personal health records, and one within Internet studies about whether or not individuals understand network externalities and how the information they disclose in various social media spaces is being used. Another risk to privacy is confusion between the expectations of social network users and the default privacy settings of social network applications. There is an explosion in the number of social networks, in the number of people using multiple networks, and in the number of privacy settings being offered by each network. Privacy may be safeguarded by providing users with a representation of their privacy state as a privacy risk score, promoting privacy interoperability between networks, and by enabling data analytics on anonymized social network data.

Ethical considerations (Nagel and Anthony)

The use of social media for psychotherapy and peer support presents opportunities and risks for mental health care providers and consumers. Social media provide instant communication from robust (blogs and online journals) to brief (tweets and Facebook updates). Understanding the implications for confidentiality and the possibility of dual relationships is essential to protecting the integrity of the clinician-client relationship. In addition, providers should support and promote ways for consumers to engage in peer support safely and securely.

Evaluation of online communities (Nelson and Anton)

Quality health care requires an educated consumers who takes an active role in managing their health. A major responsibility of health care providers is ensuring that consumers obtain that education. Historically, they were responsible for providing the educational content; however, today, they are responsible for the health information literacy of consumers. With 46% of American adults now using social networks2, these tools can be a major resource for consumer health education. Consumers need to know how to use social networking online communities effectively in managing their health. This includes: (1) What to expect. The consumer should begin by developing realistic goals. Being pregnant and seeking to share the experience with others is different from being seriously ill and seeking information about treatment. The consumer should also think about the time and activities that are needed to establish a relationship with an online community. (2) How to find a group. Some online communities are established by health organizations, others by patients or family, and others by companies. It is important for the consumer to evaluate the motivation of the individual or group who is maintaining the online community. (3) How to join a group. Consumers should take the time to learn the privacy setting options available before submitting personal information. They should lurk until they appreciate the culture. (4) What "rules of thumb" there are for participating. When should the consumer lurk or post? How and when should they use private chat? Is there a moderator and if so, what role do they play in discussions? (5) How to leave a group. If someone has been very active and then disappears it can be a concern for the other members.

Before the Congress

Participants use social media to build an online community before the Congress. An experiment will be set up ahead of time for all interested conference participants to gather experience which will then be augmented and summarized in the workshop. The social media used are an e-mail list, a blog, Facebook, and Twitter. Health-related blogs have matured into tools for education, discussion, and collaboration among consumers and providers. Twitter has become the most popular micro-blogging service and is now being commonly used in the health care community to communicate, brainstorm, and educate. Participants are expected to be familiar with e-mail lists. Dr. Daviss (who will not attend the Congress) blogs about the workshop, the Congress, consumer health informatics, and social media. Presenters of other programs at the Congress are also invited to post. A Facebook group provides an unthreaded wall and a threaded discussion board and enables the creation of events and the exchange of photos and videos. Instructors tweet as @medinfo_socmed, and the blog also automatically tweets links to posts. Using the #medinfo hashtag simplifies following the Twitter stream.

E-mail invitations are sent to the entire Congress community, first to those who requested information or submitted proposals and later to those who register. The invitations explain how to subscribe to the e-mail list and join Facebook and Twitter, where to find the blog and the Facebook group, and how to follow the Twitter stream. No one is required to participate, and no one is automatically subscribed to any service.

Dr. Roth (who will not attend the Congress) and Mr. Sinisi (who will not attend the Congress) comment on the online group process. Group process refers to the patterns and manners in which group formations and behaviors unfold. Conscious and rationalized

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Lenhart A. The Democratization of Online Social Networks. 8 Oct 2009. http://pewinternet.org/Presentations/2009/41--The-Democratization-of-Online-Social-Networks.aspx behaviors are understood as simultaneously rooted in and impacted upon by the unconscious motivations of the individual group members, the group as a whole, and broader sociopolitical and cultural formations. No individual's behavior can be understood without also considering it as a simultaneous expression of the group's quest to establish and distinguish itself, affiliate, survive, generate norms, adopt roles, establish hierarchies and project its identity in relation to those groups that surround it. Developing an awareness of these processes allows for the possibility of engaging that group on its own terms and from within its own consciousness.

At the Congress

The experience of using social media together before the Congress is discussed and augmented at the Congress. The workshop itself will have a physical presence and a virtual social media based thread coming together during the workshop time slot of the Congress. The session begins with open-ended reflection by participants on their experience using social media together. The workshop online community and online consumer support groups are compared and contrasted. The presenters then discuss (1) potential benefits for underserved populations, (2) privacy risks, (3) ethical considerations, and (4) evaluation of online communities. Some instructors cannot travel to the Congress and present electronically. The live #medinfo hashtag stream is displayed at the session, so a text discussion including participants not in Cape Town takes place simultaneously with the discussion in the room.

The discussion is enriched by the firsthand experience of having used social media to build an online community. For example, it may allow participants unable to travel to participate in the session at the Congress; participants may disclose personal information, including personal health information, online before the Congress; clinicians may be noticed on Facebook or Twitter and be "friended" or "followed" by their clients; and participants may themselves be unsure about when to lurk and when to post.

