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Butt, Carmen M. The Role of Social Media within Participatory Medicine: Methods to Establish User-centered Design to Promote Digital Literacy

Abstract

In health care, participatory medicine, a movement in which health care providers allow patients to digitally connect and take an active role in their health care, is changing the way that patients engage in health care. Participatory medicine provides self-help options such as scheduling appointments, paying bills, retrieving their personal medical records, connecting with their physicians, and interacting with other patients through social media support groups. Overall, the health care industry has been slow to adopt social media, but recently health care institutions have become more innovative through creating apps that are user-centered for both healthy and chronically ill patients. Although health care institutions offer social media, many patients and prospective users are not digitally literate and therefore do not maximize their use of participatory medicine. Health care institutions are dedicated to developing creative methods to satisfy patients and prospective users of social media while following HIPAA guidelines, which protect patient privacy. Technical communicators could serve a role to provide health care institutions with tools to analyze usability and create content that is user-centered to promote a positive health care experience.

Keywords: health care, participatory medicine, social media, privacy, technical communication

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Chapter I: Introduction

Almost everywhere we go, someone is using a social networking tool on their cell phone, tablet, or laptop. Social media, which was introduced in 1997, has become a new way to communicate with friends and family (Boyd & Ellison, 2007). According to Pew Internet (2012), 66% of adults who go online use social networking sites. In addition to a communication method for friends and family, social media is also a growing tool for businesses to spread information to mass audiences and to connect with their clients. Health care institutions are one industry that is utilizing social media to connect with patients and prospective clients, and to promote new developments in health care.

Furthermore, health care institutions are using social media as a tool to engage in the participatory medicine movement. Participatory medicine is a movement in which "networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners" (Frydman, 2010). According to Millenson (2011), the participatory medicine movement began in 2001 when the Institute of Medicine introduced *patient-centered care*. This movement allows health care institutions to offer patient centric health care in which the ideas that the health care institutions develop are designed to optimize the patients' care (Frydman, 2010). Health care institutions use participatory medicine, and especially the social media component, to increase patient satisfaction. Renowned health care institutions such as Mayo Clinic and Cleveland Clinic have found themselves at the forefront of the latest technological advances in participatory medicine and are sharing these advances through various forms of social media.

Some health care institutions that have recently joined participatory medicine have placed social media icons on their websites, but have not developed an organizational plan or fully

adopted the use of social media within their health care institution. A wide range of social media experiences, including intermittent use of social media to active use of social media exists among health care institutions.

Patients and others who seek health care information possess a wide range of experience using social media as well. As patients and others become more active users of social media in the participatory medicine movement, health care social media coordinators and public relations specialists will likely direct their attention to usability of social media. In addition, technical communicators may also serve essential roles in health care institutions' administrative teams as health care providers strive to improve digital literacy through user-centered design. Social media will likely change the way in which patients and others retrieve health care information and communicate with health care providers.

Statement of the Problem

Social media is growing at a rapid pace. Individuals are using social networking tools as quickly as they are introduced. They use social networking tools to find information about businesses, including health and health care institutions. However, health care institutions, as a whole, have been slow to adopt social media because of the risks involved with adopting this method of communication. Many health care institutions use social media, but a study is needed to define the existing methods in which health care institutions are using social media, and to determine how health institutions can maximize the use of social media to increase connections with patients and future clients, while improving their health institutions' image and identity among other competitive health care organizations. In addition, some users may not be digitally literate, and therefore not possess an understanding of the content or how to participate in social

media. Health care administrators will need to assess their patients and users to determine how to create a user-centered platform to increase their presence in participatory medicine.

Purpose of the Study

This research study attempts to answer which social media tools health care institutions use, how these institutions use social media, and the benefits and risks of health care institutions' use of social media for public relations and for the distribution of health information. Health care institutions vary in their offering of social media tools, as well as in their social media usage. Some health care institutions use social media such as Facebook and Twitter daily to connect with patients and community members, while other health care institutions appear as intermittent users of social media. Social media use is still rather new to the health care field and thus is a topic that warrants further investigation to determine social media's role in health care public relations.

In addition, the study will address the role of social media within participatory medicine frameworks and suggest methods to establish user-centered social media to improve digital literacy. The participatory medicine movement can be seen through patients taking control of their health care decisions. Social media has become a visible tool to promote the participatory medicine movement; however, not all patients are digitally literate, and therefore health care institutions require additional assistance to meet the needs of patients and community members. Usability testing and user-centered design may possibly aid health care institutions to advance the use of their social media.

Assumptions of the Study

With the relatively new use of social media among health care institutions, tools, benefits, and risks of social media are in question, but some assumptions of the study exist, including:

- 1. Social media is a new communication tool in the health care field.
- 2. A public relations representative is involved in the direction of social media within health care institutions.
- 3. Health care institutions that are using social media have discussed the use of social media with health care administrators.
- 4. Health care institutions are using social media to promote their services and organizations.

Definition of Terms

Several key terminologies are important to understand the health care field and social media use to communicate with health care personnel, patients, and future patients.

Baby Boomer – The generation born between 1946 and 1964. "The 79 million member Baby Boomer generation accounts for 26% of the total U.S. population" (Cohn, Taylor, 2010).

Blog – "A Web site that contains an online personal journal with reflections, comments, and often hyperlinks provided by the writer" (Merriam Webster's Dictionary, 2012).

Digital divide – "A term used to describe the discrepancy between people who have access to and the resources to use new information and communication tools, such as the Internet, and people who do not have the resources and access to the technology. The term also describes the discrepancy between those who have the skills, knowledge and abilities to use the technologies and those who do not." (Webopedia, 2012).

Digital literacy – "Theory and practice that focus on use of digital technology, including the ability to read, write, and communicate using digital technology, the ability to think critically about digital technology, and consideration of social, cultural, political, and educational values associated with those activities." (Trepte & Reinecke, 2011).

e-Patient – A patient who" can access and share information interactively." (American Academy of Orthopaedic Surgeons, 2012).

Facebook – A social networking tool that allows people to digitally connect. "Facebook's mission is to give people the power to share and make the world more open and connected" (Facebook, 2012).

Foursquare – A social networking site that allows users to share their location. "Users also earn points and 'badges' for checking in frequently, or at a certain time." ("What is Foursquare?", 2010).

Health care institution – "Any hospital, convalescent hospital, health maintenance organization, health clinic, nursing home, extended care facility, or other institution devoted to the care of sick, infirm or aged person" (The Lectric Law Library, 2012).

HIPAA – The Health Insurance Portability and Accountability Act of 1996. "The HIPAA Privacy Rule provides federal protection for personal health information held by coveted entities and gives patients an array of rights with respect to that information" (U.S. Department of Health and Human Services, 2012).

Linked In – "A business-oriented social networking site that enables users to connect with colleagues, look for a job or business relationships and get answers to industry questions" (PCMag.com, 2012).

Millennial – "The American teens and twenty-somethings who are making the passage into adulthood at the start of the new millennium" (*Millennials: A Portrait*, 2010).

Needs assessment – "An analysis of requirements. It determines what people, functions, or systems are currently lacking in order to achieve goals of an organization" (PCMag.com, 2012).

Organizational plan – "The end result of the process of setting medium and long term objectives for an organization and then developing a strategy to accomplish those goals" (BusinessDictionary.com, 2012).

Participatory medicine – "A cooperative model of health care that encourages and expects active involvement by all connected parties (patients, caregivers, healthcare professionals, etc.) as integral to the full continuum of care" (Society for Participatory Medicine, 2012).

Patient-centered care/Patient-centered medicine – "As a form or practice, it seeks to focus medical attention on the individual patient's needs and concerns, rather than the doctor's" (Bardes, 2012).

Pinterest – An online pinboard to organize and share information (Pinterest, 2012).

Protected health information (PHI) – "Any information that concerns health status, provisions of healthcare, or payment for healthcare that can be linked to an individual" (Bariatric Nursing and Surgical Patient Care, 2012).

Social media – "A form of electronic communication (as Web sites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (as videos)" (Merriam Webster's Dictionary, 2012).

Social Network – "A community of people who share similar interests and activities who interact through online and mobile technologies" (Eytan, et. al, 2011).

Social Networking – "A Web site that provides a virtual community for people to share their daily activities with family and friends, or to share their interest in a particular topic, or to increase their circle of acquaintances" (PCMag.com, 2012).

Tweet – "A post made on the Twitter online message service" (Merriam Webster's Dictionary, 2012).

Twitter – "A very popular instant messaging system that lets a person send brief text messages up to 140 characters in length to a list of followers." (PCMag.com, 2012).

Usability – "How well users can learn and use a product to achieve their goals and how satisfied they are with that process." (Usability.gov, 2012).

User-Centered Design – "It is a structured product development methodology that involves users throughout all stages of Web site development, in order to create a Web site that meets users' needs." (Usability.gov, 2012).

Virtual community – "A group of individuals who share a common interest via e-mail, blogs, instant messages, chat rooms or newsgroups." (PCMag.com, 2012).

Web 2.0 – "A second generation of the World Wide Web that is focused on the ability for people to collaborate and share information online." (Webopedia, 2012).

YouTube – "YouTube allows billions of people to discover, watch and share originally-created videos. YouTube provides a forum for people to connect, inform, and inspire others across the globe and acts as a distribution platform for original content creators and advertisers large and small" (YouTube, 2012).

Limitations of the Study

Limitations of the study include the number of responses received. Only 6 of 38 health institution personnel responded to the request for an interview and 4 of those 6 responded to the interview questions. Information from the interviews is based on information from health care institution personnel who are actively engaged in using social media at their health care facility.

