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Developing a Medically Informative and Socially Supportive Interactive Online Network (MISSION)

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DEVELOPING A MEDICALLY INFORMATIVE AND SOCIALLY SUPPORTIVE INTERACTIVE ONLINE NETWORK
(MISSION)

A Thesis
Presented to
the Graduate School of
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In Partial Fulfillment
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Master of Arts
Professional Communication

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by
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Accepted by:
Tharon W. Howard, Committee Chair
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ABSTRACT

This thesis discusses virtual communities and social networks and their current and potential uses in health and medicine, proposing a novel virtual health network called a "Medically Informative and Socially Supportive Interactive Online Network" (MISSION). The purposes of a MISSION are to 1) serve as an information resource for patients, 2) to facilitate conversation between patient and provider, 3) to potentially aid in office tasks (such as scheduling, billing, etc.), and 4) to aid in community-building acts in patients' own local, physical communities. In this thesis, the concept of virtual communities and social networks are explored, the legal and ethical ramifications of a MISSION are surveyed, current applications similar to a MISSION are analyzed, and recommendations for designing a MISSION are offered. This thesis is intended for an audience of health care communication and information systems professionals who can help put a MISSION into action through working with health care providers and organizations.

DEDICATION

I dedicate this thesis to my parents, Stuart and Susan Adams, without whom I would not be where I am today. There are no words to describe how thankful I am for all the support they have given me, in so many forms. I love them more than tongue can tell.

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First I would like to thank Dr. Tharon Howard who has served as an invaluable resource throughout my graduate school experience. Over the past two years he has been my professor, committee chair, mentor, and friend. He challenged and encouraged me throughout the process of writing this thesis, and I could not have done it without him. I am eternally grateful for the guidance and support he has given me.

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TABLE OF CONTENTS

Page

Table of Contents (Continued)

LIST OF FIGURES

Figure Page

CHAPTER ONE

INTRODUCTION

A Virtual Community in Action: PostSecret

In December 2007, I joined the online PostSecret community based on the PostSecret project (www.postsecret.com). People from all over the world use this community as a forum to chat about secrets featured on the website, their own secrets, or anything they might want to share or discuss. I came across a thread started by Leema, a 22-year-old girl who had just discovered she was pregnant but who lives in a country where it is “almost accepted” to kill a woman for having premarital sex. She was frightened and alone, not wanting to flee her country but not wanting to stay and risk her life. Some members of the community who responded to her only offered support saying, “I’ll pray for you” or asking questions about her situation and offering kind words. Others went into action and did research; they offered her websites and phone numbers and addresses leading to people in her area who could help. When she told them she couldn’t turn to anyone local for risk of being exposed, they looked for international aid organizations.

Over the course of nine days and 147 member posts, Leema got information from community members, and they in turn learned about coping with unwanted pregnancies and about how her society operates. She ultimately acquired a pharmaceutical abortifacient from her boyfriend, and while some members of the community raised issue with its origin and safety, Leema decided it was her best option.

During the day the drug took effect, Leema stayed in bed so as to diminish the painful side effects. While all her community friends waited anxiously for her return and a report of her health, they left messages such as these three in a row: jaycee began, "I've been refreshing this page all day and praying for her every time that I see she hasn't posted yet. I really really hope and pray that she is ok," LConfused said, "I am still refreshing [the page], near tears with worry for her. Oh Leema, you have a whole bunch of us on your side sweety [sic]," and Ro_x replied, "She sure does [have people on her side]. I even looked up what time it is in Jordan (1:30pm), I just hope she's still resting after an exhausting day." When Leema returned to the community, these were the first words of her first post: "I want to say I love you all so much, please stay the way you are, not for me but for anyone in need, I don't know what I would have done without your support."

The members of this community may very well have saved Leema's life by sharing information with her. In sum, she may have been able to solve her problem without their help, but judging by her foreknowledge about the situation, she would have put herself in danger while enduring it alone and afraid. Not only did she get the help she sought, but other members know that they helped her, and they most likely felt good about doing so.

Through this example, it is apparent how beneficial a virtual community alone can be to health care. In this thesis, I am proposing the development and use of a network that utilizes the characteristics of a virtual community alongside other tools to aid health care givers and consumers, a network called a "MISSION" (Medically

Informative and Socially Supportive Interactive Online Network). While there are many websites today that offer elements of what the ideal MISSION contains, none match my ideal description. Perhaps not all interactions within a MISSION will be as grave and awe-inspiring as Leema's, but they can be just as important and meaningful to those who participate. A place for people to come with questions and advice about health can help people in need just like the PostSecret community helped Leema. Users can search for information themselves and reach out for support from others when, for whatever reason, traditional clinical interactions fall short of what patients need.

What is an Ideal MISSION?

The proposed MISSION is an online environment wherein patients of a particular health care organization can seek information and can communicate directly with their health care providers and fellow community members. The MISSION should have an element of community, enabling members to interact with their health care providers and/or medical office staff, and members should be able to interact with each other. These interactions can occur through different types of technology, but the element of social support through communication is vital. Apparent in Leema's story, the power of social support can be invaluable to people coping with health and medical issues. The MISSION would serve as a go-to resource for patients seeking health information or just wanting to chat with others who can offer support.

Each network would be limited by a health care organization. Only patients of a particular organization can participate in its MISSION in order to better manage the network and provide personalized attention to patients. One of the things unique to the MISSION is this membership restriction. The patient-users' own providers administer the site (directly or by proxy) and can give patients personalized feedback, providing a sense of privacy to users and preventing outsiders from abusing the system. Many medical-related sites existing today provide free membership, requiring users to register with merely an e-mail address and to create a username and password. A local MISSION should require more information from its members to ensure they are authorized to use the system. For instance, patients might use a password given to them by their health care practitioner to access the site, thus denying access unless to anyone not going through the physical organization to get there. While health-related websites currently in use may have medical professional consultants on staff, these consultants are (usually) not local to the users' area. Patient users are probably more likely to trust administrators they know and have a personal relationship with (such as their own practitioners) or administrators who know the patients' local cultures well.

In addition to a portal for communication, a MISSION would offer refereed health and medical information deemed valid and appropriate by its administrative health care providers. Reference information would need to be authored by professionals who have authority to present health-related information, such as the MISSION's own practitioners or practitioners and experts from other organizations.

These networks should be accredited by some authoritative body, deeming the information accurate and reliable (see more about accreditation in the third chapter). To avoid misleading patients, all information written by community members (i.e., message boards, private messages, chat, etc.) should provide a disclaimer that the content may not be trustworthy. Reference information (i.e., explanations of diseases, therapies) should be clearly presented as such so that patients will know the information is accurate and reliable.

The network should not be funded by or affiliated with a source that could bias its presentation of information. For example, a website sponsored by a pharmaceutical company has a sense of responsibility to that company and may result in favoritism toward that brand. Even if biases are not glaringly obvious, a MISSION should stay clear of commercial funding. Instead, they can be funded through user fees or grants from private or government sources.

Incentives to participate in communities would be a good thing to see in a MISSION, but I found no examples that have any sort of incentive program. An incentive might be a coupon for a discount on prescriptions or a free series of visits to a local gym. The thing that keeps members actively participating is the reciprocity, the remuneration of feeling good about giving advice, the hope that giving advice entitles users to receive advice. Perhaps in a MISSION incentives could be implemented to keep users participating. It is difficult to give virtual incentives, but since a MISSION is geographically local and familiar, maybe small rewards and giveaways could be used as incentives to engage in more MISSION activities.

When building a MISSION, the bottom line is to make sure the patients are getting an unbiased, helpful experience. They should want to participate in the network in order to help themselves and fellow members, and they should feel safe using it.

Users need to know that the information provided on the site from its administrators is true and in their best interest.

Why would a MISSION be Beneficial?

As health care practitioners' time is strained and as patients become better advocates of their own health by using the Internet to do research, there is a need to move part of health care out of the office and into cyberspace. An August 11, 2003 press release from the Centers for Disease Control and Prevention (CDC) states that over half of all physicians' visits were from people over the age of 45, a number that has no doubt increased as more baby boomers have reached this age (2003). In 2001, office visits that included counseling and education increased by a whopping 34 percent compared to those in the previous decade. This same survey revealed that about 16 percent of all visits to doctors were for preventive care, and understandably, those without health insurance were less likely to see their physicians for this reason or for mere educational matters (CDC Media Relations, 2003). This lack of access to preventive medicine only increases the physical, emotional, and financial burden on the consumer later as they develop chronic diseases that could have been prevented (I consider a "consumer" to be someone who is the recipient of health care, either passively receiving it or actively seeking it out themselves).

Medical care becomes less curative and tertiary as we are living longer and are suffering from chronic, not acute diseases. As evidenced in the same survey data from the CDC, patients are relying on physicians more to educate them and to help them prevent or delay the inevitable, or to cope with diseases with which they have already been diagnosed (2003). The “physician-as-miracle-worker” is a model that is becoming less viable as medicine, public health, and our lifestyles have transformed the course of disease. At the same time, computer and technology use become increasingly social and communicative in nature; as advancements in technology are made, they enable us to interact with each other while managing our lives more easily and efficiently.

George Demiris (2006) has explored the notion of using this communicative technology in health care and defines such a place as follows:

> A virtual community in health care refers to a group of people (and the social structure that they collectively create) that is founded on telecommunication with the purposes of collectively conducting activities related to health care and education. Such activities can include actual delivery of health care services, staff or patient education, a platform for providing support, discussing health and treatment related issues and problems, sharing documents, consulting with experts and sustaining relationships beyond face-to-face events (p.179).

Demiris’ words describe an ideal MISSION; this network is comprised of a group of patients sharing the same health care provider or organization who purposefully discuss health-related topics, problems, and activities. Within this MISSION, practitioners may deliver actual care through consultations and the communication of results and reports. Campaigns, tutorials, videos, quizzes, and text may be delivered to educate patients. The MISSION would not take the place of traditional health care but rather supplement it. This enhancement of traditional health services is something the health care industry is already starting to pay attention to.

Health information technology has been a multi-billion dollar industry for many years (Federal Register, 2000). If the bandwagon of social networks and the future of mandated electronic health records don't move practitioners to adopt computer-mediated communication (CMC), perhaps the notion of such large expenditures will. The effort and money that are beginning to be poured into health-related information technology speak volumes for its demand and future importance. While virtual community technology has existed for decades, it is only beginning to catch on in the field of health care, its potential not yet recognized.

Virtual communities and networks like the proposed MISSION have the potential to revolutionize patient-provider and community interaction. However, building such a network is a daunting undertaking for most health care providers, particularly since there is not yet a single definitive source to which they can turn to guide such a system's development. Furthermore, information about social networking exists independently of health communication practice and theory, making qualities of a "successful" system hard to define.

Theoretical Foundation

In addition to discussing what features a MISSION should possess and its potential impact on consumers, it must also be understood why patient-users will benefit from particular characteristics. Turning to the Social Cognitive Theory developed by Albert Bandura, we see how communication influences thought, affect, and action (2001). According to Bandura, communications systems operate through two pathways – direct and indirect. In the direct pathway, communications media promote changes by informing, enabling, motivating, and guiding participants. This form of communication would be seen in virtual resource libraries and multimedia messages found within the MISSION. Users would seek and retrieve information on various subjects such as sample low-sodium or gluten-free diets, tutorials for managing diabetes, and comparisons of different methods of contraception.

In the indirect socially-mediated pathway, participants are linked through various media to other participants within social networks and communities. The socially-mediated pathway exists in the MISSION's virtual community aspect. Here, information gets passed on through communication between and among participants, through bulletin board posts, chats, or listserver e-mails. These socially-mediated pathways provide personalized guidance, incentives and social supports for desired changes (Bandura, 1997, 2001). A MISSION would merge the two pathways to ensure users get an immersion of health information.

At the very core of following health advice is Bandura's construct of *self-efficacy*; we only perform actions we think will yield a desired outcome (2001). Solicitors of advice believe a solution exists; givers of advice impart self efficacy by persuading others that the advice is valid. We follow advice based on what we expect from it; John Smith will only go through the trouble of taking vitamins if he believes the outcome will be positive. As Bandura states, "people do not live their lives in individual autonomy. They have to work together to secure what they cannot accomplish on their own," (2001, p. 270). The MISSION relies on this social interaction; patient-users must be driven to use the network, must believe they are able to, and must believe they will benefit from using it.

Objections to and Concerns about a MISSION

Not every patient within a health care organization will fully embrace the MISSION or even want to use it. The use of the MISSION will follow the same pattern as do other innovations (Bandura, 2001; Robertson, 1971; Rogers, 1995). After its introduction to the population of patients, many users will not want to participate in the MISSION; it will be unfamiliar to them and somewhat risky, as there is currently no other network or community exactly like the proposed MISSION. However, a number of people will begin to use it and learn more about it, passing their discoveries on to other potential users.

This second tier of users will join, embracing and using the MISSION to its potential once they realize it is safe to do so. After this surge of adopters, the number of new users will plateau and hopefully stabilize. Not every potential user within a population of patients will want to participate in a MISSION, particularly older generations who are not as familiar with computer technology as younger generations. Additionally, people will not want to participate in the MISSION if it requires a large fee or advanced skills (Bandura, 2001). By having either a small fee or making the system free of charge, and by making the system user-friendly and offering tutorials, fewer potential users will be inhibited, making them more likely to use the MISSION.

Some anti-social people will not want to join the MISSION; people with many social ties are more likely to adopt innovations than those with fewer ties (Rogers & Kincaid, 1981). While these people may be discounted and considered losses, they may still be persuaded to join the MISSION if they believe the benefits outweigh the risks (Bandura, 2001). A major task in the development of such a system will be to entice these reluctant people to join by providing training sessions and incentives. Enabling this group will be especially important; most of the populations who shy away from technology or do not have access to it are the populations who have higher health disparities than the majority of the population (i.e., geriatric, minority, and non-English-speaking patients).

Chapter Overview

Since both the risks and benefits of a MISSION have the potential to be great, health care professionals should be armed with as much knowledge as possible before launching such a system. As statistics show, more people each year are accessing the Internet and using it more frequently. This means that the Internet could serve as a successful forum for health care delivery due to its efficiency, familiarity, and popularity with users. Health organizations are beginning to move services online (such as bill-paying and e-mail consultations), and these services need to be regulated and customized to meet the needs of consumers while protecting individual rights to privacy. Therefore, my goal for this thesis is to assess the factors that need to be taken into consideration in order to construct a usable MISSION.

In the second chapter, I will define virtual communities and social networks and their potential impact on health, as well as explore beneficial health outcomes and economic benefits of preventive health. I will cover the legal and ethical implications of building a MISSION in the third chapter, including the protection of users' privacy and the protection of the health care organization from litigation. In Chapter Four I survey a few web-based health applications in use today that share some key elements with (but none are identical to) the proposed MISSION. Also, I explore the design and usability of a MISSION, discussing the importance of usability testing throughout the entire design process to ensure the system is successful with its intended users. Finally in Chapter 5, I will present some potential future applications of the MISSION.

I have written this thesis in the hopes that health care professionals, administrators, benefactors, professional health care communicators, and information technology specialists may consider how a MISSION could benefit their health care organization and begin the steps necessary to implement their own. Therefore, I will examine the factors essential to a successful network and provide these professionals with guidelines for building their own. This is by no means a step-by-step "how to" manual, but rather a collection of things to consider when preparing to launch such a system. The idea of bringing health and the Internet together is by no means a novel one; however, now that people are relying on their computers more to organize their lives and to connect to people and services, it would behoove the health care industry to act now.

CHAPTER TWO

WHY USE VIRTUAL COMMUNITIES AND SOCIAL NETWORKS IN HEALTH CARE?

Time spent face-to-face with physicians is usually taken up by content-related communication, leaving little time for emotional support. A MISSION can pick up where practitioners leave off; users can find more information to answer questions and talk to one another to gain support. By exploring the impact social networking and virtual communities have on society, we can make the link between this form of communication and positive medical outcomes. By discussing problems and solutions, MISSION members can gain understanding about their own health conditions and health care, thereby improving their health outcomes.

What is a (Virtual) Community?

Before discussing virtual communities and social networks, it is necessary to establish a "traditional" understanding of these terms first. Because the word "community" has differing definitions depending on who is asked and what discipline is studied, I will start further back with one scholar's definition of the word "community." In his book, *A Rhetoric of Electronic Communities,* Tharon Howard reviews literature on the definition and nature of the word "community," (1997). Howard examines the 1955 work of George Hillery, who wrote that the "ideal" community is the native village, "a social group inhabiting a common territory and having one or more additional common ties" (Howard, 1997, p. 64). Several years after his first attempt, Hillery qualified his definition, writing, "possibly some day man can ignore these [geographical] barriers" (1959, p. 240), presaging the era of virtual social networking and virtual communities. In Hillery's previous article (1955), he researched 94 definitions of the word "community" and found three necessary elements of communities: 1) area, 2) common ties, and 3) social interaction, in order of increasing importance.

Howard also cited Michael Taylor (1982) who argued that communities should share some set of beliefs and values, that their members must communicate directly, and that they should possess a characteristic called "reciprocity." Howard summarizes this term as "members of a community make short-term sacrifices in order to receive the long-term benefits of membership in the community," (1997, p. 65). In other words, members invest in the community to get something in return. Nelson (1948) asserted that members "…have a sense of belonging together and … through their organized relationships share and carry on activities in pursuit of their common interests," (p. 71) Returning to Albert Bandura, he claimed that:

> The more efficacious groups judge themselves to be, the higher their collective aspirations, the greater their motivational investment in their undertakings, the stronger their staying power in the face of impediments, the more robust their resilience to adversity, and the higher their performance accomplishments (2001, p. 270).

As members of a MISSION assemble to help each other solve problems and to share information, they aspire to be healthier. As interactions within the network motivate members to come back, their confidence in the power of the group to solve problems and offer support will grow.