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Expected attendees and goals

The workshop is devoted to academics, consultants, educators, government officials, health informaticians, health professionals, lawyers, and researchers interested in the use of social media in health care.

After the workshop, participants should be able to use different social media to build an online community; give examples of potential benefits for underserved populations, privacy risks, and ethical considerations; and evaluate online communities.

Workshop instructors

- Robert Hsiung, MD, DFAPA, Department of Psychiatry and MacLean Center for Clinical Medical Ethics, University of Chicago, founded and oversees Psycho-Babble, an online peer support group with over 900,000 posts to date. He has co-led four online groups at meetings of the American Group Psychotherapy Association and edited “E-Therapy: Case Studies, Guiding Principles, and the Clinical Potential of the Internet” (Norton). He is a past president of the International Society for Mental Health Online. As @dr_bob, his Twitter Grade is 93.
- Dr. Thomas Wetter, Full Professor of Medical Informatics, Institute of Medical Biometry and Medical Informatics, Heidelberg University, is a vice chair of the IMIA Consumer Health Informatics working group, will release a tailored diabetes primary prevention web service in 2010, and is writing a textbook for Springer.
- Tyrone Grandison, PhD, leads the Intelligent Information Systems team in the Computer Science department at the IBM Almaden Research Center, where one of his projects is to develop theoretically sound and practically efficient privacy-protecting methods and systems that will produce valid data analytical results without disclosing private information, alleviate the cognitive burden of social-networking users in managing their personal information, and enhance the public awareness of privacy protection. He was the 2009 National Society of Black Engineers Pioneer of the Year and a 2009 Black Engineer of The Year Science Technology Engineering and Mathematics Modern Day Technology Leader.
- Samantha Adams, PhD, is Assistant Professor of Information Technology and Patient Participation at the Department of Health Policy and Management (iBMG) of the Erasmus University Medical Center. Her work has included extended research on constructing the reliability of health web sites and shorter-term projects on health care-related blogging, public participation in hospital decision-making, and agenda-setting in biomedical research. She has published in the International Journal of Medical Informatics and Science, Technology & Human Values, and other journals.
- DeeAnna Merz Nagel, LPC, DCC, is a psychotherapist, consultant, international expert on online counseling and the impact of technology on mental health, and a past president of the International Society for Mental Health Online. She specializes in text-based counseling and supervision, assisting individuals and families by normalizing the use of technology and social media and helping them to overcome Internet and cybersex addictions, and ethical considerations for the mental health practitioner.
- Kate Anthony, MSc, FBACP, is a psychotherapist, consultant, and international expert on online counseling and the impact of technology on mental health, and a past president of the International Society for Mental Health Online. She runs

onlinecounsellors.co.uk, a training company for mental health practitioners who work with clients online. She has published on the use of e-mail, bulletin boards, IRC, videoconferencing, and virtual reality in the practice of psychotherapy.

- Ramona Nelson, PhD, RN-BC, FAAN, ANEF, is president of Ramona Nelson Consulting and Professor Emerita of Nursing at Slippery Rock University. Her primary area of research is nursing informatics with a focus on theoretical concepts in nursing informatics, consumer informatics, and distance education. Her latest book is the 5th edition of Introduction to Computers for Health Professions (Jones & Bartlett). She is a fellow of the American Academy of Nursing, a nursing education fellow of the National League for Nursing (NLN), and the chair-elect of the NLN Educational Technology and Information Management Advisory Council. In 2008, she received the annual Recognition Award from the Rutgers University College of Nursing for the advancement of computer technology in health care.
- Bonnie B. Anton, RN, MN, eRecord Administration Department, UPMC St. Margaret Hospital, is the project manager for the development and implementation of electronic order sets used in the electronic health record, is the 2009-2010 chapter president of Western Pennsylvania Hospital Information Management System Society, and has over 20 years' experience as a registered nurse in acute care settings.
- Steven R. Daviss, MD, DFAPA, chair, Department of Psychiatry, Baltimore Washington Medical Center, and Clinical Assistant Professor, Department of Psychiatry, University of Maryland/Sheppard Pratt, is also co-chair of the Behavioral Health Work Group of the Certification Commission for Health Information Technology, co-editor of “Shrink Rap”, a psychiatry blog, and producer of “My Three Shrinks”, a psychiatry podcast. As @HITshrink, his Twitter Grade is 95.
- Jeffrey D. Roth, MD, is Medical Director of Working Sobriety, an intensive outpatient treatment program for recovery from alcoholism, chemical dependence, and other compulsive behaviors, and workingsobriety.com, a recovery assistance program. He has been the director of 5 and a staff consultant at 16 group relations conferences and a lecturer in the Department of Psychiatry at the University of Chicago. He is the president of the Chicago Center for the Study of Groups and Organizations of the A.K. Rice Institute and the editor of the Journal of Groups in Addiction and Recovery.
- Vincenzo Sinisi, MA, is a clinical psychologist in private practice. He sees adults and adolescents for psychoanalytically and group-analytically informed individual and group psychotherapy.