Another limitation is that the researcher assumes that the participants will answer the questions honestly given that they received no reimbursement for completing the interview questions. In addition, the researcher expects that the information provided by the participants is accurate and represents their health care institution. Due to time constraints and availability of the participants, the researcher limited the questions to the number initially asked and did not conduct follow up interviews. Valuable and pertinent data was collected and is reflected in Table 1, which contains the responses from participants.

Methodology

Contact information for the public relations, social media, or IT departments at the health care institutions that were canvassed was obtained online. The personnel from these small, medium, and large health care institutions from across the United States were then contacted through email and telephone during a period from March 1, 2012 through April 30, 2012. Health institution personnel were invited to participate in a research study involving the use of social media by health care institutions. Participants signed a consent form and then received the interview questions through email or by a Skype interview. (See Appendix A for a complete list of questions.) The University of Wisconsin Stout Institutional Review Board (IRB) approved the study, and interview questions were disbursed to the participants who signed the consent form.

Chapter II: Literature Review

Introduction

Each year as the world becomes more innovative, and new technology is introduced, the use of social media and new technologies becomes more addicting (Kneipp, 2012). The use of social media has transformed the world. Not only are individuals using social media sites like

Facebook and Twitter, but many businesses have also adopted these communication tools as a way to connect with their current and prospective clients. Social media has many benefits, but also legal issues when connected with businesses, especially the health care field. Health care institutions have been passive to embrace social media because of the risks involved. Although health care institutions in the United States are slowly adopting social media for marketing purposes, other countries are using social media to connect with patients. For example, the Netherlands, Norway, Sweden, and United Kingdom have high levels of hospital social media adoption (iHealth Beat, 2012). Although these countries are actively using social media in health care, in general the health care industry is less proactive than other industries in adopting social media (iHealth Beat).

Still, over the past year health institutions in the United States have implemented social media and developed social media plans to keep up with the growing **participatory medicine** movement. Additionally, and to accomplish this task, health care institutions have gathered together administrative teams of public relations, technical communicators, information technology, and health care administrators. **Usability** and **user-centered design** are important concepts for such administrative teams to consider while implementing a social media plan or updating website design and content in order to meet patients' needs and the health care

community. According to Neuhauser and Kreps (2003), research suggests that health communication is more effective when it reaches people on an emotional as well as a rational level, relates to people's social contexts, is a combination of interpersonal communication and mass media, and is interactive. Social media provides patients and those concerned about their health with a communication method to connect to both their health care institution and patients who may experience similar health issues. As patients and others continue to use social media to retrieve health care information, health care institutions will employ tools for usability and user-centered design to address patients' needs and abilities to improve **digital literacy** in participatory medicine.

Social Media Background

The Internet and mobile technologies have changed the way people retrieve information and how they socialize. The Internet provided patients with a way to search for health information using such websites as WebMD, National Institutes of Health, Medicine.Net, and Mayo Clinic. These websites provide users with a description of common health issues, symptoms, and treatment options. Websites are usually more static, whereas social mediums are interactive because of their ability to offer a discussion between two or more people. Moreover, information has increasingly become portable, personalized, and participatory (Percell, et. al , 2010). The penetration of smart phones into society has significantly changed the way in which people are searching for information. More than half of American cell phone customers use smart phones (Goldman, 2012), which allow them access to the Internet any time and any place.

Social media is an instantaneous communication channel that allows individuals to communicate quickly and easily. Users receive more immediate feedback through using common social networking tools and apps. Current popular social media sites include Twitter, Facebook,

LinkedIn, and YouTube; in addition, millions of individuals publish their thoughts and interests through blogs (Backman, 2011). Social media has accelerated into a popular form of communication because of its ability to facilitate talking as well as listening. Like face-to-face communication, social media provides a two-way communication channel for users to share information and is becoming increasingly popular. Downloading of apps to Apple iPhone and Google Android devices rose by 28% from 2011 to 2012, averaging 41 apps per smart phone (Goldman, 2012). Health care institutions are beginning to develop their own applications (apps). One example is Boston's Children's Hospital, which has developed Boston's Children's Hospital MyWay app for parents to access their children's health records, physicians, request appointments, and more (Dolan, B., 2012).

On an individual level, people have been using social media for several years, and it is not just the younger generations using it. According to Pew Internet Research (Madden, 2010) in a social networking use among American Internet users ages 50 and older nearly doubled—from 22% to 42%—between April 2009 and May 2010. During this same time period, the survey also found that half of users ages 50–64 and one in four users ages 65 and older used social networking sites (Madden, 2010). A report from eMarketer, a New York-based business information service, shows that online penetration among users ages 65 and older in the United States is beginning to rival newspaper and radio usage (Frogatt, 2011). Not only is social media use increasing among millennials, but also among baby boomers. Millennials, however, according to Madden (2010) are still the heaviest users of social media.

Although social media is widely used on an individual scale for personal use, many businesses are just beginning to join the social media bandwagon. According to Sarringhaus (2011), "Social media is still in its infancy and its depths are undiscovered and its advantages are

only partially realized." The advantages of social media are that the online tools bring people together and give them a place to share information. Many customers use social networks to share information about experiences where they have conducted business with companies or organizations. Future clients review businesses through analyzing posts made on social media networks prior to conducting business with companies. In addition to evaluating businesses, social media is also used to share information with the public, such as community events and news involving the company or organization.

Although health institutions have been apprehensive to adopt social media, in the past five years there has been an influx of hospitals and medical organizations using social media to build community relations and to establish brand identity. Many health institutions are using social media to create awareness of their brand, but need further training and an organizational plan to maximize the use of social networking tools to connect with patients and employees. A variety of social networking tools already exist, but many more emerging. Health care administrators will need to gather together to discuss the best **social networking** tools to meet the needs and abilities of their patients and prospective users.

Social Networking Tools

Social media is not only a social tool to use to connect with friends and family, but it is also a line of communication that health care institutions use to connect with the public. Sharp (2011) explained, "Social media is here to stay in health care, but it will evolve quickly." He added that patient engagement will continue to characterize this change and organizations will be forced to use social media tactically within their overall marketing and communications efforts (Sharp, 2011). Social media is not a fad. "The Internet and social media are not going away," said Dr.

Mukewar, a researcher from Cleveland Clinic. Social media use is only expected to increase, therefore, health care institutions will need to find innovative ways to use social media.

With the knowledge that consumers are actively using social media to find health information, administrators may be eager to delve into the social media revolution and adopt several social networks. However, the Center of Disease Control (CDC) suggests beginning a social media project that is considered low risk and uses only a few resources, and then slowly acquiring more resources and support (CDC, 2012). Choosing which social media resources to use can be determined by reviewing user statistics and demographics (CDC). Different social media tools target different groups of people. Health communication disseminated through social media should be accurate, consistent, and science-based (CDC). A variety of social media channels exist for which health care institutions can use to distribute and share information.

Blogs were one of the first social media forums in which users could share information through providing content on a blog post and also providing feedback on other users' blog posts. "Many patients and family members of patients with chronic illnesses use a blog to create an online support group for others with or caring for patients with a particular ailment" (American Academy of Orthopaedic Surgeons, 2012). Kevin MD (2012), also known as Dr. Kevin Pho, explained that a blog is a home base and foundation for any social media plan. Dr. Pho's blog on Kevin MD includes information on medical ailments, health care policies, and breakthroughs in treatments (Kevin MD, 2012).

Many health care institutions have started using Facebook and Twitter, two of the most familiar social media tools. Mayo Clinic has the most popular medical provider channel on YouTube as well as an active Facebook page with over 65,000 connections (Mayo Clinic Center for Social Media, 2012). Facebook is a common social media tool used by hospitals and other

health institutions. Most health care institutions are using Facebook as an extension of their marketing plan (ECRI, 2012). Health care institutions' Facebook posts tend to focus on general medical news and the health care institution's services and events (ECRI, 2012).

In addition, Twitter is also used to connect users and takes the form of a mini-blog. Twitter members send more than 200 million tweets a day (International Telecommunications Union, 2012). Although each tweet is a maximum of 140 characters, Twitter is a useful communication tool to spread contextual information to a large group of people. Kevin MD (2011), suggested that health care institutions should begin their social media plans with Twitter. Twitter has less room for liability issues and limits how much people can engage with health care institutions, so it is less likely that clients will share private health care issues (Kevin MD, 2011).

Many health care institutions use Twitter to connect to consumers. Mayo Clinic has more than 260,000 followers on Twitter (Mayo Clinic Center for Social Media, 2012). Health care institutions are finding ways to maximize the use of Twitter because of the ability to gather information from a wide variety of users. One example of Twitter's use in health care is that in 2010, it was used to track reported cases of influenza and the symptoms associated with the illness (Schmidt, 2012). The use of Twitter provided physicians with useful information to determine locations of illnesses. In a study by Nicholas Christakis, Harvard University professor and James Fowler, University of California San Diego professor found that the analyses of social networks can help the health care industry predict flu outbreaks earlier than traditional tracking methods (Schmidt, 2012).

You Tube, which was founded in 2005, is another social media tool that health care institutions use to provide the public with information. Mayo Clinic and Cleveland Clinic have their own You Tube channels in which the public can view videos that are of interest to them.