With responsibility to a community comes identity with that community; members perceive themselves as members, and membership in that community becomes part of their identity. Lowry Nelson stated that the members of a community "…have a sense of belonging together and who through their organized relationships share and carry on activities in pursuit of their common interests," (1948, p. 71). People who develop a sense of identity with their community and hold it in high regard are more likely to reciprocate help and support to fellow members (Constant, Sproull, & Kiesler, 1996). Having said that, the idea of a cohesive community is crucial to its success; members must feel like they belong and must trust their fellow members. By establishing a "community" to which members can belong, there develops that great responsibility and trust that make members want to keep participating. In the example of the PostSecret Community, members became captivated by Leema's plight and wanted to help her and to know how she was doing. Some members would check back several times a day, and many posted several times with well-wishes and advice. Her story had become a part of them; they felt something akin to a duty to see that she came out of the situation healthy and safe. This responsibility toward the group is felt in all examples of a community.

Regarding virtual communities, I will use Howard's notion of "RIBS" as a tool to describe their characteristics (Howard, forthcoming). He has developed a succinct list of characteristics that virtual communities must possess, consisting of: remuneration, influence, belonging, and significance (Howard, forthcoming). Members of a virtual community feel rewarded by their contributions; they “get something out of it.” Either through altruistic feelings or reciprocated advice, members are *remunerated* for their contributions to the community. Members also *influence* one another in a cyclical pattern. The culture developed within the community changes according to its constitutive interactions, and this resultant culture influences members through norms and sanctioned activities. This culture allows members to have a sense of *belonging* to the community, and the shared interests allow members to contribute to and be a part of something larger than themselves. Because they share common interests with others, members of a virtual community feel accepted and wanted by their fellow members. These shared interests are *significant* to its members, as the interests are the initial force drawing members to the group. Members keep participating in the community’s activities because the community is socially significant enough for them to put energy into.

Each virtual community has a purpose; this purpose can be an interest or a need, a place to exchange information, or a service to provide others. In other words, there must be an explicit reason for the community to exist (Preece, 2000). The virtual community has policies in the form of understood norms, assumptions, protocols, or rules/laws that govern action within it, just like a “traditional” community. Members must communicate directly – fostering social ties, developing relationships, and allowing networks to grow in size and depth (Taylor, 1982). Its members socially interact to satisfy their own needs or to perform special community roles like leading or moderating (Preece, 2000). This direct communication among members is mutually beneficial as it leads to trust and reciprocity (Howard, 1997).

There is a give-and-take among members; a sense of responsibility to the community needs to be established in order to make members return, either to give or receive information. Inherent in this notion of reciprocity is mutual trust among members (explained further later). Members must trust that by providing personal information to others when looking for support, others will in turn confide in them when the tables are turned. Members trust that others will keep confidential what does not need to be said to people outside the network.

As Howard Rheingold was somewhat of a pioneer in his book, *The Virtual Community* (first published in 1993), it is interesting to see the possibilities that he predicted for virtual communities. Rheingold described a "virtual village" and the creation of a veritable new culture as social contracts are built and changed within a virtual community (2000, p. xvi). He called virtual communities an "ecosystem of subcultures" and offered that they exist as spaces to exchange scientific discourse, places for political rallying, places to meet potential romantic partners, places to advertise goods for sale, or places to let it all out for the purpose of psychotherapy (2000, p. *xviii*). Rheingold's bottom line seems to be that a "community" is merely the name given to a network of people with a shared interest, regardless of physical location.

For the purpose of this thesis and the network I am attempting to describe, the community element of the proposed MISSION is both geographical and virtual. For a hospital system or medical care provider group, the pool of consumers is more than likely within a close geographic region, a characteristic that closely follows Hillery's (1953) notion of the native village. The consumers are a group of people inhabiting the same territory, and their initial common ties result from their common health care provider and their desire to participate. However, it is almost certain that after joining the MISSION, members will discover that they share common interests with other members of this network. Due to these shared interests, the MISSION might grow from a health-only network into a community-building network, creating and fostering relationships that bring MISSION members and their geographic communities closer.

What are Social Networks?

Many people think of social networking websites like Facebook® or MySpace® when they hear the term "social networking." The term is sometimes used interchangeably with "virtual community," as the definition of a network can mean "an association of individuals having a common interest, formed to provide mutual assistance, helpful information, or the like," similar to the definition of community (Dictionary.com, 2008a). Social networks are comprised of social relations between people based on ties like friendship, employment, or information exchange (Garton, Haythornthwaite, & Wellman, 1999). These social ties are the basis of Facebook® and other social networking sites – users can connect and link to each other based on relationships. Facebook®, created by Mark Zuckerberg, is valued at $15 billion and encompasses 50 million users; a mere 1.6 percent stake in the company was purchased for $240 million by Microsoft (Quittner, Hempel, & Blakely, 2007). In July 2007, Facebook® was the sixth most-trafficked site in the US and had over 40 billion page views every month (Locke, 2007); put into perspective, that's like every single US citizen logging into the website about four times per day. In 2008, it was reported that Facebook® attracted 123.9 million unique visitors in the month of May alone (McCarthy). Nearly half the people who went online in the U.S. in October 2007 (83 million) visited MySpace® or Facebook® (Hamilton, 2007). Hamilton's description of social networking sheds light onto this phenomenon:

> Whether you realize it or not, social networking is something you do every day. Each time you tell a friend about a good movie, bore a neighbor with pictures from your kid's birthday party or catch up on gossip at work, you are reaching out to people you know to share ideas, experiences, and information. The genius of social-networking websites such as MySpace® and Facebook® lies in their ability to capture the essence of these informal exchanges and distill them online into an expanding matrix of searchable, linked Web pages (2007).

Indeed, social networking is something we are used to doing in our "traditional" communities. We have grown accustomed to engaging in these aforementioned social rituals and perpetuating social norms, and they become part of our lived community. We share values and interests with our friends, co-workers, and neighbors with whom we exchange movie reviews, pictures, and gossip. When engaged in communication, people provide mutual feedback and influence each other; interaction within these social networks is multidirectional (Rogers & Kincaid, 1981). The virtual social network can either be an extension of this “real” social network, taking the ties one has made in real life and representing them virtually, or an entirely new network created through computer-mediated communication (CMC), comprised of individuals who share common interests.

Large loosely-bound social networks can contain close-knit communities and smaller groups (Garton et al., 1999; Wellman, 1997). For the purposes of this thesis, a community is specific to an ongoing interest or common connection; its members have strong ties to one another and do not make up a mere “adhocracy” for a short time or single purpose (an adhocracy is a group of people who come together to solve a specific problem, disbanding once they have reached their goal) (Howard, forthcoming). The community is dependent upon its constituent relationships and its members’ emotional connections to each other. On the other hand, a social network is constituted by the weak ties of its members, regardless of how they know each other. Its members may have a common connection, but there is little emotional interest or reciprocity among its members.

When an online relationship is established merely for information exchange, its constituent members have little emotional interest vested in it and therefore have “weak ties” (Preece, 2000). These weak ties are easy to maintain and are important for exchanging information, making new contacts, and raising awareness. However, a community has a purpose greater than mere information exchange. The bond among members consists of stronger ties that allow for true social support and relationships.

While some people assert that participation in virtual communities and social networks alienates us from “real” relationships (Preece, 2000), others suggest that CMC may help to integrate society and promote social ties by making it easier to build new relationships and maintain existing ones (Putnam, 1995). This latter point is foundational to the idea of a MISSION; by putting members of the physical community in touch with each other and alerting them to resources available to them, new relationships will flourish between people (patients and professionals) who can help and support each other both online and off.

I consider a MISSION to be a social network made up of small communities. All the members of a MISSION have weak ties; they share the same health care practitioners and live in a fairly localized region (bonds that do not constitute a community). Until they interact with other members and form those RIBS of a community, they are only participating in a social network and are not community members. The people who make up small communities within a MISSION feel an emotional tie to one another and their collective interests and want to help each other on the path to good health. An example of a community within a MISSION would be a support group for middle-aged heart attack survivors; they can identify with each others’ plight and easily communicate due to shared values that come with age.

Members feel responsibility toward each other and value the supportive relationships that constitute their respective communities; they get something out of talking to each other about their shared struggles and interests and can benefit from advice given by others. In a contrasting example, a sixty-year-old man with diabetes has little in common with an adolescent girl facing puberty. Unless these two are in a community whose focus is independent of their ages, genders, and health statuses (a community about yoga, for example), they are not likely to be fellow community members. However, as members of the larger MISSION population who share the same general practitioner, these two people are in the same social network.

Sociability

"Sociability" refers to the act or condition of being social, the very concept that social networks and virtual communities are built upon (Dictionary.com, 2008b). Sociability includes the communication that provides the basis for a MISSION, and inherent in that communication is mutual trust among members. "Trust" is "…the expectation that arises within a community of regular, honest, and cooperative behavior, based on commonly shared norms, on the part of the members of the community," (Fukyuama, 1995, p. x). Trust manifests in the expectation of good, unbiased advice from a practitioner, but it also arises in communication with other community members through the discussion about confidential and sensitive health-related information.

The goal of the MISSION is to share medical information for the sake of learning and support; trust among members plays a major part in fulfilling this goal. By sharing information about him or herself, a community member trusts that other members will share their own information in return. By even using the MISSION, members trust that their information will be kept private by practitioners and other members. However, the virtual electronic nature of the MISSION may keep members from trusting others.

Rheingold acknowledges that the lack of physical cues in a virtual conversation and the manner by which members come to interact with each other both have negative impact on trust within virtual communities (2000). If two members of a MISSION have not previously met in person, it could be difficult for them to trust each other with sensitive material, and they might have reservations about sharing too much. While this is perfectly understandable, a MISSION thrives on the reciprocity mentioned earlier; members must give and take to create relationships.

Because trust and reciprocity are major components of a MISSION, communication between members is fundamental. Not only will the MISSION exist to provide communication between patients and their providers, it will also strive to foster communication among its members. The hope is that patients can give advice and support each other through moderated virtual conversations, but they must trust and communicate with each other in order for that to happen. Chapters Three and Four discuss ways to build users' trust in the MISSION through the exploration of health care provider ethics and the survey of user-centered design.

What Role Might Virtual Communities and Social Networks Play in Medicine?

Social Support

Virtual social networks are extremely successful, flourishing financially and possessing very high participation rates. The financial figures and population statistics of social networks alone should be enough to move health care professionals to develop a plan to reach their customers online. With the popularity of social networking sites and virtual communities and the funding that reputable, successful companies are willing to invest in them, it is obvious that they are a lucrative avenue for health care organizations to explore in order to can reach and engage large audiences. With tens of millions of people already familiar with the concept and format of social networking sites, it is a platform worthy of embracing and building upon.

A familiar example of virtual communities in medicine is virtual support groups, existing in forms such as real-time chat rooms and asynchronous bulletin boards. They are constituted by members who all have something in common and are looking to give and/or receive information and/or support. A virtual support group within a MISSION operates just like its face-to-face antecedent but does not require members to physically relocate. Members gather virtually and discuss issues and concerns over their computer – it allows meetings to occur more conveniently and with relative anonymity.

Conversations taking place within a MISSION can serve to help build outcome expectancies among members (Bandura, 2001). By hearing about or reading someone else's experiences, members can develop expectations about their own health-related experience, thereby reducing anxiety or increasing self-efficacy necessary to perform tasks. It may be difficult for some users to divulge potentially embarrassing health-related information due to risked stigmatization of their condition. However, allowing users to participate in discussion groups offers them some anonymity and permits them to speak more freely about their concerns with less fear of being judged (Berger, Wagner, & Baker, 2005).

It was found that people suffering from stigmatized psychiatric illnesses were more likely to seek health information and to communicate with a health care professional on the Internet, and these patients reported that using the Internet increased their use of health care services and communication with their health care providers (Berger, Wagner, & Baker, 2005). Joining new social networks as an anonymous member could also be especially useful for consumers seeking health information related to socially-stigmatized illnesses such as sexually transmitted diseases, mental illnesses, and urinary diseases who do not wish to have their identities known (Berger, et al., 2005). Sometimes the embarrassing questions we should ask our practitioners are repressed due to fear of stigmatization. By using the MISSION, patients can ask questions of their practitioners and retrieve posted information with a reduced sense of the embarrassment that would have otherwise prevented them from doing so in person. Perhaps most importantly, the Internet may even serve to de-stigmatize health conditions by providing a venue to discuss them in a place and manner where users feel safe.

Although some questions to fellow community members may go unanswered or ignored, the MISSION's monitoring by medical professionals can guarantee attention to every question or concern raised by its users. Perhaps not every single post or thread can be monitored by a physician, but a staff member could have the task of monitoring threads looking for questions (or attempted answers) that need attention.

Resource Information

Posted information sought by patients is another benefit of virtual networks in medicine. In an era where we turn to Google™ or WebMD® for our medical queries, it is highly probable that patients can receive bad information and advice on the Internet from disreputable sources. A trend is emerging wherein knowledge about health and medicine is decentralized and democratized (Eng, Maxfield, Patrick, Deering, Ratzan, & Gustafson, 1998). This is occurring for several reasons:

- People are using their Internet connections to educate themselves about clinical options and decisions. No longer are they dependent on their health care practitioners to feed them information – they are seeking it themselves.
- There are so many advances in medicine and health care that it has become difficult for health care professionals to keep track of them all. With new diagnoses and new treatments being discovered and developed as often as they are, it is nearly impossible for physicians to keep up with them all.
- Medical visits between patient and provider are increasingly shorter. This can be attributed in part to the attempt to keep medical care spending down.
- Preventive medicine and self-care are encouraged by health plans and employers. This, too, is an effort to keep medical costs down. Preventive medicine is far less expensive than curative medicine (surgery, prescription drugs, therapies, etc.).

- The population is aging. As consumers get older, they inevitably have more health problems; as a result, there are more people seeking answers to health-related questions.
- And finally, people are becoming interested in alternative health care options. Some are not content to deal only with a medical doctor, but are seeking their own answers in the realm of holistic health.

Since this information-seeking phenomenon can hardly be contained, health care professionals need to embrace it early and provide their patients with an ethically-sound accurate bank of information and source of support not yet offered by any other site or application. Patients who seek answers on other sites without appropriate guidance may very well base their medical decisions on inaccurate information, potentially leading to harmful consequences.

A proposed MISSION can host refereed information posted by health care professionals within an organization. Patients are able to do their own research knowing that information they find on the MISSION is reputable and deemed appropriate by their own trusted practitioners. The American Medical Association asserts that physicians should improve communication and should point their patients in the direction of accurate health information (further discussed in Chapter Three) (Felkey, Fox, & Thrower, 2006). This also means that practitioners should present unbiased information on their site or network. Patients trust that they will receive good information not polluted with unsolicited commercial advertising.

In addition to serving as a resource, social networking is also quickly becoming a marketing and advertising tool for health concepts; word-of-mouth takes on a whole new role as it becomes the media itself (Preece, 2000). Not only does word travel quickly among a network of interconnected people, but members also trust each others' judgment and advisement. Trusting that fellow MISSION members have no commercial agenda within the network makes referrals within such a network highly credible and persuasive. Indeed, with regard to marketing in social networks, Facebook®'s Mark Zuckerberg said, "nothing influences people more than a recommendation from a friend," (Hamilton, 2007, p. 48). Clearly, this form of marketing can be harnessed to benefit health and wellness.

Instead of learning about health through trial-and-error (blindly guessing and trying a remedy for a rash without knowing the implications, for example), MISSION users can learn through observation, either through direct or socially-mediated communication. People act based on what they know, limited to their experiences and perceptions within their personal realities. When considering the wealth of information potentially provided by interaction and multimedia within a MISSION, its members' realities are expanded farther than ever before, allowing them to learn more about their health and society (Ball-Rokeach & DeFleur, 1976).

What is the Economic Benefit of Preventive Health Programs?

In 2007, heart disease, cancer, and stroke were the first, second, and third leading causes of death in the United States, respectively (CDC, 2007). These three chronic conditions are largely preventable by changing health behaviors such as smoking, poor eating habits, and physical inactivity. To illustrate the economic impact of preventable chronic diseases, in 2008 the estimated direct and indirect costs of cardiovascular disease and stroke alone are estimated at $448.5 billion, with approximately one in three adults having one or more types of cardiovascular disease (American Heart Association, 2008). One-third of the cancer deaths in 2007 are assumed to be related to obesity, physical inactivity, and/or poor diet while close to an additional one-third are estimated be caused by tobacco use (American Cancer Society, 2007).

Conventional education and wellness programs have been widely established to help people make decisions toward a long and healthy life. Many cost-effective, proven preventive services (e.g., smoking cessation programs, diet planning tools and guidelines, etc.) are underutilized but have the potential to make a significant difference in health outcomes. Specifically, cost-effectiveness ratios reported in various studies include: $14,000 *per year of life saved* from screening women ages 20-74 for cervical cancer once every three years (Eddy, 1990); $900 *per Hepatitis B infection prevented* among infants from prenatal screening of their expectant mothers (Margolis, Coleman, Brown, Mast, Sheingold, & Arevalo, 1995); and $5,000 *per quality-adjusted year of life saved* by a public education campaign to promote folic acid supplements for the prevention of neural tube defects (Kelly, Haddix, Scanlon, Helmick, & Mulinare, 1996).

While a MISSION would not deliver health care directly, it would serve to educate patients about the efficacy of preventive measures and help them develop outcome expectancies and self-efficacy needed to perform these tasks (Bandura, 2001). By sending web-based reminders to perform self exams, enabling reminder and scheduling services for screening appointments, or providing information about the importance of prevention, a MISSION has the capacity to create awareness about and reinforce the adoption of prevention efforts within a virtual community.

What Impact Might Computer-Mediated Communication Have on Patient Health?

The Pennebaker Paradigm

Writing about trauma and its resultant emotions has shown to be an effective avenue for psychological interventions (Lange, Schoutrop, Schrieken, & van de Ven, 2002), in some cases having a long-term positive impact on health outcomes (Greenberg & Stone, 1992; Pennebaker & Beall, 1986; Pennebaker, Colder, & Sharp, 1990; Petrie, Booth, Pennebaker, Davidson & Thomas, 1995). This effect, called the *Pennebaker writing disclosure paradigm*, has inspired a number of e-mail and web-based therapeutic applications (Lange, Schoutrop, Schrieken, & van de Ven, 2002).

During traditional Pennebaker therapies, patients write about their experiences with trauma, health-related problems, or a situation that has caused them distress. This writing exercise is mostly in the form of journaling – a patient's monologue meant for themselves alone (perhaps monitored by their practitioner) rather than a dialogic discussion with others. During Pennebaker's studies, experimental subjects reported feeling sad and depressed during and immediately after writing about their troubling experiences, but after several sessions of writing, these subjects reported happiness and found significant meaning in the work they had performed (Pennebaker, 1991).

Since it has been established that one-sided writing is therapeutic, we might be able to assume (or at least have reason to examine further) that writing to peers who have similar issues has a positive outcome as well. If this assumption is true, communication activities taking place within a MISSION will have positive outcomes on patients' health, not only due to medical attention by providers, but also due to the psychosocial benefits of "venting" through their writing.

Even if the act of writing itself has no positive impact on the writer, the help they can get from a MISSION as a response to their writing will most certainly benefit them. By disclosing health-related information to other members and professionals, a patient user can receive information, help, and support. The purpose of a MISSION is not to merely share information but to be proactive in improving and maintaining health. Even if the act of disclosure itself does not have an effect on health status, the results of divulging will.

Perceived Social Support

The perception of low social support felt by a patient with coronary heart disease can increase his or her risk for cardiac events (heart attacks, strokes, etc.,) (Lett, Blumenthal, Babyak, Catellier, Carney, Berkman, Burg, Mitchell, Jaffe, & Schneiderman, 2007). Both depression and low social support have effects on the prognosis of disease; the less social support the person feels he or she has and the more depressed he or she is, the worse the prognosis will be (Barth, Schumacher, & Herrmann-Lingen, 2004;

Hemingway & Marmot, 1999; Lett, Blumenthal, Babyak, Sherwood, Strauman, & Robbins, 2004; Lett, Blumenthal, Babyak, Strauman, Robbins, & Sherwood, 2005; van Melle, de Jonge, Spijkerman, Tijssen, Ormel, van Veldhuisen, van den Brink, & van den Berg, 2004). Perhaps depression and low social support do not *cause* cardiac events, but the correlation should be explored. A MISSION can increase both social support and the perception of social support; conversing on a regular basis or even an irregular basis – just knowing someone is available to talk to – may help improve a user's mood by "getting it all out." With an increase in social support, the patient will not only feel better but will also create a network of informational and instrumental support. By communicating with others, patients may improve their moods, but they will also make contact with fellow community members and health care professionals who can offer information or help.

Chronic Disease Management

With the prevalence of chronic diseases today, many Americans are likely to find that a lot of their daily time and attention are devoted to their health. Patients who are involved in their own care and who are motivated to manage their health have better disease outcomes and greater satisfaction with symptom control (Lorig, Sobel, Stewart, Brown, Bandura, Ritter, Gonzales, Laurent, & Holman, 1999; Wagner, Bennett, Austin, Green, Schaefer, & Vonkorff, 2005). By taking ownership and responsibility for their own health, patients seem to be more interested and invested in it and devote more time and energy to improving and maintaining it.

One theory that provides a useful framework to analyze the potential benefits of a MISSION is Bandura's Social Cognitive Theory. Self-efficacy, a major construct of this theory, refers to a person's belief that he or she is able to perform a task or reach certain goals (Bandura, 2001). To illustrate, if a person believes he or she is able to perform a task like managing blood sugar or organizing prescription drugs, the individual is more likely to try and to be successful. A MISSION could improve the self-efficacy of its members through providing information from professionals and through the support of community members to each other. Furthermore, by discussing setbacks and successes with others, members can be motivated to attempt tasks they might have previously done incorrectly or to continue performing healthy tasks they are currently performing correctly.

In addition to helping manage pre-existing conditions, the MISSION can aid in the prevention of future illnesses. By offering preventive advice and tips from the administrators and by providing a place for members to help each other follow healthy regimes, the MISSION can serve to motivate its members and increase their self-efficacy. By helping to provide procedural knowledge (Bandura, 2001) on how to carry out tasks like performing a breast, testicular, or skin self-exam, by providing alerts and reminders (Bandura's *modeling reinforcement*) to members, and by offering them a space to discuss concerns and expectations of outcomes (Bandura, 2001) with other members, the MISSION could be a wonderful tool for promoting self-care and disease prevention.

Conclusion

In sum, the popularity of virtual communities and social networks today make them a topic worthy of further exploration and consideration in regard to health and medicine. A MISSION can make health care and social support more accessible and constant, thereby improving users' health outcomes. Following the definitions of "virtual community" and "social network," a MISSION should be thought of as a broad social network filled with smaller virtual communities created on the basis of their members' common values and interests. Members of a MISSION should gain a sense of remuneration from involvement in the network, should identify themselves as members of their respective communities and of the MISSION as a whole, should feel as though they belong to their community, and should consider their involvement in the MISSION significant (Howard, forthcoming).

Due to the current prevalence rates of chronic disease, health care is doing more to help patients adopt healthy habits and lifestyles in order to prevent those diseases. Constant exposure to reliable health-related information and dependable social support from a MISSION can help patients adopt healthy behaviors and raise awareness of health issues, thereby improving their health and lowering overall health care costs.

CHAPTER THREE

LEGAL AND ETHICAL CONSIDERATIONS

The practice of medicine has always included legal and ethical debates, but with the advent of “telehealth” and “virtual medicine” (administering medical care and consultation from geographically separate locations with the help of communication technology), these topics need to be considered more seriously than ever. As health care handles some of the most sensitive information in human nature, ethical guidelines are imperative for a clinical organization to practice good medicine. A major benefit of sharing medical information on the Internet is the access factor; a large audience can be reached with far less effort and fewer resources than traditional means of communication. However, therein lies the risk of sharing information on the Internet – it is entirely too easy to accidentally or maliciously distribute confidential information unless proper measures are taken to ensure its privacy. Additionally, there has been an ethical shift from traditional, “paternalistic” health services to those that promote more patient autonomy**.** In light of this ethical shift, a delicate balance must be struck between giving patients orders and guiding them to options (Mills & Sullivan, 1999).

A virtual network is an effective portal for giving patient-users the autonomy to search for information on their own, but they still need a trusted resource to consult for guidance when needed. A MISSION can provide access to all this, but the ethics and legislation surrounding that network need to be carefully considered and closely monitored while the safety of private information needs to be maintained. Disregarding safety and privacy could lead to financially- and professionally-devastating legal consequences for practitioners, not to mention negative social and job-related outcomes for the patient whose health information is compromised. The “safety” that needs to be regarded “…includes protecting the integrity, confidentiality, and availability of information assets such as patient information, key components of the technical information system, and critical personnel,” (Collmann, Coleman, Sostrom, & Wright, 2004, p. 312).

This chapter will discuss legal and ethical factors that must be considered when building a MISSION in order to protect the rights and safety of both patients and practitioners. First, I will discuss the basis of ethics and why they must be considered before addressing the duty a practitioner has to his or her patient. Beyond that, codes of ethics will be addressed, as well as several security guidelines suggested by professional organizations and committees. Next, current laws regarding the privacy and security of health information will be explained; a significant portion of the chapter will be devoted to the Health Insurance Portability and Accountability Act of 1996 since it permeates every aspect of a MISSION. Finally, the chapter will conclude with difficult ethical considerations that have no “right” or “wrong” answer, but need to be decided on a case-by-case basis.

What Are Some Legal and Ethical Issues with Extending Health Care into the Internet?

Federal agencies have begun to respond to the expansion of health to the Internet by passing some precautionary legislative actions. The National Expert Panel on Community Health Promotion convened by the CDC recommended to the National Center for Chronic Disease Prevention and Health Promotion in 2006 that public health officials seek to “promote an electronic mechanism to facilitate virtual community health promotion with capabilities to share knowledge, disseminate evidence-based programs and promising practices, and promote the dialogue between communities and CDC,” (Navarro, Voetsch, Liburd, Bezold, & Rhea, 2006, p. 2). A decade prior to this expert panel’s meeting, the Federal government wrote into law the regulation of electronic-based medical networks. Title II Subtitle F Section 261-264 of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104-191, the Administrative Simplification Regulation, requires the establishment of national standards for electronic health care transactions and national identifiers for providers, health insurance plans, and employers (Federal Register, 2000, p. 82463). This regulation creates a minimum standard to which all electronic health care transactions must adhere regarding patient privacy and the handling of medical records. Although the regulation does not refer to a virtual network vested solely in communication, it does refer to telemedicine, thus creating a basis for the development of virtual communities and social networks related to health.

The HIPAA Administrative Simplification Regulations have these three purposes: to protect consumers’ rights by allowing them to control their own health information, to improve health care quality by restoring trust in the health care system among those who provide care and those who receive it, and to improve efficiency and effectiveness of health care delivery by creating a framework for privacy protection that relies on a concerted effort from all parties involved (Federal Register, 2000). Abiding by these regulations will require a large amount of collaboration and effort from various health care providers. The framework for privacy protection has taken health care organizations a considerable amount of time to get accustomed to using. Allowing patients to control their own health information will require a carefully orchestrated set of protocols, organized and agreed upon by all health care providers. Clearly, these activities take a considerable amount of effort to complete. However, when they are followed successfully, these regulations can make health care more efficient and better able to serve the consumers.

Beyond the notion of consumer privacy, authorship and intellectual property must be considered at all times, especially when disseminating information through a content management system (Huntington, 2003). Also, because laws regarding intellectual property and electronic information are often complicated and change according to changing technologies, health care providers and organizations are advised to consult legal counsel when developing Internet ventures.

Another legal issue that has been raised regarding medical information on the Internet is that of medical malpractice. If consumers follow bad advice they find online, can they sue the practitioner who gave them the advice? In this regard, there can be a justifiable reason to file a malpractice lawsuit if a duty of care toward the patient has already been established (Huntington, 2003). If there is a “real” patient/provider relationship established with a plan of treatment, then that provider has a legal, moral, and ethical duty to provide good care to the patient. The best way to address potential malpractice suits is to prevent them altogether by providing a disclaimer for users to sign stating that the MISSION should not be used as a primary delivery mode of treatment and that users should seek proper medical care when attempting to diagnose or treat any health condition (Huntington, 2003).

To illustrate potential litigious concerns, a reported 89 percent of the 52 million Americans who have used the Internet to get health-related information are worried that the websites they visit might sell or give away information about what they did online, and 63 percent of those 52 million think that putting medical records online is a bad idea, even on a secure password-protected site (Van Brunt & Salehizadeh, 2001). While health care providers must be sympathetic and understand their patients' concerns, they should try to convince patients that health information is secure in a MISSION due to technological precautions taken like those regulated by HIPAA. While urging their patients to use a MISSION, practitioners must be cautious as to not abuse their power to persuade patients who do not want to use it. *Ethos* of the health care provider and codes of ethics of the organization should be adhered to in order to ensure providers and organizations are behaving ethically and respectfully toward their patients.

***Ethos* of the Provider and Organization**

Patients trust the professionalism and accuracy of their physicians and trust that they provide sound advice and care. Health care professionals have a level of credibility bestowed upon them by both their education and experience, and it is this credibility that allows their patients to entrust them with their lives. The term "*ethos*" used by Aristotle refers to a speaker's moral character through their knowledge and expertise; what makes a MISSION so reliable and trustworthy is the *ethos* of the organization or practitioner behind it (Aristotle, 1991). For patients who know their health care professionals and trust their judgment, a MISSION should be an extension of the care and advice provided during regular office visits. A network endorsed by a health care provider or organization should be founded on the ethics upheld by its creators and should operate under a code of ethics that reflects the *ethos* of its creators thereby protecting the rights of those who use it.

According to Aristotle, the three components of a person's *ethos* are good sense, good moral character, and goodwill, and anyone who possesses all three components will inspire trust in their audience (2001). In order to adequately care for patients and lead them on the right path to good health, practitioners must behave ethically with the patients' best interests at heart. They must be professional and use their knowledge and judgment to make educated decisions about plans of care. While ethics are sometimes considered personal and changeable, a health care organization should share a code of ethics and act with that code in mind at all times, much like a mission statement. Next, I will discuss the development of an ethical code and provide examples of some that are in effect.

Codes of Ethics

When dealing with uncharted territory as in the case of a MISSION, a mission statement and code of ethics created by an organization can be helpful tools for developing unfamiliar applications. The first “code of ethics” worth mentioning is the Hippocratic Oath, typically recited by physicians upon graduation from medical school (Public Broadcasting System, 2001). The text can be found, in both ancient and modern versions, here: http://www.pbs.org/wgbh/nova/doctors/oath.html. The Oath addresses the duty of a physician to treat patients to the best of his or her ability, the obligation to respect patients’ privacy, and the responsibility to consider the consequences of patients’ diseases and treatments. Concisely, ethical codes should emphasize these principles.

Some health care organizations involved in virtual activities have begun to establish sets of ethical standards. For example, the e-Health Code of Ethics was generated by the nonprofit, nonaligned Internet Health care Coalition. This code was developed through a partnership of traditional health care organizations, commercial Internet health information publishers, regulatory organizations, and individual consumers (Mack, 2004). Its purpose is to offer a moral and ethical framework for web-based health organizations to follow, and it contains eight key elements:

1. *candor* (the site should make its motives and financial support explicit);
2. *honesty* (the site should not provide misleading information);
3. *quality* (information and advice provided by the site should be of good quality and of reputable origin);
4. *right to informed consent* (users should know if their personal data will be shared with third parties);

5. *right to privacy* (no one should be able to access personal information without the users' consent);
6. *a patient's right to know about virtual health care's limitations* (a health website should not be presented as infallible with regard to its offerings or its security);
7. *a practitioner's duty to differentiate trustworthy and untrustworthy information sources* (it is the practitioner's or administrator's responsibility to present quality information);
8. *accountability to the patient* (the mission of the website should be to improve patients' well-being and to foster a positive experience in using the website) (Mack, 2004).

The American Medical Association (AMA) has also adopted ethical standards that define honorable behavior for a physician to possess (Felkey, et al., 2006). While these principles are at the foundation of medicine and should always be at the forefront of health care professionals' minds, they can be reconsidered and adapted when health care professionals build a MISSION. Some highlights of these guidelines are:

1. health care professionals should be dedicated to providing competent medical care and should possess compassion and respect for human dignity and rights;
2. health care providers should always remember to respect their patients' rights by maintaining a level of confidentiality, especially when working with protected health information on the Internet;
3. health care professionals have a responsibility to seek improvements in legislation according to their patients' best interests;

4. they also have a duty to act as educators in addition to healers by offering sound advice and performing research to pass on to their patients;
5. finally, health care practitioners should recognize their responsibility to participate in community- and public health-improving activities.

All of these points can be made specific to a practitioner’s MISSION activities. These guidelines apply not only to physicians but to all practitioners, and they are no longer confined to the walls of an office; these new considerations regarding privacy, especially in light of technological advances, must be upheld for the health and well-being of the patient.

Because the concept of virtual communities and social networking are so new to medicine, ethical principles must be explicitly followed to protect the patient and organization. Legal standards have not yet been established for such a network, so rules-of-thumb and ethical codes are the best that practitioners can follow. Fortunately, there are several industry-developed codes of ethics to follow or to guide the creation of an organization’s own code of ethics. One such industry code is the HONcode, (Health On the Net) designed for both the general public and the web publisher. This is touted as the “oldest and most used ethical and trustworthy code for medical and health related information available on the Internet,” (http://www.honcode.ch, 2007). When a health care consumer sees the HONcode seal on a website, they know that the information found there is ethical and trustworthy.

According to this organization, an ethical health website offers:

1. *Authority: Indicate the qualifications of the authors.* This gives the information credibility and lets readers know that what they are reading is trustworthy.
2. *Complementarity: information should support, not replace, the doctor-patient relationship.* Because of the patient's safety and potential legal conflicts, care either should not be administered at all or should be administered with great caution over the Internet. A wrong diagnosis due to miscommunication about symptoms can lead to dangerous consequences for patients and malpractice lawsuits for practitioners.
3. *Privacy: respect the privacy and confidentiality of personal data submitted to the site by the visitor.* If private health information about a patient is distributed to parties not meant to receive it (employers, insurance companies, friends, families, etc.), a patient's life can be severely negatively impacted. Also, the HIPAA privacy law includes large fines and possible jail time for those who violate it (Felkey, et al., 2006).
4. *Attribution: cite the source(s) of published information, date and medical and health pages.* This allows patients to determine if information is credible and up-to-date. While it is the responsibility of the organization or webmaster to keep track of articles and information provided on or linked from the MISSION, it is good practice to include publication information and dates of articles on the MISSION so that patients can make educated decisions about what advice to pursue.