Mayo Clinic has a popular medical provider channel on YouTube which features videos on Mayo Clinic news and events, innovative medical technology, research on diseases, and new treatment options. Mayo Clinic has seen many new patients come to the health care institution as a result of content they viewed on Mayo Clinic's YouTube channel (Case Study: Mayo Clinic, 2011). One example is a 10 ½ minute YouTube video in which Dr. Ruben Mesa explains myelofibrosis, a rare form of blood cancer (Case Study: Mayo Clinic, 2011). Over 50 patients have come to see Dr. Mesa as a result of viewing his YouTube video (Case Study: Mayo Clinic, 2011).

In addition to sharing information with the public, physicians can also benefit from the videos through using them as learning tools to advance medicine (Kneipp, 2012). Physicians and clinicians can view You Tube videos to learn about various updates in technology use, disease outbreaks, surgery techniques, and treatment options. Social media provides many resources and opportunities for health care providers to learn new information and share with other health care institutions. For example, Memorial Hermann Hospital in Houston, Texas live-tweeted a double by pass open heart surgery from beginning to end (Twitter, 2012).

Health care institutions are also using other less popular, but advancing social network tools such as **LinkedIn**, **Pinterest** and **Foursquare**. LinkedIn is used to recruit health care professionals. Pinterest is like a bulletin board in which users can group and pin up related information. "Pinterest has the potential to aggregate diverse content from different parts of the web that help advance education and patient engagement" (Sandlin, 2012). Sandlin provides the example of a birthing center which may offer a breastfeeding e-book on their website and an informative video series from their lactation specialist from their YouTube channel. The health care institution could pin the information from the e-book and video series on a board called

"The Benefits and Basics of Breastfeeding" (Sandlin, 2012). Foursquare is another social networking tool that some health care institutions are offering users. Lutheran Medical Center in Brooklyn, New York offers users a Foursquare site to learn about the Center's events and to allow users to connect with a community of patients who use the Center (Figure 1). As this section highlights the benefits of social media use in health care, the next will consider the risks.



Figure 1 Screenshot of Lutheran Medical Center in Brooklyn, New York Foursquare site which offers users the opportunity to connect with others who also use the health institution.

The risks that many public relations and information technologists fear include posts that may present negative images of the business. Privacy concerns and vulnerability on online social media accounts present the most apprehension among businesses seeking to adopt social media (Sharp, 2011). Because of the issue of privacy, many health institutions have been slow to adopt social media as a method to share information with the public.

Risks: Legal and Ethical Issues of Social Media

Social media tools have many advantages for both patients and employees, but the use of social media also generates many legal and ethical issues. Many health institutions have abstained from using social media until the communication method becomes more widely used in health care. According to Cain (2011), many businesses and health care institutions choose not to join social media at the organizational level because of the legal and ethical issues involved with the shift. Organizational concerns regarding social media exhibit a variety of perspectives, but mainly fall into three main categories: reputation issues, productivity issues, and privacy issues (Cain, 2011).

Reputation issues

Issues with reputation can be a concern when considering the use of social media in a health institution. Negative dialogue on social networks such as Twitter, YouTube, Facebook, or blogs has the potential to reflect poorly on the institution and can also be difficult to control (Cain, 2011). No organization wants their reputation tarnished, especially online where it can be difficult to counteract the damage. Conversations on social media are accessible to a wider audience and also can linger for a longer period of time than conventional conversations and traditional media. Frivolous comments, posts, and videos may be entertaining at an individual level, but may be captured and disseminated to the public, tarnishing an organization's image. Any information posted on an open access site can be accessed by the public and potentially can be infinite.

Health care institutions that engage in social media possess more control over the reputation of their institution and physicians. Enabling patients to tell stories and share experiences can help to build a positive reputation (American Academy of Orthopaedic Surgeons, 2012). "Social

media is the only way to protect your online reputation and head off negativity before your nightmares become reality" (American Academy of Orthopaedic Surgeons). Social media coordinators or public relations specialists at health care institutions are able to monitor and remove negative social media posts before they damage the reputation of the institution. The American Academy of Orthopaedic Surgeons recommends immediately addressing negative experiences posted on social media and to extend a simple gesture showing the patient that the health care institution is listening, which could in turn encourage them to post again to explain the situation has been resolved.

Productivity issues

Productivity is also a concern when social media enters the workplace. With smartphones, employees can access social media networks throughout the day, unless there is a clear policy that explains how employees are to use social networks. Social media can help improve productivity, if it is used correctly, but it can also decrease productivity with inappropriate use. One way in which employees can increase productivity is through using social networks to retrieve information (Nerney, 2011). Turning to social networks usually provides users with prompt and accurate answers explained Nerney (2011). Social networking can also help employees advance professionally through learning about educational and training opportunities, as well as professional advice (Nerney, 2011). Health care institutions are also using the social networking tool, LinkedIn to recruit physicians (LinkedIn, 2012). LinkedIn allows physicians and other employees to provide their education, experience, and contact information for employers to review.

Although social media use can be beneficial, it can also decrease productivity through being a source of constant work interruptions. A March 2011 survey by harmon.ie, a social email

software vendor, nearly 60% of work interruptions involve a combination of technology tools, including email, text messages, and social networks (Nerney, 2011). Two of three respondents in the survey said that they would communicate digitally during a group meeting (Nerney, 2011). These interruptions are costly, but social media is predicted to be a part of the workplace for many years to come. "Companies that block access to social networks and non-business websites run the risk of alienating employees and losing out on the many advantages created by the social revolution," explained Nerney (2011). The best approach, according to Nerney, is to focus on worker's effectiveness.

Privacy issues

Privacy issues are also a concern when considering the implementation of social media. Many forms of social media involve disclosure in some form, including location, identity, pictures, or more intimate aspects of a person's life (Trepte and Reinecke, 2011, p.35). According to PricewaterhouseCoopers (2012), the dissemination of their personal information online is the leading social media concern for consumers. Privacy can be governed by three main mechanisms. According to Trepte and Reinecke (2012), privacy can be protected through legal regulation, ethical self-regulation, and privacy-enhancing technology.

The Department of Health and Human Services offers legal regulation which requires health care institutions to follow the **Health Insurance Portability and Accountability Act (HIPAA)** signed into law in 1996, which states that communications regarding Protected Health Information (PHI) must be secure and transmitted only to permissible parties. This encompasses information in a patient's medical record, including name, address, birth date, social security number, images, conversations between practitioners, health insurance information, and billing information (Hader and Brown, 2010). There have been instances in which employees have been

reprimanded and terminated as a result of HIPAA violations, which involved the use of social media. The protection of patient privacy is essential in health care, and social media by health care providers must be used in a manner that does not violate law or ethics. Patients also need to be informed that they should not post any information or pictures that could reveal their identity when sharing health issues.

The HIPAA law impacts how health care institutions and patients are able to use social media to communicate. According to Graham (2012), when a physician can be identified as the author of a social media post, a patient's identity can be more easily ascertained, possibly leading to an unintentional HIPAA violation. According to Hader and Brown (2010), breaches in confidentiality can result in job loss, disciplinary action by state licensing boards, and even criminal investigations. The American Medical Association (AMA) published a Professionalism in the Use of Social Media policy in November 2010 to guide physicians in their use of social media (American Medical Association, 2012). The policy aims to help physicians maintain positive online presence and to preserve the integrity of the patient-physician relationship (American Medical Association). The policy suggests that physicians use privacy settings to safeguard personal information, routinely monitor their own Internet presence to monitor content posted about them by others, maintain appropriate boundaries of the patient-physician relationship, consider separating personal and professional content online, and to recognize that actions online and content posted can negatively impact their reputations and careers (American Medical Association).

Patients can also generate a HIPAA violation by posting their personal information. "Unfortunately, some individuals are susceptible to sharing too much information; therefore, it is important to ensure that selected bariatric staff members monitor the page at least daily for

postings that need to be removed" (Walters-Salas, 2012). Patients should be informed to only post general information, or else sign a consent form. According to Walters-Silas, individuals who continue to violate the health institutions' guidelines should be denied access to the institutions' social media sites. This is important because with HIPAA compliance, there is no implied consent (Walters-Salas).

Ethical self-regulation involves users' etiquette and personal morality (Trepte and Reinecke, 2011, p. 49). Therefore, users need to consider prior to posting, which personal information will they share, and which information they will keep private based on their individual morals. Privacy-enhancing technology can be achieved through purchasing computer hardware and software that offers additional privacy. Firewalls also provide privacy through blocking requests for information from social media sites (Microsoft, 2012). Privacy settings on social media sites can also help to keep personal information private on media sites. Users can set social media sites to not allow tracking, therefore limiting receivers of information with additional information about users' profiles.

Although there are risks for health institutions to use social media, there are also risks for not participating. The absence of social media can create a gap between patients and clinicians (Eytan, et. al, 2011). Ressler and Glazer (2010) predicted that as social media evolves more security features and privacy control will become available to users. Despite being cautious, health care institutions will not want to wait too long to get involved with social media. "One of the greatest risks of social media is ignoring social media," said Don Sinko, Chief Integrity Officer of Cleveland Clinic (Social media "likes" healthcare, 2012). Although there are risks involved in using social media, health care administrators need to develop a social media plan to minimize the risk and legal issues to be competitive in the health care field.

Social Media Plan

Developing an **organizational social media** plan is one important step to implementing social media into a health care institution. Through developing a social media plan, health care institution administrators can discuss the legal and ethical issues involved with using social media in a health care environment and develop a proactive plan to address these issues. Health care institutions are cautious and seek to prevent risk, so therefore a social media plan will help health care administrators minimize risk (Sharp, 2011). Health care administrators generally do not adopt technology trends unless they possess a clear value to their health care organization (Sharp, 2011). The administrative team within a health institution should discuss the value of using social media through conducting a needs assessment. The health care institution can then move forward to develop an administrative team to create a social media plan.