5. *Justifiability: site must back up claims relating to benefits and performance.* This point relates more so to organizations making a claim of a service or product, but it can also relate to primary care in that the professionals should somewhere justify their establishment of a MISSION and should explain their practice of advice-granting versus treatment over the Internet and the claims they make regarding advice.
6. *Transparency: accessible presentation, accurate e-mail contact.* The user should know who wrote the information and should have the opportunity to get in touch with the author to ask questions or make suggestions. The information on the site should be organized so that it is easy to find and provides a clear view of the organization's intentions and those of its constituent professionals.
7. *Financial disclosure: identify funding sources.* This is another point that has great significance in medical sites making claims; by disclosing who funds the site, it may be revealed that the claims made are about a product made by the sponsoring company. Nevertheless, if grants or donations have been awarded to the organization to aid in the creation and upkeep of the MISSION, those relationships should be disclosed. Certainly information in a MISSION should be completely unbiased and objective, but patients should know where funding of the MISSION comes from.
8. *Advertising policy: clearly distinguish advertising from editorial content.* Another point to distinguish commerce from valid advice, advertising should be marked

> as such so that users will not mistake an ad's claims for truth imparted by their practitioners.

This general code was developed with health information websites in mind, but the points can also be applied to web applications like a MISSION. In any instance of communication between patient and provider, there should be a list of guidelines to ensure that the rights of both patient and provider are protected.

Laws Regarding Virtual Health Care

While medicine administered over the Internet is still a very novel approach, its precursor, telemedicine, is governed by certain laws. Telemedicine is "the rapid, electronically mediated exchange of medical information between persons and institutions involved in the health care process for the purposes of patient care, education and administrative tasks…it tries to improve health care, support patient management and reduce economic effort," (Zahlmann, Obermaier, & Mertz, 2000, p. 20). The National Institute of Medicine has recognized that telemedicine can be administered through telephone, video, and electronic transmission (Spielberg, 1999). The practice of telemedicine and practice from separate geographical locations raises the question of medical licensure. Medical professionals are licensed on a state-by-state basis and must be licensed to practice medicine in the state where the patient is during the teleconsultation; medicine is considered to be practiced wherever the patient is located (Demiris, 2006; Weiss, 2004).

Logically, Internet-based medicine follows these standards and should be treated as if administering phone-based or teleconference medicine. However, it can be difficult to assure that the person on the other end of a computer conference is, indeed, who they claim to be. This is yet another reason that members of a health organization's MISSION should only be patients who have previously been examined in the medical offices and why access to the MISSION should be password-protected. Medical practitioners need to ensure that they are providing care and giving advice to the patient they intend to. Offering bad advice – either to someone who has joined a MISSION without being examined previously or to someone masquerading as an already-enrolled patient runs the risk of malpractice litigation.

By first screening patients in person, physicians get a better idea of conditions or risk factors that need to be considered when diagnosing or during treatment. Describing selective symptoms over the Internet while omitting others can lead to misdiagnoses and malpractice suits – a reason why true diagnoses and treatment plans should be made in person. There exists the issue of whether physicians should make recommendations based on the information they are given, or whether they are responsible for taking the initiative to obtain more detail prior to giving recommendations (Weiss, 2004). If a physician listens to a patient's symptoms over the phone or reads them on the Internet and recommends the patient come in for medical attention, that physician has a duty to treat that patient and is legally accountable for all interactions between them (*Ricks v. Budge,* 1937). To avoid this hassle of technicality and semantics, a duty to treat should be established in the office before a patient even has access to the MISSION. By providing passwords and usernames to patients in person and impressing upon them the serious consequences of sharing that access information, hopefully practitioners can further avoid compromising the safety of their patients and the credibility of their practice.

What is HIPAA?

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) creates a basic level of privacy protection for health care on a Federal level (beyond that, each state has the option of creating more rigorous laws if it so chooses; if state laws take stricter precautions beyond the basic level established by HIPAA, they take precedence over Federal rule) (Felkey, et al., 2006). Overall, HIPAA is concerned with informational privacy, the “right to determine when, and to what extent, information about a person can be communicated to others,” what information is gathered and stored, how that information is used, and how the patients are involved (Felkey, et al, 2006, p. 345).

The Act, through the U.S. Department of Health and Human Services (DHHS), standardizes electronic patient health information, administrative, and financial data; it establishes unique health identifiers for individuals, employers, health plans, and health care providers; and it sets security standards protecting the confidentiality and integrity of “individually identifiable health information,” (Felkey, et al, 2006, p. 359). The penalties for violating HIPAA include fines up to $25,000 for multiple violations of the same standard in a calendar year, and fines up to $250,000, imprisonment up to ten years, or both for knowing misuse of individually identifiable health information (Felkey, et al, 2006).

HIPAA requires the Secretary of DHHS to adopt standards for the electronic transmission of health information regarding: health claims or equivalent encounter information, health claims attachments, enrollments in and disenrollments from health plans, eligibility for health plans, health care payment and remittance advice, health plan premium payments, first report of injury, health claim status, and referral certification and authorization (National Research Council, 2000). Beyond these requirements for the Secretary of the DHHS, the Act sets out rules for health care organizations in its Administrative Simplification provision.

Administrative Simplification

The Administrative Simplification Regulation, mentioned at the beginning of this chapter, has the explicit purpose to protect privacy and security of health information while also promoting efficiency through the use of standards in electronic transactions (DHHS, 2007a). This Administrative Simplification has four parts: 1) Electronic Transaction Standards, 2) Security Rule, 3) Privacy Rule, and 4) Unique Identifiers Standards (Felkey, et al, 2006).

The purpose of the Electronic Transaction Standards is to improve the efficiency of health care transactions. Until its inception, many different coding formats were used to document conditions and treatments for health records and billing, and these varying codes were difficult to decipher between different organizations. Since electronic transactions are required by Medicare, all Medicare providers must adopt the standards for these transactions or contract with an outside agency to handle their transactions for them. As a result, records and billing information can be transmitted smoothly from one practitioner to another to payers and back, all without having to provide translations of different code sets.

Next, the Security Rule requires covered entities (health care organizations and practitioners) to ensure confidentiality, integrity, and availability of all electronic protected health information that the organization creates, receives, maintains, or transmits (Felkey, et al, 2006). Also under this rule, organizations are required to protect electronic protected health information (EPHI) against “reasonably anticipated” threats or hazards to security. This rule does not dictate the specific technologies that should be used, however. Covered entities may choose the specific applications they consider appropriate as long as their rationale for using those applications is supported by assessment and analysis of their organization’s needs as well as risk analysis (Felkey, et al, 2006).

The Privacy Rule was enacted to protect all private health information, regardless of the medium in which it exists. “Privacy” can be defined as the means through which information, property, and decision-making is made less accessible to others (Felkey, et al, 2006). Following this definition, the Privacy Rule creates national standards for medical records and sets boundaries on their use and release, and it establishes safeguards that must be achieved in order to protect the privacy of health information (Felkey, et al, 2006). The rule sets standards on how and when health information is disclosed, how the information is controlled, and what rights the patient has to their own health information (DHHS, 2003). The rule also requires that organizations appoint a representative as Privacy Officer responsible for overseeing privacy measures within the organization. This rule allows patients to decide how their personal health information may be used; it limits release of information to the minimum necessary number of individuals and gives patients the right to their own copy of their health records and to make corrections. This is the rule that would make possible the access of medical records over the MISSION; patients have a right to see their own medical record (after making specific requests and filling out paperwork).

The fourth part of HIPAA, National Identifier requirements, is intended to simplify health care administration processes, improve data accuracy, and reduce costs, all by reducing informational errors associated with having multiple codes for disease/illness/treatment. All coding systems for diseases, injuries, causes, symptoms, and treatments are uniform under HIPAA in order to increase efficiency between providers and payers. It is understandable that with different sets of codes for ailments, injuries, and treatments, communication between health care professionals has been frustrating without standards (Felkey, et al, 2006).

Administrative Safeguards

Defined by the Security Rule, administrative safeguards are “administrative actions, and policies and procedures, to manage the selection, development, implementation, and maintenance of security measures to protect electronic protected health information and to manage the conduct of the covered entity’s workforce in relation to the protection of that information,” (DHHS, 2007b, p. 2). In order to comply with these standards, organizations will have to evaluate the security controls they already have in place in addition to performing a thorough risk analysis. From there they will arrive at personalized solutions to protect health information in the organization (DHHS, 2007b). There are six standards under the Administrative Safeguards, all to elucidate requirements about medical records, employee access, and security measures.

Security Management Process, the first standard under Administrative Safeguards, enables covered entities to establish administrative processes and procedures they will use to implement a security program. There are four required elements in this Process: 1) risk analysis, 2) risk management, 3) sanction policy, and 4) information system activity review (DHHS, 2007b). The results of the first two elements become the baseline for security processes. Risk analysis determines what risks exist and the probability of their occurrence and magnitude, while risk management identifies and implements security measures to reduce the risks previously determined for that covered entity. The third element, sanction policy, requires organizations to apply sanctions to members who do not comply with security measures set forth during risk management. The final element, information system activity review, implements regular reviews of information system activity to determine if any protected health information has been compromised.

Second in the Administrative Safeguards section is the standard of *Assigned Security Responsibility*; it identifies who in the organization is responsible for assuring compliance with the Security Rule (DHHS, 2007b). There should be one primary security officer held accountable for the operation, but under that person, certain tasks may be delegated to others.

Third is the standard of *Workforce Security* which allows the members of an organization's workforce access to EPHI and prevents employees who do not need access from getting it (DHHS, 2007b). For each job function, the minimum EPHI needed is identified and employee access is controlled accordingly. From there, employees must be authorized or supervised when accessing information, must have clearance (ensure that the access they have is appropriate for their job function), and must have access privilege removed when changing jobs or leaving the organization.

The fourth standard is *Information Access Management*, wherein covered entities are required to authorize and restrict access to health information. This keeps EPHI secure from those who have no need or right to see it. If the covered entity is part of a larger organization, this standard requires the entity to keep its information restricted from access by the larger organization. Under this standard, access to the system is granted to those who need it, and the organization establishes documentation and review procedures for monitoring employees' access to ensure no abuse of the system is occurring.

Fifth is *Security Awareness and Training* which requires just that all its employees (DHHS, 2007b). Security measures cannot alone protect health information; the employees of a health organization also have a vital role in privacy protection. Since many security risks and vulnerabilities exist within the organization itself, training is of utmost importance. Employees must receive updates and necessary training on new security measures, must be trained on how to avoid introducing malicious software into the system, tips for secure password use, and their log-in attempts must be monitored to detect fraudulent attempts at access.

The sixth standard outlines *Security Incident Procedures* in case of a security breach. If a threat is detected, covered entities must identify it and respond to it. They must rectify any negative effect the threat has had on the system, and must document the entire incident and follow-up.

Should an accident or emergency occur, there needs to be a *Contingency Plan* (seventh standard) in order to recover access to EPHI (DHHS, 2007b). It should include a data backup plan, steps to recover from disaster, and a plan for operating under emergency. The contingency plan should be tested and revised as necessary so that if it needs to be implemented, it will be effective and familiar. The organization should also prioritize the elements of its system so that when recovering from an emergency, the most important data and applications can be restored first.

Next comes the standard of *Evaluation*, wherein organizations perform evaluative tasks to determine if their security procedures meet the requirements of the Security Rule (DHHS, 2007b). Early evaluations should confirm that the organization's security measures comply with the Security Rule. After compliance has been established, evaluations should focus on any environmental or operational changes that could affect security. The evaluation should be comprehensive, including all aspects of the security system (technical, electronic, personnel, etc.).

Finally, the last standard pertains to *contractual agreements*; it emphasizes that the contracted business associate must agree to safeguard EPHI and also outlines when contracts are not needed (DHHS, 2007b). These standards of the Administrative Safeguards serve as guidelines for electronic and networked applications that contain EPHI and should be used as tools when developing security methods for the MISSION. When developing a MISSION, it is imperative to follow all these guidelines. By doing so, protection of both the organization and the people it serves are insured. Failure to comply with HIPAA's regulations and standards mean hefty fines, imprisonment, and ethical violations that have the potential to ruin patients' lives.

Other Ethical Considerations

E-mail and Medicine

A MISSION would have several modes of communication, from real-time chats to asynchronous bulletin boards and private messages. Although laws have not been considered in regard to virtual networks like the proposed MISSION, we can examine ongoing discussions regarding the legality of medicine practiced over electronic mail (e-mail). Since the inception of e-mail, physicians and other medical professionals have struggled with how it can or if it even should fit into their practice. Weiss asserts that patient-provider e-mailing can increase access to care, enhance patient education, and improve adherence to treatment plans and can provide less costly consultations for capitated patients (2004) – all concepts included in a MISSION. In 1998, a study found that 50 percent of physicians will respond to unsolicited e-mail consultation requests from patients, and 84 percent of those responders will offer a diagnosis and therapeutic advice (Eysenbach & Diepgen). Although it is not medical attention in the traditional sense, is e-mail a form of clinical consultation? Regardless of its classification as such, virtual interactions between patient and provider still need to have stringent regulations to protect both parties. However, e-mail and other means of private electronic correspondence between patient and provider have been largely unregulated and are promising resources that are mostly untapped, though increasingly more people seem to be using them. In order to legally protect both patient and providers, the rules of e-mail and private electronic correspondence (i.e., non-patients seeking advice, diagnosis via e-mail) need to be established before these interactions take place

Even today with the abundance of security measures protecting private information on the Internet, e-mail is a flawed method of communication. E-mail correspondence between patient and provider needs to be considered unreliable as the content of e-mail is not always secure. While HIPAA mandates both for electronic communication, the law does not specify the level of encryption necessary or the specific technology that should be used to encrypt data, only that the encryption tool should ascertain the identity of both the sender and recipient (Spielberg, 1998). More information about these technologies can be found in the chapter on designing MISSION, but it should be known that the health care organization is responsible for protecting all electronic correspondence from being intercepted.

CMC and Social Isolation

Some opponents of virtual communities believe the use of them disconnects us from each other, that we rely too much on computers to communicate and are losing the personal perspective of traditional conversation and interaction. The term “progressive dehumanization” has been used to refer to the decline of inter-human close contact that occurs in face-to-face meetings; some believe conversing via computers may eventually compete with spatial interactions and physical organizational entities (Demiris, 2006). Can computer-mediated communication (CMC) really replace face-to-face consultations and interactions? Gunter suggests that engaging with computers is sufficient for certain instances and minor health enquiries, but more specific, personal issues require more in-depth consultations that CMC just cannot provide (2005). It has been documented that patients will reveal more symptoms and undesirable behaviors (i.e., substance use, sexual activity) when taking computer-based surveys than when being interviewed face-to-face (Gunter, 2005). Perhaps this trend can be used to the organization’s advantage through the administration of periodic electronic surveys in an attempt to garner information that might otherwise be kept personal. However, as stated before, it is not the intention of a MISSION to replace traditional standards of care. So while the dehumanizing qualities of CMC may be valid concerns for other uses of virtual networks, measures are taken within a MISSION to ensure that interactions are built upon a pre-existing traditional patient-provider relationship.

Anonymity

Anonymous consultations via Internet-mediated systems are possible and may allow better care if patients are more honest about their behaviors without fear of being identified. However, is it ethical to treat an anonymous patient? If someone on a network reveals they are doing something to harm themselves or others, or they describe symptoms that necessitate immediate and serious medical attention, is an anonymous consultation the best plan of care? Certainly it can be argued that without this anonymous outlet, no attention or advice may have come to the patient's condition at all. Conversely, without identification of the patient, further knowledge of their health history, and awareness of other symptoms they may be withholding, accurate advice may be impossible. As an example, if an anonymous user reveals he or she is contemplating suicide, a practitioner would have no way of reaching them beyond that isolated interaction. Perhaps some counseling may take place during that time, but the follow-up care and monitoring that patient deserves is impossible without an identity. It is apparent how difficult the decision is to provide anonymous consulting; however, it is a decision members of each organization must make based on their own perceived risks and benefits.

Users with Limited Computer Access

For patients who are not digitally literate and who are unsure know how to operate websites and social networking applications, should it be the organization's responsibility to teach them? A MISSION should only be a supplemental sector of health care services, should be joined voluntarily, and thus should not "punish" those who have limited access for whatever reason. Recalling a point in the aforementioned American Medical Association's code of ethics, physicians should help the advancement of their community, and Internet access fits perfectly in that description. It may be beneficial for an organization to conduct a mini-workshop every so often to teach new users how the MISSION works. People who have their own computers but are not comfortable with virtual communities and social networking can be given advice on how to put their computers to good use. People without home computers and/or those who are computer illiterate could be taught the basics and how to access the MISSION through public-access computers. Each organization must consider how much time to devote to these tutorials, who would administer them, and what kind of user support system to employ to help those who will inevitably have trouble.

It is important when offering a remote-access network like a MISSION to note where public access computers are and to alert clients of those locations. Even though a MISSION should be voluntary and supplemental to regular health, all patients within a health care organization should have equal opportunity to access it. Public libraries, community centers, and Internet cafes are places where patients can find public access to computers and thus gain access to this network. Additionally by providing such a service to the community, the organization can advocate increasing public Internet access. Fundraising, lobbying, and other means of support can all be considered to help raise awareness and funds for public computer access improvements.

Conclusion

While these and many other decisions must be made by organizations on a case-by-case basis, codes of ethics, security tips, and legal discussion included in this chapter can give organizations a better idea of how to handle them. Guidelines and codes of ethics should be adapted to fit individual organizations' values while HIPAA rules should be scrutinized and followed to the letter in order to avoid legislations. Patient-users should be informed during of their rights along every step of a MISSION and should be given the option not to participate if they do not feel comfortable. As a supplement to traditional medical care, participation in a MISSION should be voluntary and complementary, but in the legal sense, use of a MISSION should be valued just like regular medical care.

CHAPTER FOUR

DESIGNING FOR SOCIABILITY AND USABILITY

Since the definitional, theoretical, and ethical foundations of a MISSION have been established, the next step is determining how to craft those features into a comprehensive MISSION. Technology changes rapidly, and many technical elements of a MISSION will vary depending on each organization's situation, making it nearly impossible to give an absolute "how-to" for everyone looking to create one. It would be wise for organizations to work with a consultant who can set up the MISSION and either maintain it themselves or teach someone in the organization to do so. However, this chapter will begin to describe the design and creation of a MISSION to give an idea of the work involved. First, I will systematically review existing health-related virtual applications and analyze which portions are desirable for a MISSION. Then I will outline and define some technical aspects to consider while also discussing arguably the most important part – the usability of the MISSION.

Existing Applications

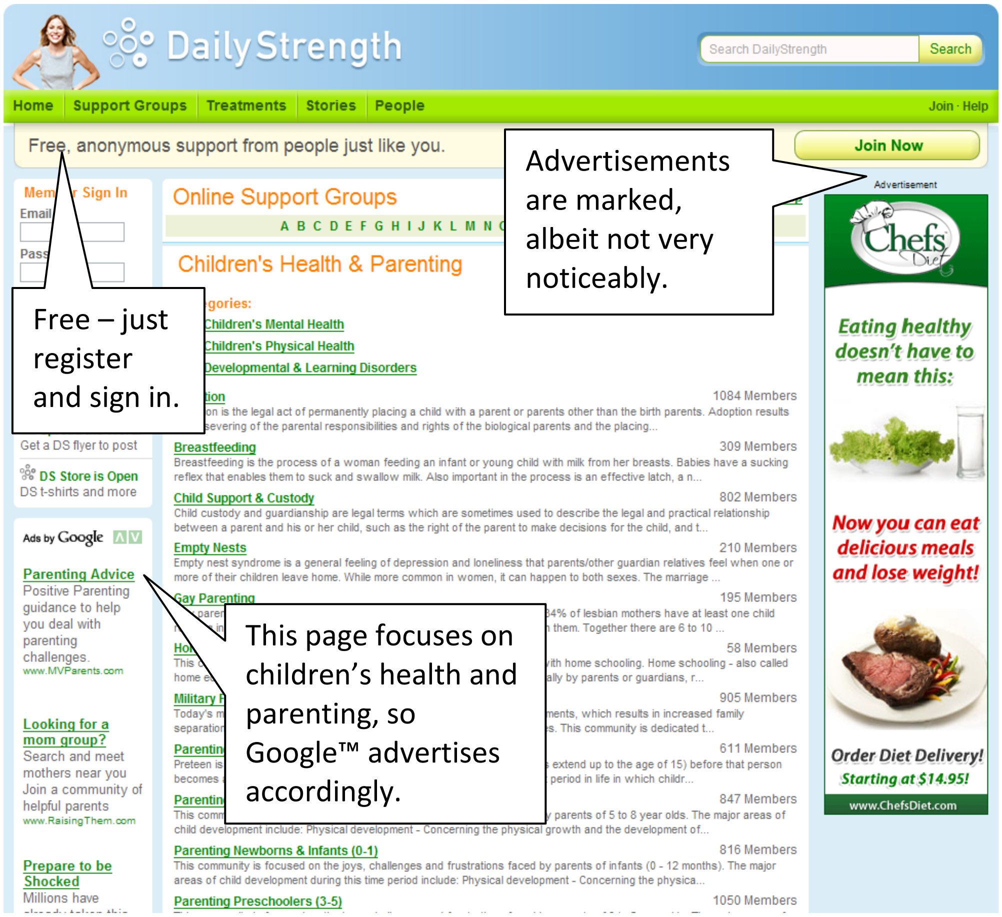
There are many websites and applications that use a virtual community or social network platform to aid communication and the dissemination of information. Health-related applications are starting to grow rapidly, though none that I have encountered parallel all the aspects of a proposed MISSION. In this section, I will provide screen captures of a few websites and compare and contrast them with the features of an ideal

MISSION: authorship, reference information, social interaction, and funding. First is DailyStrength, a website that shares many elements with an ideal MISSION; next is WebMD®, a popular commercial website initially based on information only that is now becoming more interactive and community-based; third is OrganizedWisdom®, a site based on the search and retrieval of health information; and finally, Yahoo!® Health and Wellness Groups are designed specifically for virtual community interaction.

Daily Strength

This site (www.dailystrength.org) hosts over five hundred community-based support groups from “Abstinence and Celibacy” to “Zellweger Syndrome” and provides information on fifteen hundred treatments reviewed by its members. (*Figure 4.1*)

Figure 4.1: DailyStrength Screen Capture



Free – just register and sign in.

Advertisements are marked, albeit not very noticeably.

This page focuses on children's health and parenting, so Google™ advertises accordingly.

tion 1084 Members
on is the legal act of permanently placing a child with a parent or parents other than the birth parents. Adoption results
severing of the parental responsibilities and rights of the biological parents and the placing...

Breastfeeding 309 Members
Breastfeeding is the process of a woman feeding an infant or young child with milk from her breasts. Babies have a sucking reflex that enables them to suck and swallow milk. Also important in the process is an effective latch, a n...

Child Support & Custody 802 Members
Child custody and guardianship are legal terms which are sometimes used to describe the legal and practical relationship between a parent and his or her child, such as the right of the parent to make decisions for the child, and t...

Empty Nests 210 Members
Empty nest syndrome is a general feeling of depression and loneliness that parents/other guardian relatives feel when one or more of their children leave home. While more common in women, it can happen to both sexes. The marriage ...

Gay Parenting 195 Members
34% of lesbian mothers have at least one child
them. Together there are 6 to 10 ...

58 Members
ith home schooling. Home schooling - also called
ally by parents or guardians, r...

Military 905 Members
Today's m ments, which results in increased family
separation s. This community is dedicated t...

Parentin 611 Members
Preteen is extend up to the age of 15) before that person
becomes period in life in which childr...

Parentin 847 Members
This comm parents of 5 to 8 year olds. The major areas of
child development include: Physical development - Concerning the physical growth and the development of...

Parenting Newborns & Infants (0-1) 816 Members
This community is focused on the joys, challenges and frustrations faced by parents of infants (0 - 12 months). The major areas of child development during this time period include: Physical development - Concerning the physica...

Parenting Preschoolers (3-5) 1050 Members

Authorship This site was created by three "Internet veterans" who boast more than twenty years of collective experience creating and maintaining some of the largest "communities" on the web, such as Yahoo!® Mail, Photos, Personals, Message Boards and Groups as well as Yahoo!® GeoCities, Facebook®, and My Yahoo!®. The site employs health experts, including physicians and therapists, as "Advisors." These specialists contribute to "feature design and community creation" as well as interact and participate in various message boards. On January 29, 2008, the Centers for

Disease Control and Prevention (CDC) partnered with DailyStrength on several joint programs (DailyStrength, 2008).

> “Under the partnership, CDC will gain access to DailyStrength’s powerful community networking tools, and DailyStrength will bring CDC’s expert health information and science to DailyStrength’s users.”

DailyStrength is accredited by Health on the Net’s HON Code (HON Code, 2007). This accreditation assures the users of a health-related website that the information found on that site is credible and accurate.

Reference Information Members can research treatments that have been reviewed by fellow community members. Each member can write a review about the treatment as well as testify to their effectiveness. I assumed the blurbs were written by administrators or experts, but some include a Wikipedia® link after the summary; the site does not say who wrote each summary or that the Wikipedia® links imply a cited source. It is interesting to note that although this site employs several expert advisors, their work is not credited to them.

Social Interaction Aside from treatment reviews from other members, DailyStrength offers forums for members to discuss ailments and treatments with one another in an asynchronous bulletin board-style format. There is also a journal feature for members to write or create video journal entries and share with others if they choose, as well as a feature allowing members to view the journals of others who have opted to make theirs public. Members can “befriend” other members and send them private messages and virtual “hugs,” and they can add photos to their own album to share with others.

Funding and Affiliation Members use DailyStrength for free and are not charged for any features. The site is funded by commercial advertisements that flank the central content. The ads are marked as such to avoid confusion of site-authored content with third-party advertisers. However, the ads (by Google™) change according to the DailyStrength content being viewed. For example, while looking at endocrine support groups, the ads focus on products for thyroid conditions. Because the advertisements are appropriate to the subject matter being viewed, users may be more likely to click on a link that appeals to their interests, potentially leading to an ethical problem. Users exploring the site for unbiased information may mistake an ad’s claims for medical truth and be persuaded to purchase a product or service advertised. The content itself seems to be unbiased, even if the ads try to persuade users to explore them.

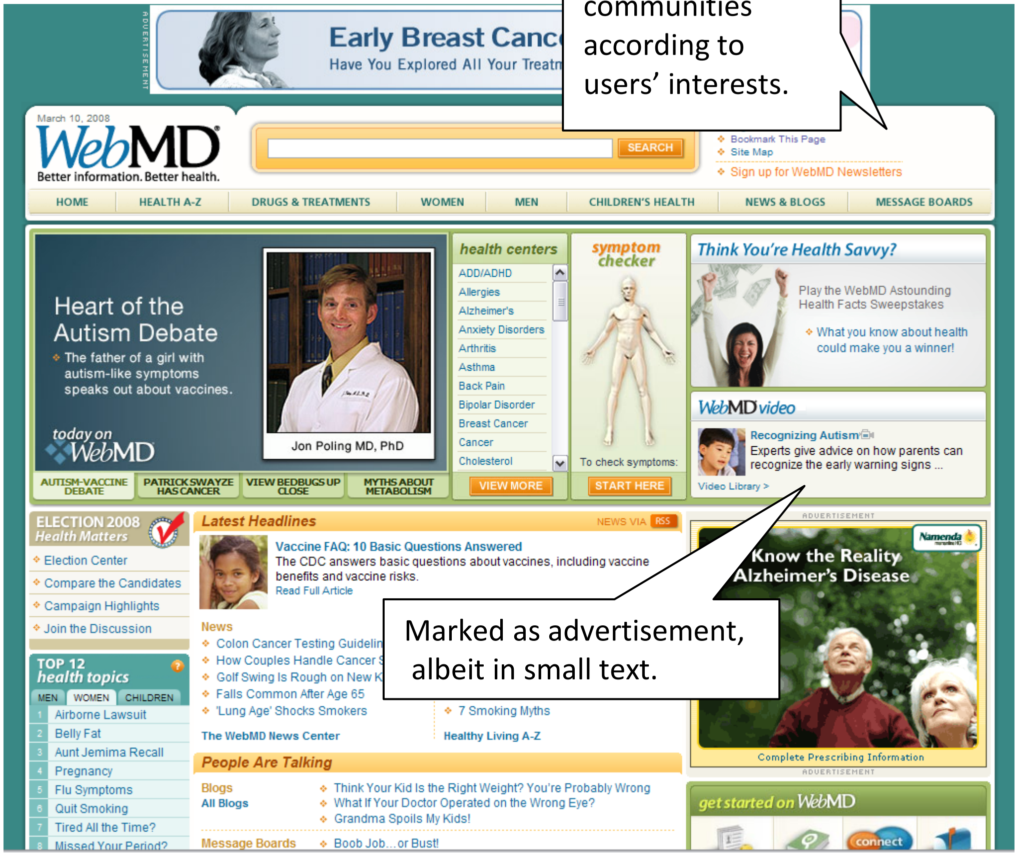
Conclusion This site is close to a MISSION; it offers expert advice as well as community support. The things that differ between DailyStrength and a MISSION are the geographically-local pool of users and the personalized practitioner-to-patient interaction that are both vital to a MISSION. DailyStrength utilizes the opinions and advice of experts, but these people are not points of contact (or if they are, it is unclear how users may get in touch with them), and community members’ posts go unmonitored. If users *are* able to talk directly to the experts, the experts neither personally know the users’ histories nor have their health information at their fingertips like a user’s own practitioner would in a MISSION.

WebMD®

This popular site (http://www.webmd.com) is a "go-to" resource for about 35 million readers each month (Tracy, 2007). It provides a vast amount of information about diseases and treatments, and it utilizes tools like questionnaires and symptom-checkers to help diagnose and shed light on conditions. (See *Figure 4.2*)

Figure 4.2: WebMD® Screen Capture

Join message board-based communities according to users' interests.



Marked as advertisement, albeit in small text.

The father of a girl with autism-like symptoms speaks out about vaccines.

Play the WebMD Astounding Health Facts Sweepstakes

What you know about health could make you a winner!

Recognizing Autism

Experts give advice on how parents can recognize the early warning signs ...

Vaccine FAQ: 10 Basic Questions Answered

The CDC answers basic questions about vaccines, including vaccine benefits and vaccine risks.

Read Full Article

- Colon Cancer Testing Guidelin
- How Couples Handle Cancer S
- Golf Swing Is Rough on New K
- Falls Common After Age 65
- 'Lung Age' Shocks Smokers
- 7 Smoking Myths

- Think Your Kid Is the Right Weight? You're Probably Wrong
- What If Your Doctor Operated on the Wrong Eye?
- Grandma Spoils My Kids!
- Boob Job…or Bust!

Authorship The site employs an impressive number of experts, and most have their own message board, blog, and support groups. Similarly to the experts, users have their own blogs and message boards. Articles display an author's name as well as an expert reviewer's name. These multimedia communication outlets are what a MISSION will ideally have – advice and information directly from the professionals' as well as refereed information from other authors. By knowing who wrote the articles, users can determine if the advice given is trustworthy. The site is accredited by the Utilization Review Accreditation Commission (URAC), its privacy is verified by the TRUSTe program (monitors privacy compliance on websites), and it is certified by the Health on the Net Foundation's HON Code, allowing patients to feel confident in the information they garner from WebMD®.

Reference Information Aside from blogs and reports written and/or reviewed by medical professionals, there are symptom checkers to guide users toward an understanding of what they are suffering from, videos on everything from interviews to how-to's, quizzes, calculators, self-assessments, guides, and general information about diseases and treatments. This site first started as a reference only and is becoming more focused on communication.

Social Interaction WebMD® offers message boards in an asynchronous bulletin board format. In these message boards, members can post questions and advice, but the good thing about WebMD®is that their expert consultants participate in these message boards. For example, an asthma message board containing everything from attack triggers to non-traditional remedies is monitored by an internist specializing in asthma. Also, the WebMD®panel of experts each has their own blog on their topic of expertise.

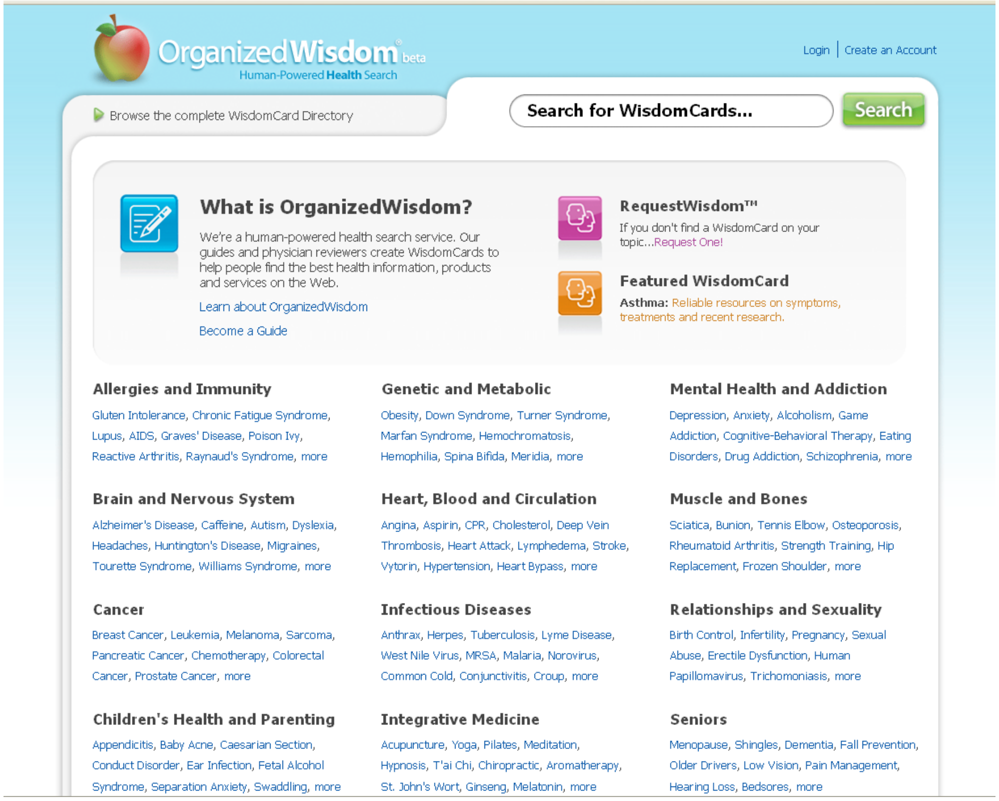
Funding and Affiliation WebMD®is also free to members as it utilizes sponsorships to commercially benefit the organization. The site claims that sponsor information also benefits the user by providing them with information. The "About Our Sponsors" page explains the sponsoring and advertising policies, and even teaches users how to differentiate sponsored and third-party-funded information from expert-authored information. The site does claim that some editorial content is funded by third parties, but states that the funders have no influence over the content. Like DailyStrength, WebMD®'s ads seem to change according to page content; an ad for Nexium® is featured on the heartburn information page.

Conclusion Although the commercial status may raise a few ethical eyebrows, WebMD® has a good foundation for a MISSION, though like DailyStrength, it lacks the personal attention members would get from their own physician and the local support they might get from people in their own geographic region. However, the expert-authored content as well as expert-refereed community message boards are vitally important and thus provide a model for building a MISSION.

Organized Wisdom®

Organized Wisdom® (http://organizedwisdom.com) is not a social networking site but a reliable resource, a "human-powered, physician-guided search service for health," (found on the "About" page of the Organized Wisdom® website). The premise is that the site provides health information that has been reviewed by health experts in order to weed out the bad or unrelated information. (See *Figure 4.3*)

Figure 4.3: OrganizedWisdom ™ Screen Capture



What is OrganizedWisdom?

We're a human-powered health search service. Our guides and physician reviewers create WisdomCards to help people find the best health information, products and services on the Web.