The development of a social media plan involves a team of health care administrators from various areas of the organization. Cleveland Clinic and Massachusetts General Hospital created social media plans which involved marketing, public relations, human resources, and legal departments (Fiore, 2012). Cleveland Clinic also received help from clinicians, while Massachusetts General Hospital invited the nursing department and information systems team (Fiore). When developing a social media plan, model plans from other health care institutions and even businesses outside of health care can assist administrators to devise their own plan. The University of Maryland Medical Center and Mayo Clinic's Center for Social Media provide examples of social media policies on their blogs (Fiore, 2012). "You have to figure out what's best for your institution. There's no one template that works for everyone," said Donita Boddie, Director of Public Affairs at Massachusetts General Hospital (Fiore). Although there are social media plan models, health care administrators need to evaluate their own needs to determine the components to include in their organization's plan.

One of the initial steps to develop a social media plan includes conducting a **needs** assessment. A needs assessment is an important aspect to determine the users of the service. The needs assessment determines which social media forums and content would best serve the organizational mission. Although developing a needs assessment takes time, administrators may realize that they can reach a broader audience through using social media. It is important for organizations to know the demographic information (geographic location, age, patient needs, etc.) of their audience to reach the needs of each audience segment. The information and feedback that social media participants provide, allows health institutions the ability to identify, analyze, and implement strategies to meet the needs of their audience (Sarringhaus, 2011). For example, some users of health care social media discuss common health care issues such as breast cancer and diabetes. From this information health care institution administrators are able to track users when users enable tracking on their social media site. According to Privacy Rights Clearinghouse (2012), information can be gathered about consumers online using "cookies". Tracking information includes which websites the user has visited, movement from website to another, and building a user profile (Privacy Rights Clearinghouse) Health care institution administrators will be more prepared to define a target audience for certain health services after receiving feedback from a needs assessment.

Many health institutions have incorporated, or are discussing the implementation of social media. The Emergency Care Research Institute (ECRI), recommends that health institutions that are interested in adopting social media develop social media plans that include the audience for social media, level of involvement in social media, who will manage social media, and methods for addressing risk management issues (ECRI Institute Issues New Guidance, 2012).

Through conducting a needs assessment, administrators will be able to determine their **target audience** for social media. Younger consumers are more comfortable with using social media for health care than older consumers. Of consumers in the 18-24 year old range, 80% of them said that they are likely to share health information through social media, whereas only 45% of 45-64 year olds would share health information on social media (Terhune, 2012). For example, in a study by PricewaterhouseCoopers (2012), respondents in good health ages 18-24 were more likely to share information on social media and trust information posted on social media than older users, especially of users over age 65 (Social media "likes" healthcare).

In social media, a division exists between millennials and baby boomers. This division is referred to as a **digital divide**. "The technology divide has led to problems in coordination, trust, communication, and overall organizational efficiency," explained Sarringhaus (2011). "Baby boomers' reluctance to embrace the use of social media on an organizational level has caused the healthcare field to fall behind in the application of such technologies," explained Sarringhaus. Many retail businesses have used Facebook and Twitter to communicate and share information with consumers for the past few years, but many health care institutions are just beginning to implement the use of social media to share information with the public.

The use of social media opens up an organization to **public criticism**. However, as social media experts like to say, customers are already talking about companies online—by joining them, companies can help direct the conversation (Backman, 2011). Learning to highlight the positives and manage the negatives is imperative for any organization embarking on social media (Backman). According to Pricewaterhouse Coopers (2012), organizations should collaborate internally to develop effective methods to use social media to connect with their customers in more meaningful ways that enhance trust (Social media "likes" healthcare). Developing a social

media plan provides an opportunity for health care administrators to discuss communication methods, ethics, and policies. Ongoing discussions by health care administrators provide an opportunity to collaborate on new methods to use social media to facilitate patients in their quest for health care.

Patients and health care institutions are concerned about patient privacy. HIPAA guidelines present guiding principles for health institutions to follow when adopting social media. HIPAA explains how health care providers should communicate, including the use of social media. Social media tools should not be used to contact a patient regarding anything that could be considered confidential. The discussion of HIPAA will determine the health care institution's level of comfort in social media coverage. The level of involvement by the health care institution in social media needs to be addressed in the social media plan.

When devising a social media plan, administrators must discuss how they will respond to feedback posted on social media. "The basis for social media is that it is an interactive and engaging conversation. Not responding to feedback simply communicates to users that the organization is not open to criticism and does not value input from various stakeholders" (Sarringhaus 2011). Although organizations seek to receive positive feedback in social media, when a site is public, users have the ability to post negative feedback as well. According to Sarringhaus (2011), administrators should decide as part of their organizational plan how they will address negative criticism because simply deleting or ignoring dissuades people from participating in social media with that institution. (Sarringhaus, 2011). Indeed, the Results section of this study illustrates social media coordinators and public relations department personnel value consumer suggestions and address negative criticism in a manner that follows their institution's social media plans.

After a social media plan is in place, health care administrators need to determine which department within the organization should update and monitor the use of social media. In a survey by the Health Research Institute (HRI), 82% of those surveyed indicated that their health institution's social media was managed by marketing or communications employees (Mearian, 2012). Only a few health care institutions stated that their IT departments manage social media (Mearian). Mayo Clinic has developed a large team of people who work in their Center for Social Media. The Mayo Clinic Center for Social Media exists to improve health globally by accelerating effective application of social media tools throughout Mayo Clinic and spurring broader and deeper engagement in social media by hospitals, medical professionals and patients (Mayo Clinic Center for Social Media, 2012). Their website includes videos from keynote speakers from various presentations involving social media in health care, blogs, posts and summaries of social media events and training sessions, links to Facebook and Twitter feeds, and Mayo Clinic's YouTube Channel (See Figure 2). Not only does the website include information and social media links for patients and clinicians, but also serves as an educational resource for other health institutions.



Figure 2 Screenshot of Mayo Clinic Center for Social Media website that provides links to Facebook, Twitter, and YouTube.

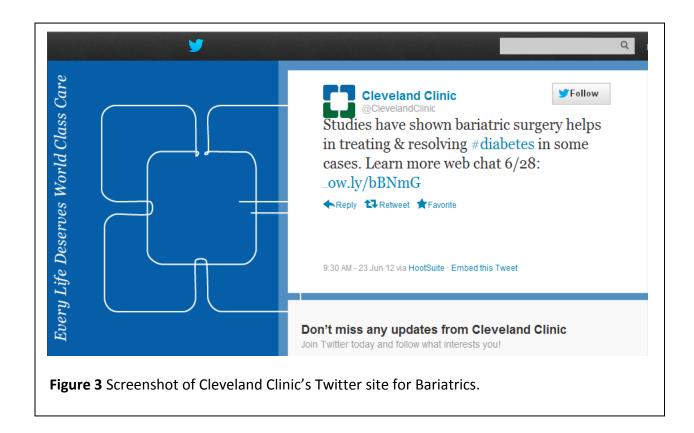
The Mayo Clinic Center for Social Media also provides resources for health care institutions to establish a social media plan through offering webinars and conferences. Those interested in using social media in health care can sign up to become a member on the Center's website to take advantage of more social media benefits.

Social Media Purpose

The advantage of social media is its availability. Most people use the internet on laptops or mobile phones, so they may at any time use social media to get information on health care. The use of cell phones, especially smartphones, has opened up a two-way communication line for clients and health care providers to share information. Cell phones provide a channel for the public to expose their concerns (Schmidt, 2012). One-third of consumers are using social media to seek medical information and express opinions about doctors (Terhune, 2012). Social media invites interaction and allows health care organizations to listen, which encourages health care administrators to develop new ideas to implement in their health care institution.

Social media serves to provide information quickly, and in a manner that is easy to read and accessible to consumers. It accelerates knowledge acquisition and dissemination of information (Eytan, et. al, 2011). Good news generated by a business helps to create good will and strengthens an organization's reputation (Eytan, et. al, 2011). Some social media serve to create more leverage through users sharing positive news with other users. For example, sending users good news about new detection devices or new treatment options via social media (i.e. tweets) also helps to block out a potentially harmful message that could be posted from a disgruntled patient.

Social media can be used to enhance relationships with patients and extend benefits to patients and potential consumers. The trend is growing for the use of social media in health care for patient education, information sharing, and professional connections with other medical professionals. Mayo Clinic developed the Mayo Clinic Center for Social Media in July 2010 to increase their commitment to social media and to expand social media beyond public relations and marketing (Case Study: Mayo Clinic, 2011). The center's focus is to adopt social media in the clinical practice, education, research, administration, other hospitals, and health-related organizations (Case Study: Mayo Clinic, 2011). "Use of social media starts an interactive conversation in which anyone can take part and demonstrates an inclusive and participative culture," said Sarringhaus (2011). Harry Greenspun, M.D., explained that social media increases patient engagement and allows for much better flow of information (Perna, 2012). An example of this is seen in Figure 3, with a Cleveland Clinic tweet promoting a web chat about bariatric surgery to help treat and resolve diabetes. Patients who are diabetic or borderline diabetic, or any of the Clinic's Twitter followers may find guidance in participating in such a web chat on bariatric surgery.



Through using social media, health care institutions benefit by creating a community of users who actively engage in conversations that promote the health care institution and build brand loyalty. Social media fosters two-way communication and helps to facilitate relationships (CDC, 2012). The use of social media stretches beyond providing information that appears on the health institution's website, such as hours of service, departments, and events. "Social media can raise awareness, increase a user's knowledge of an issue, change attitudes and prompt behavior change in dynamic, personalized and participatory ways" (CDC). Social media can be used to connect patients to their health care institution through offering social media chats and interactive blogs for patients to connect to their health care institution.