Learn about OrganizedWisdom

Become a Guide

RequestWisdom™

If you don't find a WisdomCard on your topic...Request One!

Featured WisdomCard

Asthma: Reliable resources on symptoms, treatments and recent research.

Allergies and Immunity

Gluten Intolerance, Chronic Fatigue Syndrome, Lupus, AIDS, Graves' Disease, Poison Ivy, Reactive Arthritis, Raynaud's Syndrome, more

Genetic and Metabolic

Obesity, Down Syndrome, Turner Syndrome, Marfan Syndrome, Hemochromatosis, Hemophilia, Spina Bifida, Meridia, more

Mental Health and Addiction

Depression, Anxiety, Alcoholism, Game Addiction, Cognitive-Behavioral Therapy, Eating Disorders, Drug Addiction, Schizophrenia, more

Brain and Nervous System

Alzheimer's Disease, Caffeine, Autism, Dyslexia, Headaches, Huntington's Disease, Migraines, Tourette Syndrome, Williams Syndrome, more

Heart, Blood and Circulation

Angina, Aspirin, CPR, Cholesterol, Deep Vein Thrombosis, Heart Attack, Lymphedema, Stroke, Vytorin, Hypertension, Heart Bypass, more

Muscle and Bones

Sciatica, Bunion, Tennis Elbow, Osteoporosis, Rheumatoid Arthritis, Strength Training, Hip Replacement, Frozen Shoulder, more

Cancer

Breast Cancer, Leukemia, Melanoma, Sarcoma, Pancreatic Cancer, Chemotherapy, Colorectal Cancer, Prostate Cancer, more

Infectious Diseases

Anthrax, Herpes, Tuberculosis, Lyme Disease, West Nile Virus, MRSA, Malaria, Norovirus, Common Cold, Conjunctivitis, Croup, more

Relationships and Sexuality

Birth Control, Infertility, Pregnancy, Sexual Abuse, Erectile Dysfunction, Human Papillomavirus, Trichomoniasis, more

Children's Health and Parenting

Appendicitis, Baby Acne, Caesarian Section, Conduct Disorder, Ear Infection, Fetal Alcohol Syndrome, Separation Anxiety, Swaddling, more

Integrative Medicine

Acupuncture, Yoga, Pilates, Meditation, Hypnosis, T'ai Chi, Chiropractic, Aromatherapy, St. John's Wort, Ginseng, Melatonin, more

Seniors

Menopause, Shingles, Dementia, Fall Prevention, Older Drivers, Low Vision, Pain Management, Hearing Loss, Bedsores, more

Authorship This site uses "trained expert guides" and physician reviewers as well as algorithmic search tools and social bookmarking sites. Also at the bottom of each WisdomCard™ is a form for users to recommend good health information websites to add. This site provides a disclaimer that it does not provide medical advice, diagnosis, or treatment, and the organization is accredited by the HON Code.

Reference Information This site provides information through WisdomCards™, results pages that have been created and managed by a health expert. If a user searches for a WisdomCard™ and one does not exist for the subject for which they are searching, they may create a RequestWisdom™ and request a WisdomCard™ be created for that topic. The RecommendWisdom™ feature allows users to submit links to websites they believe are relevant to a specific health topic.

When inputting a search term, the search result page, or “WisdomCard™,” opens. On the page, the manager of that particular WisdomCard™, a blurb about the condition, and a series of sections of links can be seen. Each section has a clear title, such as: “What are the Treatments and Medications for [This Condition]?” and “What are Symptoms of [This Condition]?” Each point under the sections is an external website that has been deemed appropriate by the experts at OrganizedWisdom®.

Social Interaction The site is clearly not a social network since there is no communication between users. A section in each WisdomCard™, “Message Boards, Chat and Discussions about [This Condition],” provides links to *external* message boards. This site only links to those boards; the creators and expert consultants state no responsibility for the content of the external boards. However, OrganizedWisdom® does offer a service, currently in pilot beta form, that allows users to connect in realtime to “board certified doctors, health professionals, and health advocates for only $1.99 per minute.” They do stipulate that the service is private and anonymous and does not replace a doctor visit, but users may try to substitute a call for a visit anyway. This may turn into an ethical issue as the feature implies fee-for-service, something OrganizedWisdom® may not be able to guarantee with each customer.

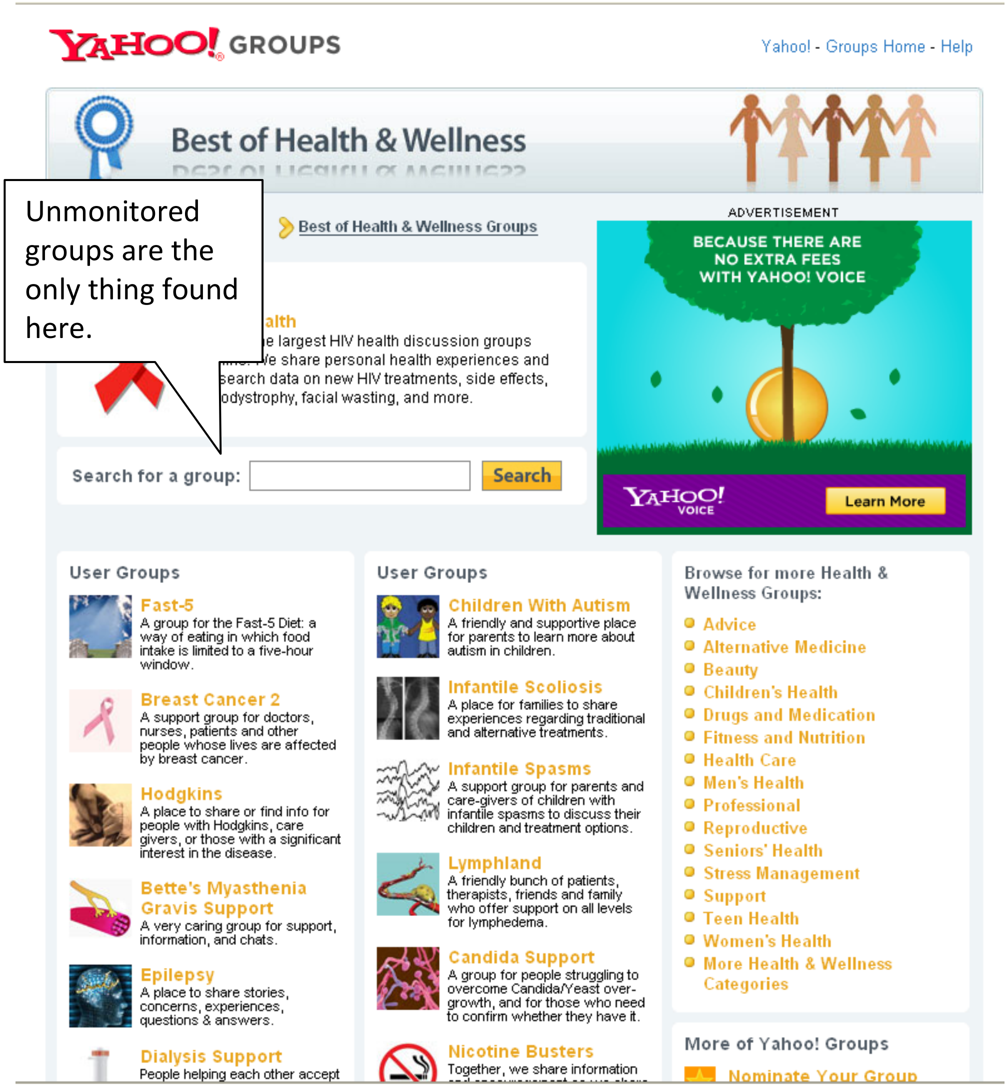
Funding and Affiliation The site does feature advertisements, and sponsors are able to place their advertisement on a page related to their goods or services, as seen in previous examples. Ads are demarcated as such by this image: Ads by Google, but this mark is easily lost on the page full of black and white text.

Conclusion This site seems to function primarily as a search engine but carries potential to accomplish more with the feature of realtime chat with health care professionals. Although it does have the social aspect of all information on the site being researched by people, it is still very impersonal. An aspect of OrganizedWisdom® that could serve as a model for a MISSION is the external links sanctioned by physicians. MISSION administrators with limited time to author original resources may opt to develop a resource bank, pointing to exterior sites they deem appropriate and trustworthy, similar to the activities found in OrganizedWisdom®.

Yahoo! ® Health Groups

Yahoo!® Groups (http://advision.webevents.yahoo.com/bestofyahoogroups/health.html) is based *solely* on user communication without providing expert advice. Yahoo!®, the parent organization, provides the space for communication and then takes a *laissez-faire* approach by not intervening or monitoring. For example, Yahoo!® may offer guidelines for starting a group or message board, but these features are not content-specific. Yahoo!® does not provide information on anything beyond *how* to use their site (See *Figure 4.4*).

Figure 4.4: Yahoo!® Groups Screen Capture



alth
e largest HIV health discussion groups
We share personal health experiences and
search data on new HIV treatments, side effects,
odystrophy, facial wasting, and more.

User Groups

Fast-5
A group for the Fast-5 Diet: a way of eating in which food intake is limited to a five-hour window.

Breast Cancer 2
A support group for doctors, nurses, patients and other people whose lives are affected by breast cancer.

Hodgkins
A place to share or find info for people with Hodgkins, care givers, or those with a significant interest in the disease.

Bette's Myasthenia Gravis Support
A very caring group for support, information, and chats.

Epilepsy
A place to share stories, concerns, experiences, questions & answers.

Dialysis Support
People helping each other accept

User Groups

Children With Autism
A friendly and supportive place for parents to learn more about autism in children.

Infantile Scoliosis
A place for families to share experiences regarding traditional and alternative treatments.

Infantile Spasms
A support group for parents and care-givers of children with infantile spasms to discuss their children and treatment options.

Lymphland
A friendly bunch of patients, therapists, friends and family who offer support on all levels for lymphedema.

Candida Support
A group for people struggling to overcome Candida/Yeast over-growth, and for those who need to confirm whether they have it.

Nicotine Busters
Together, we share information

Browse for more Health & Wellness Groups:

- Advice
- Alternative Medicine
- Beauty
- Children's Health
- Drugs and Medication
- Fitness and Nutrition
- Health Care
- Men's Health
- Professional
- Reproductive
- Seniors' Health
- Stress Management
- Support
- Teen Health
- Women's Health
- More Health & Wellness Categories

More of Yahoo! Groups

Nominate Your Group

Unmonitored groups are the only thing found here.

Authorship These message boards contain only user input and advice; they are not led or monitored by experts. There is no moderator of the site or its message boards, and anyone can post messages regardless of their expertise or personal agenda (for example, a user could post in a forum that the cure for acne is found in an herbal form which that user just happens to sell; this is obviously not true, and the user is trying to promote their own business on vulnerable members who are just looking for advice).

Reference Information The content of this site is only based on message boards; there are no reference libraries or information-based pages written by people of authority. Clearly, the lack of expert advice could potentially be a problem if members regard the information they find on the site as fact. For an example, a very persuasive member could convince others that driving without a seatbelt is safer than driving with one. Without an expert to rectify the information presented, some members may put themselves in danger by following the bogus advice.

Social Interaction Yahoo!® Groups thrives on social interaction; the site exists only as a forum for people to come together and talk. Some may be soliciting advice, others giving it, still others just “venting,” but this dialogue is central to this site. Each community has list servers so that when new threads are posted, members are alerted by e-mail.

Funding and Affiliation The site displays advertisements, and Yahoo!® separates them from content by labeling them and distinguishing them on the page from content. It appears that the ads on each page are relevant to that page’s topic or are at least health-related. This has both positive and negative ethical consequences; advertisements may lead to products or services that are actually beneficial to users (hair restoration products in a community about premature balding, for instance). However, since anyone can buy ad space, there is no guarantee that the claims in the ads are truthful. An advertisement for a “miracle” weight-loss pill in an obesity group could dupe members who are desperate for a cure into wasting their money.

Conclusion Yahoo!® Groups is only community-based, providing a model of what discussion boards can look like and how they operate. The negative consequences of having interactions like those seen in Yahoo!® Groups reiterate the need for moderation of conversations by experts.

Implications for a MISSION

These website examples are each steps in the right direction toward building a comprehensive MISSION, but none fully embrace all the features one should include. As mentioned earlier, the major components of a MISSION should be: expert-monitored health information (as seen in DailyStrength, OrganizedWisdom® and WebMD®), communication among members (as seen in Yahoo! ® Groups and DailyStrength), and contact with health professionals familiar with users’ personal medical histories (a feature none of these examples possesses).

The MISSION’s information should be accredited by some larger body deeming the information accurate and ethically sound, such as the HON Code or TRUSTe. The funding of a MISSION should not be provided by a company whose commercial interest may affect the MISSION’s content, as the search for medical information may leave users vulnerable and willing to spend money on quick fixes for whatever ails them. Instead, funding may be provided by the patients themselves or through grants. While these examples have portions of these, none of them do the job a MISSION is meant to do.

Designing the Network

Now that definitions and examples have been established and discussed, the determinants of how to build a successful MISSION can be explored. The term "sociotechnical systems design" refers to the social implications of an online community's design, and that design cannot be created independently of the social system it will support (Eason, 1988; Preece, 2000). The purpose and usage of the MISSION must be considered so as to decide what technologies will be utilized. In order to effectively build a MISSION, the users of the network and their actions within it must be carefully considered and involved every step of the way, a process referred to as "community-centered development" (CCD) (Preece, 2000) or "participatory design" (Greenbaum & Kyng, 1991; Muller, 1992; Mumford, 1983; Schuler & Namioka, 1993). This approach is based on the classic "user-centered design" which focuses on the user's needs rather than starting with technology first (Norman, 1986). By designing a network around its users, they will find the MISSION is socially appropriate for them and easy to operate.

There are five phases of community-centered development that developers must go through in order to create a user-friendly and successful MISSION (Preece, 2000). These steps create a very general outline to the details that follow later in the chapter.

1. *The community and user tasks must be assessed.* What does the community need? How will they use the MISSION? This is where the components and functions of the MISSION will be developed; community

members need a way to speak to their practitioners, they need a way to interact with each other, and they need a way to retrieve health information from the site. Identify the social exchanges that should take place in the MISSION.

2. *Select technology and plan sociability*. When a population's wants and needs are established, the network elements that would fulfill those needs can then be developed. To formulate a sociability plan, determine exactly how the above tasks will be completed and with what software or hardware. Based on the user assessment, technologies can be tentatively assigned to the project. Determining how the MISSION can fit the social needs of the community occurs at this stage.
3. *Prototypes should be designed, implemented, and tested*. Based on the community's needs assessment and resulting sociability and technology plans, prepare prototypes for usability testing. Parts of a MISSION can be tested one at a time before building the entire network and having to make changes.
4. *Sociability and usability should be refined and tuned*. The testing is done on a larger scale now, perhaps in a pilot test in which people can access the network in their intended environment (from their own home). After testing the prototype for usability, make any fine-tuned changes before settling on the final product

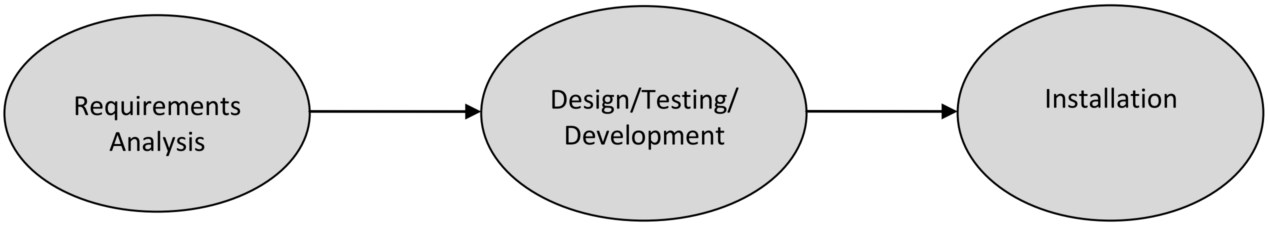
5. *Welcoming and nurturing the community*. This is the stage in which the website goes "live" and is launched for users to join.

Members who will make up the community need to be involved from start to finish ensuring that the network is usable and relevant to their needs. The users' demographics, skill levels, and expectations need to be taken into consideration, but first those issues need to be unearthed through research. The Usability Engineering Lifecycle, explored in the section below, describes the phases of research necessary for creating a MISSION.

The "Usability Engineering Lifecycle"

Mayhew (1999) presents a very detailed step-by-step approach to usability and user-centered design (UCD) in what she calls the "Usability Engineering Lifecycle." Developers spend a lot of time on these factors in order to increase the users' productivity within the system, decrease time users need to learn it, decrease user errors, and decrease their need for technical support (Mayhew, 1999). Overall, the process has three major steps (*Figure 4.5*) (Mayhew, 1999). Because usability is absolutely essential to consider when building a MISSION, this chapter will fully examine and apply each step of the process as it applies to building a MISSION.