According to Kaufman (2011), one-third of health care institutions are using social media for professional reasons including business development. Businesses that accurately and

efficiently use social media become more credible to patients and the public through offering information that interests readers (Kneipp, 2012). Dr. Farris Timimi, medical director of the Mayo Clinic Center for Social Media explained at the World Health Care Congress' panel discussion that hospitals need to adopt social media to help advertise their services and to assist with rare disease research (Nafziger, 2012). To support his strong suggestion to health care providers to adopt social media, Timimi provided an example of a young woman who suffered from debilitating wrist pain for five years until she participated in a Twitter chat with Dr. Richard Berger, a Mayo Clinic physician (Nafziger). Social media can help people find solutions to health issues in a more interactive manner than websites. For example, users are able to communicate through social media's two-way communication to discuss symptoms and treatment options.

Social media provides new opportunities for people suffering from debilitating illnesses. Mayo Clinic and Cleveland Clinic are innovators in the social network area. Cleveland Clinic maintains profiles on Facebook, Twitter, and LinkedIn. In addition, the health care institution also offers health chats that provide professional-grade health-care information. Users can gain information by anonymously submitting questions and searching archived questions and answers. Social media provides new opportunities for how patients manage their health because virtual communities create a more comfortable environment where people can engage in and share information, but often stay anonymous (Pricewaterhouse Coopers, 2012, p.8). Using social media can help patients find connections that they otherwise would not have with traditional forms of media.

Another benefit of using social media is that it is free. Printing pamphlets and mailing them in bulk costs thousands of dollars. With free services, such as Facebook, Twitter, LinkedIn, blog

hosting sites, and YouTube, social media is a cost effective method for health institutions to communicate with consumers. Social media also offers a venue for communicating with consumers quickly and inexpensively, such as promoting new wellness programs, marketing new services, and announcing the latest achievements in patient care. In fact, the only cost involved is paying employees to manage the social media.

Building an identity and brand loyalty are other purposes for using social media. Social media attracts new patients, builds loyalty among existing patients, and opens up new opportunities (O'Connor, 2012). According to Sarringhaus (2011), social media gives health care institutions an identity beyond just their names and functions. Through using social media, health institutions also can strategically target certain aspects of their marketing program. Maintaining an online presence keeps the health organization's brand at the forefront of people's minds and builds positive exposure and credibility (O'Connor). Through creating a social media presence, health care institutions have more control over what is posted about their facility and physicians, and can impact online conversations.

Social media provides new opportunities for health care administrators to target certain markets. Unlike traditional forms of marketing materials, social media marketing talks "with" rather than "to" the audience (O'Connor, 2012). Health care providers have an opportunity to connect with patients to form human relationships which leads to increased trust and credibility (Pricewaterhouse Coopers, 2012, p. 17). Hospitals are moving from experimentation to strategic use of social media to enhance brand loyalty and recruit new patients, explained Sharp (2010). Health care institutions are aware of the competition that is arising in social media and are working strategically to find innovative ways to establish their brand in the social media market.

Strategies for using social media for marketing will continue to evolve. Social media offers marketing departments many benefits, including cost savings, because social media is less expensive than print media. In addition, social media reaches a global audience because of its ability to reach anyone connected to the internet. Social media is no longer an optional marketing strategy. "Access to health information online is empowering patients and forcing medicine to become part of a more consumer driven market," said O'Connor (2012). With digital access readily available on cell phones, patients expect to be able to quickly access health information away from home.

Building relationships has been an important aspect of marketing strategies, and social media serves to connect users and also builds trust. Social media is a communication channel that allows health care institutions to offer a human touch. O'Connor (2012) explained that consumers expect companies to be more human in their interactions. Some larger health care institutions also offer specialized programs and support groups on social media for patients to connect with physicians and other individuals experiencing the same health issue. From this information users are able to share common experiences, which also help them to cope with their current health situation. One example of this is bariatric patients (Walters-Salas, 2012), who thrive on support and guidance. "Facebook, along with other forms of social media has the capability to provide an instant answer to a question, give immediate direction to a help source, or it can give bariatric patients the support of being connected to others who understand their challenges" (Walters-Salas, 2012). Social media provides users with social interaction that is necessary to overcome serious health problems.

Usability

Books and brochures were some of the first forms of traditional mass media that health care institutions used to share health information with the public. The public's reliance on information gathered from the Internet has changed how health care institutions share information with the public and how consumers retrieve health care information. Patients have educated themselves on health conditions using a variety of websites including Web MD, Medline Plus, and Clinical Trials (Keselman, et. al, 2008), but advances in technology have changed how patients are accessing health information. **Web 2.0** has enabled users to access information and interact with websites creating a user-directed flow of information (American Academy of Orthopaedic Surgeons, 2012). Social media is part of the Web 2.0 platform.

Social media has transformed the way in which Internet users seek information. For example, users seeking health care information are utilizing Facebook, Twitter, and YouTube, among other social networking tools to find answers to health care issues. When a health care institution engages in social media, the team developing the site should consider the usability of the site. With the wide cross-cultural audience that health care social media sites serve, usability will help the social media team to develop a user-friendly site. Usability measures the quality of a user's experience when engaging in a product or service involving technology, such as a website or software (Usability.gov, 2012). Usability includes the ease of learning, efficiency of use, memorability, error in frequency and severity, and subjective satisfaction (Usability.gov). Ease of learning involves how easy it is for users to learn basic functions of the site. Efficiency of use relates to how fast a user can navigate the site once basic tasks are learned. Memorability involves the relationship between past use of the site and future visits and how much the user remembers about the site. Error in frequency and severity involves the number of errors and

severity of errors that a user makes while on the site. The last component of usability relates to whether the user likes using the site. All of these factors are important when considering the impact of a site on a particular user.

Many obstacles exist to achieving maximum usability. Berry (2012) found the following barriers to usability: limited patient access to technology, older age, lower income, lower education level, and low computer literacy of both patients and clinicians. These barriers are important for social media coordinators, IT specialists, technical communicators, and public relations specialists to consider when examining their target audience for participatory medicine. Users must have access, feel comfortable, and know how to navigate the social media site to effectively gain use of health care information.

User-Centered Design

Another component of usability is user-centered design. User-centered design considers the needs, limitations, and preferences of the users (Usability.gov, 2012). According to Neuhauser and Kreps (2003), research suggests that health communication is more effective when it reaches people on an emotional as well as a rational level, relates to people's social contexts, is a combination of interpersonal communication and mass media, and is interactive. Social media provides patients and those concerned about their health with a communication method to connect to both their health care institution and patients who may experience similar health issues. For example, Mercy Health System provides a social media support group for bariatric patients (Mercy Health System, 2012). Patients are able to connect with other patients to discuss this sensitive health topic. Health care institutions are examining the emotional and social aspects of users to create user-centered social media options in participatory medicine.

Digital Literacy and Technical Communicators

Digital literacy is an important component for technical communicators and social media coordinators to consider when developing information for social media sites, especially with the rapid digitization of health information on social network sites. Technical communicators translate technical printed texts into more easily understood online text to meet the needs of the participatory medicine user. According to Spilka (2011), information design and usability have become increasingly important components of technical communicators' jobs (p. 103). Technical communicators will find language to articulate concepts that may be otherwise left unspoken, according to Spilka (p. 104). For example, technical communicators work with the audience and personas in mind, and possess training to select language that is colorful and connects with the specific target audience.

Information design is also an important consideration when developing digital content for participatory medicine. Technical communicators are useful in healthcare because they investigate the problem of complex information design, particularly the design of informative and instructive text (deJong, 2011). Technical communicators are specially trained in placing text, and consider the impact of typography and font on the users. In addition, technical communicators also have training in appealing to cross-cultural audiences. Visual representations can be misinterpreted when viewed by cross-cultural audiences. Health care administrators need to be aware of how the content is projected and understood by the audience.

Technical communicators can provide the necessary link to ensure that the content is accessible, vivid, and appropriate for the audience. According to Eric Ford, PhD, a study author and professor of business at the University of North Carolina, Greensboro, accessibility is

especially relevant to health care institutions (Dolan, P. 2012). Ford found in a study that accessibility is often lacking on health institutions' websites.

One of the issues involves user understanding of content. Ford explained that the general rule for consumer sites is to write at an eleventh grade reading level (Dolan, P. 2012). In the same study, Ford also found that the content of many hospital sites were written at a graduate level (Dolan, P.). Ford found that the sites used jargon-heavy language that would be a challenge for users to decipher (Dolan, P.). Ford uses the example of one health institution site discussing ventilator-acquired pneumonia, but only used the acronym (VAP). "While it makes sense to those of us who work in the field day in and day out, to the average person just trying to figure out what's going on, it requires a fair amount of health care-specific knowledge," said Ford (Dolan, P.). Technical communicators can help to write the language in understandable terms for users, particularly since social media is marked by its reliance upon informal language.

Participatory Medicine Users

Three groups of users participate actively in participatory medicine and E-Health care exchange, including health care providers, patients and their immediate caregivers, and others including healthy person who wish stay well (Keselman, et al, 2008.). Patients and other users of health care social media utilize social networking tools to express their thoughts on products, services, and health care issues. The inclusion of talking, listening and participating in social media can help to build trust among the network users.

Health care providers

Although health care institutions use social media to share information and to develop communities, few physicians have connected with social media, at least at a public level.