Figure 4.5: *Usability Engineering Lifecycle Overview*

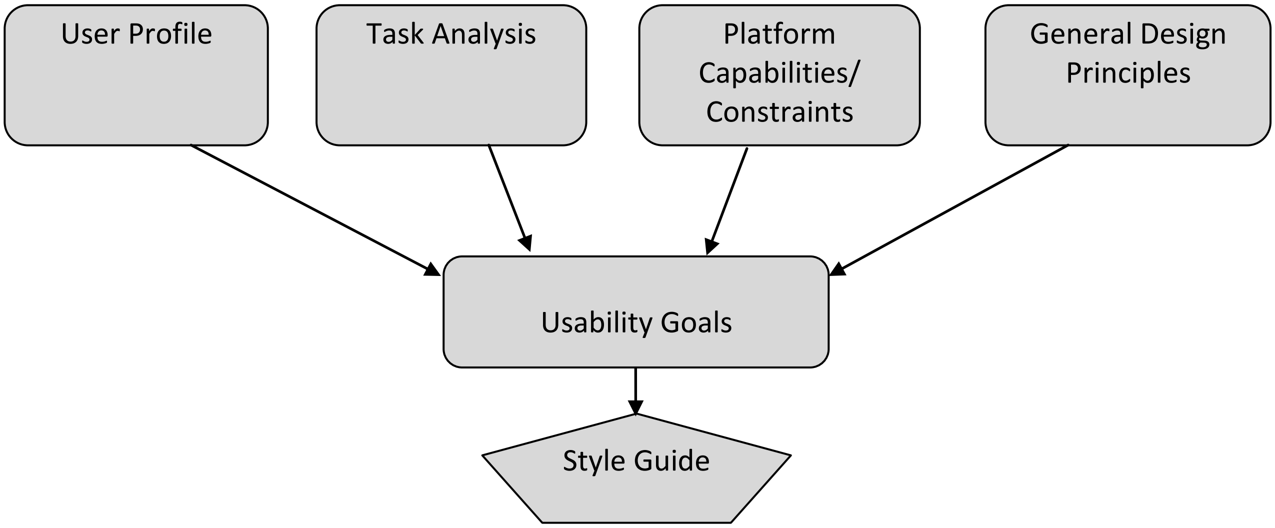


User-Centered Design and Usability

Usability Engineering Lifecycle: Requirements Analysis

A successful MISSION must be designed as something its members will actually use. Research must be done ahead of time to lay the foundation for the community and its features. Before deciding anything about the MISSION's content or its technologies, who will use the MISSION and what needs it will serve need to be determined. In the *Requirements Analysis* phase, there are five considerations that begin the usability process (Mayhew, 1999). This is also the stage in which sociability is analyzed; determining who the users are and how they will interact with one another and the site will shape many features of the MISSION (*Figure 4.6 below*).

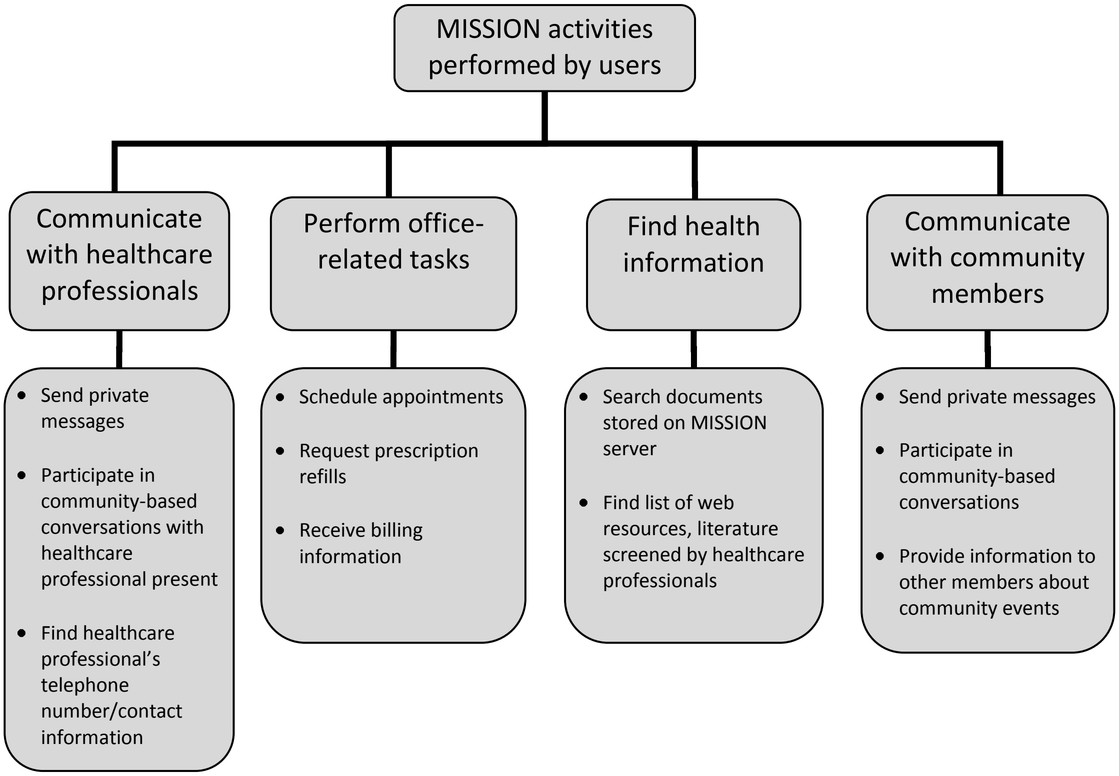
Figure 4.6: Usability Engineering Lifecycle: Requirements Analysis



First a *User Profile* is created; this includes specific user characteristics that will have an impact on the design of the MISSION. How computer literate are the users? How often will they use the system? Are there elderly or disabled users who will require special features in the MISSION? Demographic statistics are helpful here.

Second, performing a *Contextual Task Analysis* allows developers to look at what activities the users already participate in that are similar to the MISSION, allowing the developers to see what users' personal skills and goals are (Do they use search engines to find health information? Do they participate in web-based discussion groups for social support?). Building a hierarchy of activities the users will perform in a MISSION will be helpful; this will act as a guideline when developing a map of how the MISSION actually operates (see *Figure 4.7)*.

Figure 4.7: Usability Engineering Lifecycle: Task Hierarchy



Third, during *Usability Goal Setting*, consider information gathered about the MISSION's users and their abilities in order to develop goals for the usability of the system. Here, criteria of a "successful" system and user performance are defined for later testing. For example, a goal in this stage might be, "the user is able to locate his or her provider's private message-sending form within 10 seconds."

Fourth, in considering *Platform Capabilities and Constraints*, users' computer platforms and hardware capabilities should be identified. Will the MISSION be optimized for one web browser only? Will dial-up users have difficulty downloading pages and documents?

Last, *General Design Principles* are considered; these are guidelines developed through empirical research that can be found in usability literature, including elements of cognitive psychology and basic tried-and-true design principles such as the laws of Gestalt (Coe, 1996). From the *Requirements Analysis* phase, the end product is a *Style Guide* that will act as a guideline throughout the rest of the usability testing process.

During the process of user-centered design, there are many methods of determining and testing usability of products and applications before, during, and after their design; since ensuring the usability of the MISSION is of the utmost importance, there are several methods of understanding how users feel about, understand, and use the MISSION (DHHS, n.d.). Usability research methods need to be implemented in the early stages of development to know what patients want from a MISSION. When the general goals and features of a MISSION are decided upon, patients can help developers decide how to best organize the MISSION's layout to be easily accessible and user-friendly. After the network has "gone live," users can give feedback to let developers and network administrators know what they like and what they want to see changed. *Appendix A* contains descriptions of different methods of usability testing adapted from Mayhew's book, *The Usability Engineering Lifecycle* (1999), wherein representatives of the MISSION's users will reveal how they feel about the network and its features as well as how easily they complete tasks within the network. Different usability research methods can be used in conjunction with each other when developing the MISSION to better understand how to design the system for the benefit of its users. Each gives developers a deeper understanding of the people for whom they are designing the MISSION and what those people need and want from a virtual community.

Planning Sociability and Selecting Technology

Based on the user assessment, technology and software will be assigned to meet the users' needs. Determining usability and sociability really go hand-in-hand and cannot be separated into sequential tasks. Since the purpose of the MISSION is to promote communication and sociability, it must successfully do so in order to be usable. While determining what the MISSION should offer users (i.e., talking to each other, talking to experts, retrieving information) and evaluating the sociability of the members' interactions, think of how the MISSION's technology can fit the social needs of the community.

Sociability

First, decide exactly how the users' tasks will be completed (Preece, 2000). How will users communicate with one another? How will they retrieve information from the site? How will patients get in touch with their medical care providers? How will patients request prescriptions or make appointments? Make a list of things the MISSION should enable users to do, and match that action with a corresponding technology or feature (i.e., software, site design, password-protected areas). The chart on the following pages (*Figure 4.8*) lists some actions and issues that can be answered by applications within a MISSION and can be used as a tool when designing and personalizing one.

Figure 4.8: MISSION Action-Response Design Planning Chart

Action by User	**How MISSION Responds**
Only patients of the MISSION's health care organization should be users	MISSION users should be required to register before using the site. They should be given passwords by their practitioners to ensure that the only people able to access the MISSION are those who have been granted permission. Password-protecting the MISSION secures patient information that may be confidential or that users may not want spread outside the MISSION community.
A message board post from a lay community member offering advice or information may be regarded as truth by his fellow members.	A disclaimer needs to be clearly displayed on the site, alerting users that what they read on the MISSION from other members may be inaccurate. By-laws should be written to alert members of etiquette and group norms. Also, moderators may be assigned to message boards to protect users from abuse and misinformation. They would be able to delete harmful or inaccurate posts and to dispel rumors or clear up confusion.
By becoming a member of a group (i.e., drug abuse support group), a MISSION user loses some privacy.	Determine how users identify themselves on the MISSION. Do they choose user names? Do they keep their identity secret, only to be known by that pseudonym? Will they have the ability to anonymously participate in some groups and not in others? While the example of the drug abuse support group shows an instance where members may not want their identity known, a group like a hiking club or healthy potluck dinner club would obviously have to share their identities. It might be that when users join groups, they can elect to share their name or keep it private.

Patients need to ask questions of their health care providers in confidence, where other members cannot see the conversation.	There needs to be a way for users to privately message their practitioners, either through regular e-mail or through a private message form on the MISSION interface. This message exchange should be kept secret from community message boards so that users will know that what they are saying is private and only their practitioner will read it. If a practitioner receives a question they think would benefit the community, they must make sure that any identifying information is removed so that no one can tell who asked the question or raised the concern, in order to protect the users' privacy.
Patients need to communicate with other members of the MISSION community for information exchange, support groups, and other reasons.	The community aspect of a MISSION sets it apart from mere health information websites. This interaction can happen in several ways: through a bulletin board model where members "post" messages on a shared web interface for others to see asynchronously at their convenience; through synchronous chat rooms where all parties involved are at their computer at the same time; or through list servers where a member can send a message from their e-mail to a special address and it goes to all members of a particular group who are signed up to participate. Members may also be able to contact each other through private messages that no one else in the community can see.
MISSION users want to share information about community events.	In order to share information with all the users of a MISSION, either an administrator must send it to all users, or a listserver technology or distribution list can be employed so that every member has the ability to send information out to the community. By only allowing the administrators to distribute information, the messages can be monitored for relevance and validity. Health professionals lose control by allowing any user to contact the entire group and may need to perform "damage control" if an erroneous message is distributed.
Inevitably users will have questions or problems with the MISSION	Provide a help resource; a FAQ section and the phone number and/or e-mail address of someone who can help will make users feel more comfortable and will ensure they get their questions answered in order to keep using the site successfully (Preece, 2000).

New users may not understand all the MISSION has to offer and will get frustrated and leave	When designing the MISSION, come up with some questions that new users to the MISSION might ask, and answer those questions in the design of the site. For instance, they'll want to know why it's beneficial for them to join the MISSION, how they can leave, and what the rules of the MISSION are. Answers to those questions will manifest themselves in features of the MISSION. For the answer to "why is it beneficial for me to join?" there might be a title or introductory blurb on the MISSION's home page welcoming new users and highlighting benefits of joining. For the question "how to I join and leave?," consider *who* can be a part of the MISSION and how they join. "What are the rules of the MISSION?" should invoke concerns about policies, moderators, and disclaimers (Preece, 2000).

There are many methods of communication and courses of action that can occur within a MISSION, more than can be mentioned here. Using the chart as a tool is a good way to think about a need of the community and counter it with a solution rooted in technology or site design. Determine what the community needs, the solution to fulfill that need, and what in the design of the MISSION can offer that solution.

Technology

The first question to ask here is, who will develop the MISSION? If an employee of the organization will take on the task of developing the MISSION, that person must have extensive knowledge of computer networks and Internet applications. Another option is piecing the MISSION together using software elements found in various places; this takes less expertise than building the network from scratch, but it may cause problems with cohesiveness of the network and how the elements ultimately operate together. The third option, having the MISSION designed by an outside agency, is easiest for non-web-savvy organization members, but it also takes away a majority of the organization's creative control over the project. Each option has its pros and cons which will be explored further.

Regardless of how the MISSION is developed, all will have common elements of technology. First of all, the network will be "kept" on a server. The health care organization has the option of outsourcing this to an Internet Service Provider (ISP) or buying its own server to maintain in-house – the option taken will depend on who develops the MISSION and how. A server can cost a few hundred to several thousand dollars depending on the type and capacity, and a hosting agency like http://communityhosting.net or http://www.bryght.com can cost well under one hundred dollars a month to over three hundred dollars a month, depending on the level of service provided. If the organization builds its own network from scratch, software will be needed to make it run. This software can be bought or programmed based on open-source software (owned by public domain and modifiable), but the former can be expensive and the latter requires extensive programming knowledge. By contracting with an ISP or outside agency to build and maintain the MISSION, a health care organization will probably save time and money but will lose significant control over how the MISSION looks and operates. Also, because patients' confidential information will be located on servers outside of the organization's direct control, confidentiality contracts must be signed by the ISP agency stating that they will not distribute or tamper with the confidential information kept on their servers.

Content management is a way for computer networks to store and manage content (i.e., data, media, documents, etc.) on their servers so that users and administrators can find it, update it, and understand it easily (Hackos, 2002). The MISSION will most likely employ this kind of technology as a way to organize informational documents so that users can retrieve them. This method of information management is more efficient than e-mail, for example. Instead of sending documents to patients one at a time via e-mail from administrators' computers to users', the documents reside on the server and can be downloaded at any time by any user. Also because the documents are kept on a central server and not any one remote computer, any administrator can add documents, access them and make changes as necessary.

Aside from the delivery of documents, a MISSION needs to have software to enable communication among users and administrators. Chat rooms, bulletin/message boards, and listservers all fill this need. The software to run these applications can be built from the ground up, developed from open source software, or purchased from companies. The MISSION may have all of these elements or just one or two, but since communication is central to a MISSION, the community will need some way for its members to talk to each other.

Just as each MISSION should have similar features of information dissemination and communication, each needs to have shared technological elements to ensure the privacy of information stored there. The Health Insurance Portability and Accountability Act (HIPAA) outlines general requirements for the privacy and handling of confidential patient information. It is *imperative that organizations follow the HIPAA guidelines exactly to protect patients and to protect themselves from legal repercussions*. To ensure that private data is not released to the public, a MISSION's server should have several security methods employed including encryption, firewalls, and password-protection.

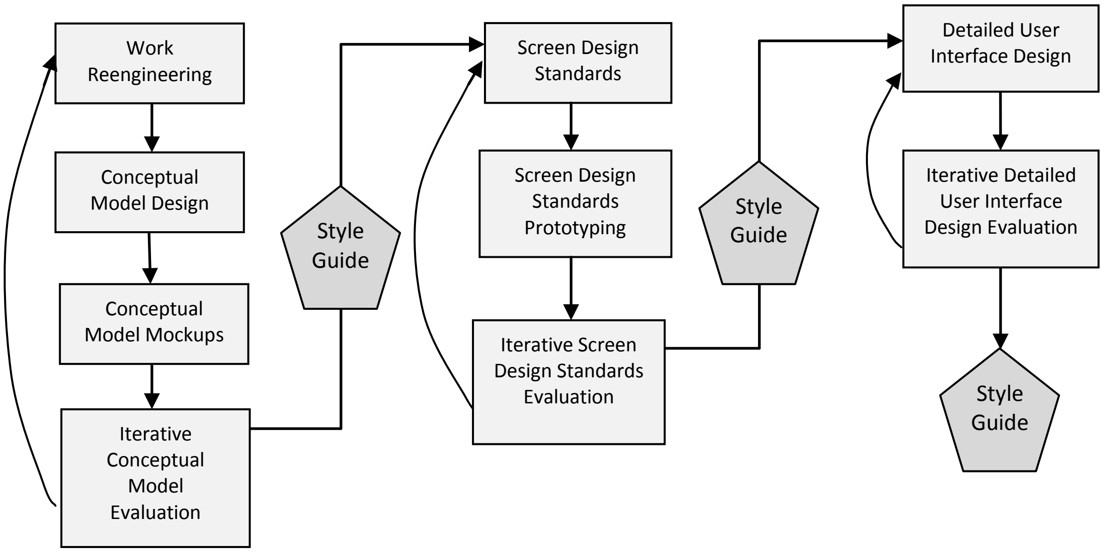
In order to protect information sent between user computers and host servers, data is encrypted using a key that only the sender and recipient computers know; the sending computer encrypts the data and the receiving computer decrypts it. This method of encrypting data ensures that hackers attempting to breach the site cannot get through. Encryption of private data as a security measure is the number one project for information technologists of North American Fortune 1000 enterprises over the next year, and data encryption ranks second on the Top 10 list of infrastructure security technologies currently in use (*Computer Workstations*, 2007). With legislations like HIPAA protecting health information, encryption is the obvious answer to protect not only those whose data is secured, but also the people who manage that data (Garretson, 2007).

Firewalls are important for protecting networks from outside hackers. A firewall creates a barrier between a network and the Internet, and it can also control traffic between two or more networks (Kokka, 1998). It filters all information coming into a network and determines whether to allow data to reach their destination. Since the MISSION's users access it through the Internet, a firewall is absolutely necessary. Without it, hackers could use the Internet to access the private information of a MISSION's patients. A third security measure, password protection, was mentioned in the chart above as a possible solution to a sociability issue. A MISSION should use password protection so that "strangers" are unable to use MISSION patients' accounts. It creates another barrier between the MISSION and those who don't have permission to access it. Also, inform users that their privacy is being maintained through all the security measures employed by the MISSION; they must know that precautions are in place in order to feel comfortable with sharing information (Preece, 2000).