Physician involvement in social media has been slow and cautious. However, this is for good

measure. Although there are many benefits of social media, there are many risks involved for physicians who post information on public social networks. The openness of social media can complicate the relationship between the professional and the private persona (Mostaghimi and Crotty, 2011). About 90% of physicians use social media, according to a 2011 report by QuantiaMedia (Baum, 2012). According to a survey by AMN Healthcare, 48% of surveyed health care providers said that they have used some type of social media website for professional networking (iHealth Beat, What Social Media, 2012). Greysen explained that although physician professional conduct should exist online and offline, social media can complicate matters and physicians and other medical staff need more guidance (Baum 2012).

Physician involvement in social media may be more risky than a health organization's involvement in social media. Physicians should be aware that giving advice on social media sites may lead some patients to respond to them with questions and requests for prescription refills and even friendship (Segovis & Rethlefsen, 2011). According to iHealth Beat (2012), physicians who are concerned with malpractice liability avoid using Facebook and Twitter.

The Federation of State Medical Boards (FSMB) released new guidelines for physicians on the use of social media in May 2012 (Cheung, 2012). The FSMB stated in its guidelines, "Physicians have an obligation to prevent unauthorized access to, or use of, patient and personal data and to assure that 'de-identified' data cannot be linked back to the user or patient" (Cheung, 2012). Physicians should never post information that could identify patients.

One of the risks of physicians using social is that of misconduct. Intentional or unintentional posts could jeopardize a physician's career. Patients or families of patients are the primary sources for reporting misconduct to medical boards (Baum, 2012). According to Baum, some of the most commonly reported violations medical boards received was inappropriate

communication with patients, prescribing medication or other treatment without an established clinical relationship by means of the Internet and falsification of credentials online. Baum explains that as social media use grows among medical staff, misconduct is also likely to become a more serious concern.

Despite the risks of physicians' use of social media, there is a need for physicians to engage in social media because consumers are using it to make decisions based on information they find there (Terhune 2012). Although physician posts on social media can be sensitive, the professional use of social media by physicians can offer many benefits. Sharp (2012) predicts that in the next two years that health care apps will enable increasing connections between patients and physicians, provided that health care institutions can overcome the legal barriers imposed by HIPAA. Mayo Clinic's Center for Social Media encourages physicians to participate in social media through joining a formal network, according to Lee Aase, Manager, Syndication and Social Media at Mayo Clinic (Case Study: Mayo Clinic, 2011). Physicians with successful online brands include Kevin Pho, M.D., internist from Nashua, New Hampshire who started Kevin MD blog in 2004. Kevin MD is one of the most popular medical blogs nationally and internationally (O'Connor, 2012). James Cleary, M.D. created a Twitter blog to advocate for hospice and palliative care (Social Media Presents New Opportunities, 2012). Cleary uses Twitter on a professional level to converse with hospice and palliative care colleagues around the world. Cleary has 900 followers around the world, including Rwanda (Social Media Presents New Opportunities).

Physicians can also use social media to connect with other physicians. Social media "offers opportunities for professional use, including connecting with colleagues or public health outreach." (Mostaghimi and Crotty, 2011). Over 130,000 doctors are using Sermo, an online

community of physicians who share information. Sermo is different than public forms of social media because only licensed physicians are allowed to participate; however, it has been described as "more than networking – it's collaborative and interacting for learning and treatment purposes," said Richard Westelman, Sermo's Chief Operating Officer (Pricewaterhouse Coopers, 2012, p. 13). The American Medical Association (2012) recognizes the importance of physicians' use of social media. "Participating in social networking and other similar Internet opportunities can support physicians' personal expression, enable individual physicians to have a professional presence online, foster collegiality and camaraderie within the profession, provide opportunity to widely disseminate public health messages and other health communication." (American Medical Association 2012). The American Medical Association suggested that physicians who are interested in using social media should establish two separate online profiles: a professional identity for medical purposes and a private identity among friends and family.

The presence of a physician on a health institution's social media site is important. "If social networking sites do not have a physician presence, the information patients find may not be correct and may lead to poor choices" (American Academy of Orthopaedic Surgeons, 2012). Physicians who maintain a blog linked to a popular media outlet, such as a television station or newspaper, can become celebrities and create demand for their services (American Academy of Orthopaedic Surgeons). As mentioned earlier in this chapter, Dr. Kevin Pho, author of Kevin MD, is an excellent example of a physician who successfully created a demand for his services through creating a blog. Now, Kevin MD also appears in Facebook, Twitter, and YouTube. Kevin MD serves physicians, patients, and caregivers throughout the world.

Patients and caregivers

Patients and caregivers seek new methods to access health care information. With the rapid development of technology and use of smartphones on the rise, patients' expectations related to accessing health care information are also increasing. "Most people expect their healthcare providers to be online, providing trust-worthy information – and the day of the static website has passed" (American Academy of Orthopaedic Surgeons, 2012). Patients take advantage of social media to share experiences and connect with their health care institutions.

Patients who access their health information online through engaging in participatory medicine, are referred to as **e-Patients**, because they "use digital technology to research diseases, treatment modalities, and the physicians who care for them" (American Academy of Orthopaedic Surgeons, 2012). E-Patients and their caregivers are active users of social media to find information pertaining to their current health condition. One of the issues surrounding the use of social media by patients is HIPAA. Some patients share too much information on health care institutions' social networks, and therefore become a liability for health care institutions because of the possibility of a HIPAA violation. Other patients are aware of HIPAA and patient privacy, and therefore secure their information. Users can set their social media sites to limit tracking and avoid sharing, however according to Trepte and Reinecke (2011), lack of sharing leads to a reduced user experience and could also be seen as anti-normative (p. 37). Consumers use social media to share experiences with others, removing the "sharing" component detaches a user from the community and projects a lack of trust on that particular social network.

Healthy persons

Health care institutions also target healthy individuals, many of whom rely heavily on the use of smartphones to communicate. Smartphones offer voice and text communication, advanced

computing and communication capabilities, including Internet access and geopositioning systems (Boulos, et al., 2011). Geopositiong systems allow users to find the location of other users. This is especially helpful for health care institutions because they are able to access information about the location of people who access their social media sites. They can then use this information to target specific audiences.

Healthy people are also using health care apps to help them stay well. For example, individuals can use their smartphone camera with Instant Heart Rate app to measure their heart rate (Kiera, 2012). MelApp, an app from Johns Hopkins helps users to identify melanoma skin cancer risk by scanning questionable skin lesions (Kiera). Health care institutions across the U.S. are developing apps to connect with healthy patients. Detroit Medical Center offers users a pedometer app that converts steps into calories (Detroit Medical Center, 2012). Offering social networking tools and apps to healthy individuals helps to build a health institution's competitive edge.

Community

Patients and others that seek health care, search for institutions that have a caring community of knowledgeable staff members that will serve their needs. Social media creates a community for the health care institution and the people it serves. Online social networking sites help health care institutions create a more loyal environment through sharing personal connections with the community and patients they serve (Sarringhaus, 2011). Through the use of social media to create a community, users feel a belonging and may participate in face-to-face activities connected to the health care institution, such as fundraising functions, support groups, and wellness workshops.

Health care institutions also use social media to promote wellness, communicate their mission and vision, describe the services they offer, and provide health education. They use social media to promote wellness, and often sponsor online support forums where individuals who are dealing with chronic health issues or catastrophic conditions can find support from others who are having similar experiences. On some sites, physicians and other clinicians educate the public on common diseases, explain what can be done to cope with conditions, and provide tips for how to maximize the quality of life for the individual who is suffering from the disease (Backman, 2011). The University of Wisconsin Carbone Cancer Center provides a Facebook page for cancer patients and those interested in cancer research a place to connect, share experiences, and learn about new research in cancer treatment (Figure 4).



Figure 4. Screenshot of University of Wisconsin Carbone Cancer Center which is one of leading cancer research centers in the Midwest.

In addition, users who connect with other patients through social media begin to develop a community and build relationships also through connecting with others with the same health issues. "People like to access and connect with other people's stories even if they're unwilling to share their own," said Ellen Beckjord, assistant professor at the University of Pittsburgh Medical Center and Hillman Medical Center (Pricewaterhouse Coopers, 2012, p. 8). For patients who experience a serious health condition, social media provides them with a communication path to information and dialogue which can be soothing when experiencing physical or emotional pain.

The use of social media to build relationships is essential to create a positive community of users. "In this business, we facilitate relationships, we really think about social media is not just a technology and a process, but also as a capability and a process, but also as a capability that can help drive connections in the value chain more effectively," said Mark Brooks, Chief Technology Officer at Health Let (Pricewaterhouse Coopers, 2012, pg. 17). In developing a community, health care administrators need to strategize and position themselves to become the core of the social media community. Health care providers need to listen to conversations that are happening in social media (Perna, 2012). "Being an active participant in those conversations moves you to the point where you can eventually drive those conversations," said John Edwards, director of health care strategy and business intelligence practice at Pricewaterhouse Coopers (Perna, 2012). Actively engaging in conversations through social media helps health care institutions to become more visible to users and provides a human connection that patients value in health care.

Conclusion

Social media is both an opportunity and a challenge. Businesses have used social media for several years; however, a majority of health care institutions are only beginning to adopt this

form of communication into their organizational plans. Despite society's reliance on it to gather and share information, health care institutions recognize the privacy and security risks involved and have been slow to implement social networking tools. But as the cost of print media increases and patients exhibit a hunger to use social media as a communication tool to interact with health care institutions and physicians, these providers feel pressure to adopt social media to maintain a share of the health care market and remain competitive in participatory medicine.

Statistics demonstrate a demand for health care institutions to use social media in participatory medicine as an opportunity for physicians and health institutions to engage with patients. Health care institutions' leaders need to embrace social media and find methods, including an organizational social media plan to implement within their institution. In addition, social media will need to be used to interactively communicate with patients, rather than used solely as a method to market services. Education will be required to train staff and to address gaps in understanding to increase digital literacy. Many legal and ethical risks exist when using social media. Privacy is one of the central issues that is governed by HIPAA, which health care institutions will need to follow carefully to successfully advance their social media presence in participatory medicine.

Privacy and social interaction are both basic human needs, and serve as components of the health care spectrum. Health care institutions will need to develop a social media plan and train employees how to use social media appropriately to receive the maximum benefits. Technical communicators should possess a role in usability and user-center design to maximize the users' experience when viewing health institution social media sites. Increasing digital literacy and ensuring that content is written no higher than an eleventh grade level will be increasingly important as the number of participatory medicine users rise. In addition, social media

coordinators and public relations specialists will be required to monitor health institutions' social media sites and other websites to keep a positive reputation.

Chapter III: Methodology

Individuals use social media to connect with friends, but health care institutions have been slow to adopt social media to connect with patients and future clients. The purpose of this study is to determine which social media tools health care institutions use, how they use them, and how they plan to improve their use of social media tools in the future to better connect with users.

After I contacted 38 subjects, six subjects agreed to participate in the interviews, but only four participants responded to the interview questions. Each interview response was analyzed using triangulation, a method which involved cross-checking information from the interviews, research, and health institution websites to evaluate the evidence. The next task involved the iterative process. Through this process, new questions evolved; some of them were able to be answered through existing data, whereas other questions may only be answered through an additional research study. The next process, constant comparison, involved coding responses and comparing them to existing research to determine patterns and then indexing responses into a table.

Subject Selection and Description

The study involved interviews with health care institution personnel with the titles, Main Social Media Manager, Digital Marketing Specialist, and Public Relations Clinical and Administrative personnel. They represent small, medium, and large health care institutions in the United States. Physicians were also invited to participate in the interview, although no physicians agreed to do so. The intent was to interview a total of six to eight health care personnel working within small, medium, and large health care institutions. The challenge was to find health care employees who agreed to participate in the study and who felt that they had sufficient knowledge to answer the interview questions. The four subjects interviewed were actively engaged in using

social media within their health care institution. Three participants received the interview questions via email, while one participant requested a Skype meeting.

Instrumentation

The interview was designed specifically for this study and consisted of eight open-ended questions directed at the health care institution's existing use of social media and future use of social media. The interview questions were developed by the investigator and approved by the University of Wisconsin Stout IRB Board. Appendix A provides a list of the interview questions.

Data Collection Procedures

Participants were provided eight open-ended interview questions. Questions were administered to six health care personnel who said that they were willing to participate in the research study; however, only four of the six responded to the interview questions. Three follow up email reminders were sent to the two participants, but I did not receive a response. One of the four interviews was completed using Skype. The other three interviews were conducted through email. Follow up interviews with participants were not conducted because of the timeframe of the study and the growing and changing social media climate.

Limitations

The major limitation of the study was to find health care personnel who were willing to participate in the study. Many subjects did not respond to the interview request or chose not to participate. In addition, physicians were also contacted, but none of them responded to the request for an interview.

A methodological limitation includes data analysis. Since the interview questions were open-ended, the data from the interviews had to be compared through coding and indexing the information provided in each question. The narrative data was then categorized according to the

question asked and the similarity of responses provided. The information was placed within a table which listed each question and indexed the responses. This was a limitation because subjects provided a wide variety of responses; as a result, many of the responses are listed individually because of the diverse answers provided. Due to time constraints and availability of the participants, questions were limited to the number initially asked and the researcher the researcher did not conduct follow up interviews. Valuable and pertinent data was collected and is reflected in Table 1, which contains the responses from participants.

Chapter IV: Results

Health care institutions use social media to keep up with the communication network that many individuals and businesses are using to share information. The main purpose of the study is to determine the role of social media in health institutions' public relations departments. Other purposes include which social media tool health care institutions use, how they use social media, and the advantages and risks of health care institutions using social media for public relations to distribute health care information.

I researched health care institutions across the United States and contacted public relations departments, IT departments, health care general contacts as listed on the health care institutions' home pages, and physicians through email and telephone calls. I requested interviews from subjects in the United States via email and telephone calls and provided an explanation for the interview. In addition, each subject was also sent a consent form to participate in the University of Wisconsin Stout IRB-approved research study. Participants responded to eight interview questions via Skype or email during a period of one to five weeks after receiving the interview questions. A summary of participants' responses are provided after each question in the table.

Table 1

Responses to interview questions

What role do you perform in determining the material that is placed on the health institution's website?

Main Social Media Manager

Digital marketing specialist and public relations

Clinical and administrative personnel

Examine focus groups with patients/visitors

Develop institutional goals

Monitor what people are saying about health care facility

Manage material placed on website

How are you involved with social media at this institution?

Update Facebook page, Google+, Twitter, You Tube Channel

Direct oversight of SM content and level of participation

Department oversees development of new sites/pages/accounts

No day-to-day management of content

Examine Google alerts

Meet with the executive team

Meet monthly with social media group

What social media tools does your health institution use?

Facebook

Twitter

YouTube

Foursquare

LinkedIn

Pinterest

Flickr

Hootsuite

Sharepoint, an internal communication vehicle that allows a defined audience that is geographically spread out to share and jointly edit documents, agendas and discussion boards and effectively manage large projects.

For what purposes do you use social media?

Awareness

Develop brand loyalty

Post information about education and events (including screenings for health issues, interesting and relevant health content, new studies)

Clinical programs

Establish presence in community and the state

Direct connection to those we care for "trusted medical friend"

Supply interesting and relevant health content

Recruitment

Faculty updates

Meetings

Community connections

Events

Education

Comment and ask questions

Build relationships

To communicate with support groups

What percentage of your health information is distributed through social media?

Majority of health information shared on social media

Make 1-3 posts/day on social media

Have consistent presence

One-fifth of health information in surgical department

Less than 5 percent of distributed information

What are the advantages of using social media for the dissemination of health information?

Dissemination of information

Get word out about healthy living when they are interested in it

Global reach

Little cost for reach

Two-way communication

Audience chooses to receive the information by "friend" or "follow"

A conversation rather than a push

Audience is exponential

Personal, current and can be powerful source of relationship-building

Learn about target audience

What are the limitations of using social media for the dissemination of health information?

HIPAA Regulations

Prevent health care institutions from sharing information about patients' experiences

Cannot share pictures without signed permission

Users share information, but have to monitor and remove

Labor intensive

Inexpensive, but requires constant maintenance

Cannot be appropriately managed by communications or marketing staff because of lack of expertise to most meaningful content

Information is generalized to the public

Hard to tailor messages

Tightly focused

Decentralized

What other ways do you foresee using social media tools in healthcare in the future?

Health forums for doctors and patients to interact via video chat

Target messages to smaller demographic

Increase use of text alerts

Improve electronic access by patients to their own medical information

Pre-registration

Appointments

Accounts

Labs

Prescriptions

Virtual office visits and telehealth

Blogs, microblogs and forums

Internal communication

Advertising and re-marketing

Using it for PR

Social media tools

FourSquare (Offer discounts for retail and services on skincare, eye wear)

QR Codes

Pinterest

Instagram

Storify

Developing own applications

Through combining the narrative data into one table, I was able to examine the common responses and index them according to categories.

Interview Questions

Assumptions made regarding responses to interview questions included that the participants engaged in using social media and were active participants in monitoring and placing social media on their health care institutions' websites. Another assumption was that participants were knowledgeable about social networking tools and had a vision of tools that their health care institution could use in the future to advance their institutions' social media presences.

What role do you perform in determining the material that is placed on the health institutions' website?

This question seeks to determine the participants' roles in selecting and posting information on the health care institutions' websites. It is important to know which departments post information on health care institution websites, and to know who is involved in choosing the material that is posted.

How are you involved with social media at this institution?

This question specifically asked participants about their involvement in social media at the health care institution in which they are employed. Since social media is the focus of this study,

this is an important question to determine how participants are involved with social media at the health care institution.

What social media tools does your health institution use?

A variety of social media tools exist, including popular tools such as Facebook, Twitter, and YouTube. An important aspect of the study is to determine which social media tools health care institutions use to share information. Each social media tool provides a different purpose; therefore, it is important to determine which social media tools health care institutions use.

For what purposes do you use social media?

The purpose for which health care institutions use social media is essential to understanding how they are using social media to connect with their community and patients. The purpose may vary depending on the social media tools for which health care institutions have agreed upon using within their administrative team.

What percentage of your health information is distributed through social media?

The percentage of health information distributed through social media provided insight into how often health care institutions are using social media to communicate with patients and the community.

What are the advantages of using social media for the dissemination of health information?

It is important to understand the advantages from the perspective of health care administrators or employees. Their responses provide insight into what health care providers find as the benefits of using social media in the health care industry.

What are the limitations of using social media for the dissemination of health information?

It is also important to understand the limitations of social media from the perspective of health care administrators or employees. Limitations may vary depending upon the social media plan in which the health care institution follows.

What other ways do you foresee using social media for the dissemination of health information?

This question provided insight into how health care institutions plan to use social media in the future. The responses are helpful because consumer usability can be matched with the social media tools that health care institutions plan to use in the future.

Summary of Data

The narrative data from the interviews was analyzed linearly and entered into a table (Table 1) which provides the interview question and the categories of responses for each questions. Public relations is the core of the administrative team that determines and places the content on health care institutions' websites. Public relations specialists also serve as social media managers at two of the health care institutions that were included as subjects in the study. All the participants were responsible for managing the content of the health institutions' social media. The participants were also part of the larger administrative team in which they met with on a weekly or monthly basis.

The most common social media tool that health care institutions use is Facebook, followed by Twitter. YouTube was also a popular social media tool, with one health care institution having its own YouTube channel. Other social media tools that health care institutions are using with consumers include Google Plus, Pinterest, Flickr, LinkedIn and Foursquare. Internally,

health care institutions are also using social media. One health care institution uses SharePoint, a Microsoft web application, to communicate with employees. SharePoint is an intranet tool powered by Microsoft that allows users to share documents and reports.

The purposes for which health care institutions use social media varies, however, the participants all responded that awareness was part of their purpose. Health care institutions use social media to create awareness of their brand, services that they offer, informational content about health care news, and events. One of the health care institutions was more advanced in using social media. This participant said that their health care institution used social media to recruit medical students and clinicians, and also used social media to build relationships in the community and also with patients. The interview participant from this health care institution also explained that the administrative team at this health care institution does not use social media to mass market the health care institution, but rather uses social media to target a clearly identified, motivated, and active audience. For example, the health care institution offers a bariatric support group on Facebook for current, past, and potential patients to comment and share tips, experiences and advice, and also to connect with program clinicians and managers.

The amount of health care information that institutions shared online varied from five percent or less to a majority of health care information. The health care institution with the most frequent posts valued using social media to build relationships rather than using social media as a mass marketing tool. Health care institutions that used social media primarily for marketing purposes, such as to promote events created fewer posts.

Social media has many advantages, and the participants expressed numerous benefits in their responses. The advantages expressed by the participants include that social media is user selected, two-way communication, and global. In addition, social media allows health care administrators to learn about the audience through analyzing accounts connected to social media responses. Social media also promotes relationship building. One participant also explained that another advantage of social media is that it appeals to an exponential audience. This is an audience that also searches for information using simple language and seeks to read information written in uncomplicated terminology. The participant who stated that social media appeals to an exponential audience demonstrated awareness of user-centered design through explaining that their institution strives to connect with their audience's needs and abilities.

The limitations expressed through the interviews were consistent. The most common limitations related to the HIPAA law which prevents health care institutions from sharing any patient information or stories through social media or any other communication vehicle. Although the participants expressed that HIPAA stands in the way of their use of social media to communicate with patients, they also expressed that adhering to HIPAA standards and their patients are their priority and they value protecting their patients. Another limitation that the participants stated was the labor intensity of monitoring social media. Although social media tools are free, the participants explained that they spend many hours monitoring social media to ensure that users are not posting information that violates HIPAA, or that is inappropriate. One participant also had the job of responding to negative comments posted on social media, removing them from the website, and then referring them to the appropriate department for which they could be addressed within 24 hours. For example, sometimes people share a picture that contains a profile of themselves, which the institution has to remove and remind users so that the institution does not violate the HIPAA guidelines. Another limitation expressed by one of the participants was that social media only allows health care institutions to provide generalized information, and that it is challenging to tailor a message for a specific audience.

With the innovation of social media tools, health care institutions are planning new strategies to use social media within their health care institution. The diverse responses which participants provided demonstrated the health care industry's growing audience. One of the most common strategies that participants expressed was using social media to target their audience in the future and appeal to a more defined audience. Other responses included using social media to present health forums for doctors and patients to interact via video chat, improve electronic access by patients to their own medical information, and offer pre-registration, appointments, labs, prescriptions, and account information. Another option that one of the participants foresaw was virtual office visits and telehealth. One participant anticipated an increase in the use of text alerts, blogs, microblogs, and forums through using social media. An increase in social media within the health care institution to promote internal communication between employees and administration was also an area in which one health care institution was seeking. All participants mentioned their awareness of HIPAA guidelines in advancing their social media tools.

Specific tools that health care institutions research and hope to implement include Foursquare, Pinterest, Instagram, Storify, and QR codes. In addition, one participant also expressed that health care institutions are working to develop their own mobile applications. The development and implementation of their own apps could launch health care institutions ahead of other businesses.

Chapter V: Discussion

This research study has addressed the social media tools that health care institutions use, how they use them, and how they anticipate using social media tools in the future. Through the implementation of interviews, four health care institution representatives from the United States who work with social media were asked questions about their health care institutions' involvement in social media.

Limitations

The most challenging aspect of the study was to find health care personnel who were willing to participate in the study. Many subjects did not respond to the interview request or chose not to participate in the study. In addition, physicians were also contacted, but none of them responded to the request for an interview.

A methodological limitation includes data analysis. Since the interview questions were open-ended, the data from the interviews must be compared through coding and indexing the information provided in each question. The information was then categorized and placed within a table which listed each question and indexed the responses.

Conclusions

Health care institutions use social media for a variety of purposes. Some use social media as a marketing tool, while others are more user-centered, and therefore offer social media as a tool for patients to engage in support groups. Some larger health care institutions such as Mayo Clinic and Cleveland Clinic incorporate social media for both purposes, to market their products and services and to offer patient support groups. Other purposes include the presentation of information about health breakthroughs and local information on news events and disease outbreaks.

Health care institutions recognize similar challenges in their advancement of social media. HIPAA standards somewhat limit health institutions' abilities to upgrade their social media presence, but the health care institutions value their patients' privacy and adhere to the HIPAA law. Health care institutions look to the future when privacy settings on social media will change and allow them to better meet the needs of their patients. Users who choose to disclose information on social media must sign a consent form, which then allows the health care institution to use specific information, such as patient photographs on their website or social media site. Health care institutions that violate the HIPAA law and release Protected Health Information without a consent form are subject to fines and criminal action.

Public relations department personnel and social media managers are the primary health institution personnel who monitor and add content to both the institutions' websites and social media sites. These representatives regularly monitor the comments posted on the health care institutions' social media sites and remove inappropriate comments that may tarnish the institutions' reputation, or delete personal information that users may post that violate HIPAA. Public relations department personnel and social media managers are also part of a larger team of administrators who determine which information will be posted on the health institutions' websites and social media sites. The teams generally meet weekly or bi-monthly to discuss the direction of the social media sites. Reviewing and updating information on social media sites is time-consuming and labor-intensive. In addition, from a public relations specialist or marketing manager standpoint, updating a social media site or providing new content can be a challenge because they are educated in the medical field to post meaningful content.

Health care institutions are becoming innovative. Several health care institutions are developing their own apps to connect with their patients. These apps may allow patients access

to their medical records, ability to schedule appointments, list of physicians, and other health related information. The development of these apps may technologically advance health care institutions ahead of other businesses. In addition, health care institutions seek to send out text alerts for appointments and events, and use new social media networks such as Foursquare and QR codes, which when scanned with a smartphone directs a user to a specific site.

Although health care institutions may have started out slow in the social media field, they are rapidly moving forward and seeking innovative methods to connect with their patients, future patients, as well as other health care institutions. To continue on this path, they will also need to assess the cross-cultural audience to develop content that can be easily understood by their target audience. Digital literacy will be increasingly important as the population of the United States becomes more diverse in culture and in technological experiences. The digital divide will continue and a portion of the population will always be at a disadvantage in its ability to receive information via technological means. As a result, health care institutions will need to focus upon users' needs and abilities, and also use language appropriate for the audience so that they maximize usability. Technical communications personnel could be useful through offering help to hospital administrators to conduct usability testing and provide user-centered design of social media sites.

Recommendations

Social media coordinators are versatile in that they often play a role in public relations, as well as updating content on websites and social media. Upon contacting health institutions, technical communicators were not part of the team that monitored and updated information on the institutions' social media sites. Interview participants did not express whether they acquired training in technical communication, but none explicitly possessed a technical communication

job title. Knowledge in technical communication could help social media coordinators to increase digital literacy in participatory medicine. Technical communications personnel could be assets to help health care administrators conduct usability testing, as health care institution social media sites will be more numerous and also more competitive in the future. Technical communications personnel could also help IT personnel build more user-centered designs for their websites and social media sites. In addition, technical communication personnel could also conduct usability testing, which will also become increasingly important in the future as medical records, appointments, and other personal health information becomes accessible through apps and digital media in participatory medicine.

Health care institutions that use social media only for marketing purposes should conduct a needs assessment to determine their target audience's motivations, needs, and expectations. In addition, health care institutions that have not developed a social media plan should view the social media plans of larger health care institutions such as Mayo Clinic and Cleveland Clinic and work to implement the best plan to meet the needs of their health care institution. In addition, it is recommended that health care professionals, social media coordinators, public relations specialists, and technical communicators join social media groups such as the Mayo Clinic Center for Social Media to keep informed of the newest innovations in participatory medicine.

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APPENDIX A: Interview Questions

terview Questions for Public Relations or Social Media Coordinator	
1.	What role do you perform in determining the material that is placed on the health institution's website?
2.	How are you involved with social media at this institution?
3.	What social media tools does your health institution use?
4.	For what purposes do you use social media? If it is for awareness, please also explain the impact that social media has provided to create awareness of your health institution.
5.	What percentage of your health information is distributed through social media?
6.	What are the advantages of using social media for the dissemination of health information?
7.	What are the limitations of using social media for the dissemination of health information?
8.	What other ways do you foresee using social media tools in healthcare in the future?