Usability Engineering Lifecycle: Design/Testing/Development

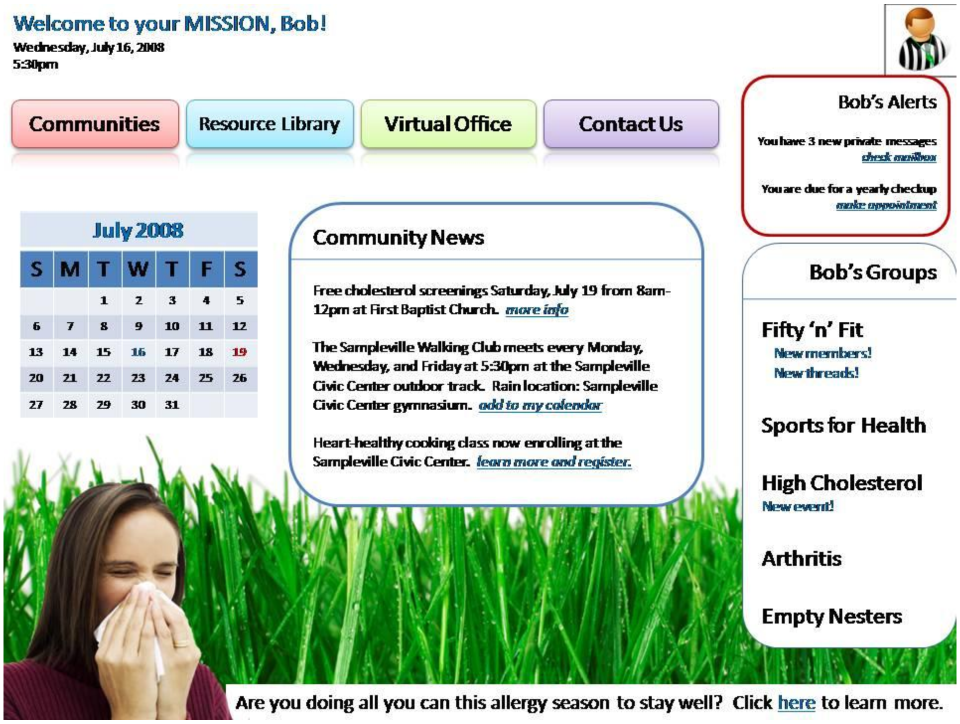
The second phase of the Usability Engineering Lifecycle is divided into three levels (Mayhew, 1999) (See *Figure 4.9* below). The first level contains four tasks regarding the design of the MISSION: *Work Reengineering* (redesign user tasks and determine how the MISSION will allow users to complete those tasks); *Conceptual Model Design* (generate design alternatives, sketch navigational pathways and major displays); *Conceptual Model Mock-Ups* (basic mock-ups based on the previous design are created); and *Iterative Conceptual Model Evaluation* (mockups are evaluated by test subjects and modified accordingly; evaluation during this task is quick and informal and the purpose is to reveal any major flaws in the design) (Mayhew, 1999). The next section covers formal "traditional" usability testing as well as other methods for assessing usability.

Figure 4.9: Usability Engineering Lifecycle: Design/Testing/Development



After testing the mockups, return back to the second task, *Conceptual Model Design*, to make changes to the mockup design. Proceed through the cyclical tasks until the mockup tests well enough to go on to the next step. Here is an example of a low-fidelity (non-interactive) mockup made in POWERPOINT (*Figure 4.10*):

Figure 4.10: MISSION Low-Fidelity Mockup



You have 3 new private messages *check mailbox*

You are due for a yearly checkup *make appointment*

July 2008

S	M	T	W	T	F	S
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

Community News

Free cholesterol screenings Saturday, July 19 from 8am-12pm at First Baptist Church. *more info*

The Sampleville Walking Club meets every Monday, Wednesday, and Friday at 5:30pm at the Sampleville Civic Center outdoor track. Rain location: Sampleville Civic Center gymnasium. *add to my calendar*

Heart-healthy cooking class now enrolling at the Sampleville Civic Center. *learn more and register.*

Are you doing all you can this allergy season to stay well? Click here to learn more.

The second level is concerned with setting standards for the system (Mayhew, 1999). The tasks in this level include: Screen Design Standards (this will ensure coherence and consistency across the MISSION interface); Screen Design Standards Prototyping (apply aforementioned standards to the design of a detailed prototype); Iterative Screen Design Standards Evaluation (perform formal usability testing of the prototype by test subjects; redesign and retest as necessary). After all the bugs have been worked out of the prototype, the result is a stable design and set of standards that can be added to the Style Guide you created during the *Requirements Analysis* phase. This *Style Guide* ensures quality, coherence, and consistency throughout the rest of the MISSION development process (Mayhew, 1999).

The third level of the Design/Testing/Development phase is completing the design of the MISSION. First during *Detailed User Interface Design*, the interface design will be completed using the *Style Guide* for direction. Next during *Iterative Detailed User Interface Design Evaluation*, formal usability testing will be conducted during the development of the final product. Evaluation is expanded beyond what has been tested before, and the system is refined and validated based on the goals of the usability testing before finally being put into action.

Installing and Moderating the Community

When the design and architecture of the MISSION have been finalized, the next step is deciding how it will be managed and by whom. Will the site developer or an ISP representative stay assigned to the project to help if problems occur? Will new personnel be hired as MISSION administrators, or will current staff maintain it? Administrative decisions should be realistic; depending on how big the user community is, maintaining the MISSION may be more than one full-time job. Community chats and bulletin boards will be need to be monitored by a medical professional on staff who can jump in and correct any misinformation posted by a member. In this installation stage, moderators learn and define their roles; these can be physicians, nurses, technologists, or administrative staff depending on the discussion they are moderating. Also, network developers monitor the software and hardware and can create a help system so that users can get their questions easily answered. During this early stage, there are bound to be problems and questions; the users and even administrators of a MISSION will need support from its creators until they can master how it operates and how they can fix it.

Other important decisions that need to be made regard things like fees; will users be charged to use the MISSION? Also, an organization's legal counsel will probably play a role in the MISSION. Besides disclaimers for users to sign, other legal documents may be necessary to protect patients and providers. What kind of training will the MISSION's users undergo? Will orientation workshops be held to teach patients how to use it?

When staffing, financial, and legal decisions have all been made and the MISSION is ready to be launched, it is a good idea to "seed" it with recruited members. These users may receive more training than others and may be instructed to begin posting discussions in community areas. Others who join later on their own can then arrive at a sense of an established community, and they will avoid feeling awkward about joining something that doesn't seem to yet be fully operational. The community is finally publicized; in a MISSION this will happen by posting information around the medical office and distributing informational material in hardcopy either by mail or in person at the office (Preece, 2000). Marketing the MISSION takes place at this stage; benefits and incentives need to be highlighted to get new users on board.

Conclusion

Though the prospects of usability research and testing may seem daunting, they are necessary and will serve to help an organization create the best MISSION for its users. From surveying and interviewing patients early to see if they would be interested in a MISSION to conducting focus groups about potential MISSION features to prototype usability testing to post-launch evaluation, the successful design and application of a MISSION cannot proceed without involving its target audience.

CHAPTER FIVE

CONCLUSION: NEED FOR VIRTUAL COMMUNITIES IN MEDICINE

The Internet has become an inescapably ingrained tool in our everyday lives. From checking movie theater schedules to finding customized driving directions to renewing library books, we have come to rely on the Internet for many aspects of daily life. One of the next logical steps is to integrate our reliance on the Internet with our health care.

Virtual communities are the chosen venue for this MISSION initiative because by definition, community members share common interests and goals and have close ties and vested interests in each other. The reciprocity found in a virtual community lends itself to health care because there needs to be a sense of responsibility to one another (Howard, forthcoming). Reciprocity in a non-health-related virtual community is essentially an “I’ll scratch your back if you scratch mine” idea. If this notion is expanded to health, the stakes become much higher and members ideally are willing to put more effort into helping each other. Giving advice is one thing, but giving health advice results in a much deeper bond since health is a common value we all share and hold in high regard.

Government

The Federal government has realized the progression of communication is guiding medicine toward the Internet and has created task forces and committees to promote health using virtual communities (Navarro, et al., 2006). Laws that regulate these networks have been put into practice in order to protect those who use them and maintain them (Federal Register, 2000). The fact is, the government and administrators have seen the need and the potential for virtual communities in medicine and have already taken the steps to enable them. This foundation allows practitioners and information architects to develop virtual communities for patients with established guidelines to ensure both their convenience and safety.

Health Benefits

Since heart disease, cancer, and stroke are consistently the top three causes of death in the United States and are largely results of lifestyle and habits, these are major targets for preventive health measures (CDC, 2007). Heart disease and stroke will cost our population almost $450 billion dollars this year (AHA, 2008) while just a few years ago, the cost of cancer was over $72 billion (MSNBC, 2008). Preventive health does not often permeate deep enough into patients' lives, especially since they may only visit their health care practitioners once a year at most. A virtual community like a MISSION can help solve this problem by giving patients a way to learn more about health and manage their own. By putting patients in touch with each other and health care practitioners on a fairly regular basis, it allows them to receive information and discuss issues often. The Pennebaker paradigm may suggest that disclosure of traumatic or stressful events or situations may alleviate distress (Greenberg & Stone, 1992; Pennebaker & Beall, 1986; Pennebaker, Colder, & Sharp, 1990; Petrie, Booth, Pennebaker, Davidson & Thomas, 1995). Following this, it makes sense that even telling someone about a troubling situation helps physiologically by "getting it off your chest." A MISSION not only helps by facilitating action through conversation, but communication within it may have inherent psychosomatic benefits. Also, the MISSION can be considered a tool to help manage health, as it can utilize reminder systems and appointment-scheduling applications.

Social Benefits

Aside from receiving information about health and helping patients manage self-care, a MISSION has inherent benefits in promoting sociability. The community atmosphere and the responsibility a member feels toward fellow members have the potential to make patients value their health more. The atmosphere of reciprocity within a virtual community keeps its members coming back, thereby increasing the time they are potentially exposed to health-related messages. By helping others in the community through giving advice and offering social support, members can feel positive about themselves. When they need a helping hand or a "shoulder to cry on," they will hopefully turn to the community expecting the same help in return from fellow members. Since members of a MISSION live geographically close, hopefully associations in the physical community will arise from interactions in the virtual community. People who converse in the MISSION about health issues and common interests may decide to meet in person to perform social activities.

By promoting social interaction in the MISSION, practitioners are allowing patients to “own” their own health and become their own advocates. By taking responsibility for learning more about issues that affect them, patients will hopefully start to care more about their habits and actions that affect their health outcomes. Also by becoming more social with individuals in their own community, MISSION members will be encouraged to be more socially active and aware of their health and the health of their community.

Promoting Usability through User-Centered Design

From the very beginning of the process, the population who will be using the MISSION needs to be involved in its development. Assessing their needs and skills is the very first thing to do, as this will dictate what the MISSION will offer. The three major steps of the Usability Engineering Lifecycle determine how the MISSION will start to take shape (Mayhew, 1999). Analyzing users’ requirements and tasks will determine what kinds of technology and software the MISSION requires. After developing prototypes, testing them on representative users will determine if changes need to be made or if the design and software are fulfilling the users’ needs. Performing various methods and stages of usability testing will ensure that the MISSION is straightforward and conducive to the tasks the users need to perform. Once all the potential problems are solved and the MISSION's design is final, it will need to be promoted to the target users. They need to know how to access it, what it offers, and why it will benefit them. After the MISSION has been in use for some time, feedback can be gained from the users to determine if the MISSION is still successful and what changes, if any, are necessary. The community is not static; it needs to evolve as its users' skills and needs change. It must always be remembered that the purpose of the MISSION is to improve patient health through promoting education, communication, and preventive medicine.

Legal and Ethical Considerations

Privacy

The privacy of MISSION users needs to be a primary concern, and everything in an organization's power must be done to protect it. Implementing stringent security controls and testing them often will improve the security and reliability of a MISSION. If the organization hasn't already done so, creating a personal code of ethics is a good way to stay ethically grounded when developing a MISSION; such a code will allow the organization to keep important things in mind such as ensuring privacy of patient information, promoting the MISSION's complementarity to traditional office visits, and monitoring communication among users to prevent dissemination of misinformation.

Legislation

The Federal government has developed some foundations for security of electronic health information, but these are only baseline considerations (Felkey, et al., 2006). The Health Insurance Portability and Accountability Act of 1996 (HIPAA) states that information should be kept private and that health care organizations must implement security features to protect the privacy of their patients. If these laws are broken, those in charge of the network will face heavy fines and imprisonment, as well as loss of licensure for health care professionals. It is quite an understatement to say that these regulations must be considered and catered to when developing a MISSION, for both the safety of its administrators and its users.

Future Applications

While communities and networks similar to the MISSION may be developed now, a comprehensive network like the one proposed in this thesis has yet to be established. Once health care organizations develop communities like these and use them successfully (it will probably take awhile for users to get accustomed to it and for developers to work out small problems), more advanced applications can be launched within the MISSION.

Though this thesis has merely outlined preliminary considerations for building a MISSION, far more needs to be done to actually put one into practice. My hope is that an expert in information systems technology can partner with health care communicators, educators, and practitioners to develop a MISSION following some of the ideas outlined here. Once a MISSION has been established and has begun to fulfill the tasks of facilitating communication among patient-users and health care practitioners, future applications of the MISSION can be considered.

As already mentioned, scheduling and prescription refill requests processed online can eliminate unnecessary rounds of phone-tag and can promote office efficiency. Reminder services can be set up to remind women to do breast self-exams, to alert men to do testicular self-exams, to inform contact-wearers to change their contacts, and so forth. The MISSION can be used as a tool to maintain health and keep up with regular health-related tasks.

Self-management of diseases can be aided by using mobile devices that sync with the MISSION. Studies have been done on diabetes (Carroll, Marrero, & Downs, 2007) and asthma (Fonseca, Costa-Pereira, Delgado, Fernandes, & Castel-Branco, 2006) and their management by using mobile technologies to keep track of therapies and disease progression. Since self-management is key for these chronic diseases and others, mobile technology can perhaps be integrated into the MISSION so that patients and their practitioners can track their care online.

Converting paper-based patient records to electronic versions is a Federal initiative meant to help improve health care by reducing costs and avoiding mistakes; by 2014, most Americans should have electronic health records (The White House, 2008). In the future, these electronic health records may be integrated with systems like the

MISSION for patients and providers to access. Though putting entire patient records on the Internet has major security and access issues, it is not far-fetched to imagine this in the near future.

Another potential use for the MISSION is the implementation of educational programs like nutrition education, smoking cessation, and minor fitness instruction. Through slides, videos, and ADOBE FLASH applications among many others, users of a MISSION can log in to learn more about health and how to change behaviors.

Beyond the inclusion of patients and health care practitioners, more research needs to be done on the role of insurance agencies and even employers in a MISSION. Should this network be confined to patients and providers only? Will these additional parties improve or harm the MISSION? Insurance companies and employers may be able to offer benefits to their clients/employees for participating in the MISSION, but will users be wary of getting these agencies and entities involved?

Although this thesis has focused on using a MISSION for social support, information dissemination, and communication only, the future most likely holds more in store for this type of network. In the short-term, a MISSION can help pick up where traditional health care must leave off due to time and financial constraints. In the future, it can do even more to help patients maintain their health and keep in constant communication with their community and health care practitioners. While visits to medical offices will always be necessary and the most important contact a patient has with their practitioner, a MISSION can help guide users on the path to complete physical, mental and social well-being.

APPENDIX

Usability Research Methods

Usability testing. The specific testing method sometimes referred to as "usability testing" is actually called "think aloud protocol." This method involves test subjects performing tasks in the MISSION while explaining their thought processes as they work, allowing researchers to understand more about how users think and act. This method involves creating sample tasks and criteria for "successfully" completing those tasks (like a specific time frame in which the user should complete the task), and it may involve several iterations of testing and revising before a final product is completed. The simplified steps of formal usability testing are as follows (Mayhew, 1999):

- *Decide*. Decide what will be tested – how easy it is to learn a new system or how easy it is to use an established one. Decide on users and tasks to focus on during the test – choose what category of users will be studied in this test (i.e., men over the age of 65), and what tasks to study (i.e., messaging a group, finding information, scheduling an appointment). For a brief example, let's say you want to test how easy it is for a user to find a specific discussion forum (in a real situation, several tasks will be tested, and the test will last an hour or so on average – never more than two hours).

- *Design.* Design test tasks – write the task in language the users will be able to understand during the test, and make it as real a situation as possible. A test should not exceed 2 hours, so budget for the slowest user and plan tasks accordingly. Design the test and materials – plan sequence of events, develop supporting materials (briefing for test observers, information for the users, questionnaires, actual tasks, data collection sheets, etc.). Design and set up the test environment – try to recreate a "natural" environment for the test user if the intended environment can't be used. For our example, you could decide to have the user access the MISSION from some public space like a library, to simulate a typical environment. Type up a few tasks on a sheet of paper that you can hand them during the test; a sample task is "find the discussion forum for 'Tips for living with plantar fasciitis' and write down the first tip you see as well as the member's name who suggested it."

- *Recruit.* Recruit and schedule a couple of pilot testers just to run through some of the tasks and make sure the system is running smoothly before administering the real usability test. Make any necessary changes after the pilot test before recruiting and scheduling several testers for the real study (3-10 per iteration is a good rule of thumb for the real study). For a simple pilot test, a friend or relative can participate; the purpose of a pilot test is to fix any glaring errors before administering the test to the real users. When the system and tasks seem ready to use, recruit test users from your population of patients; this will ensure the testers are representative of your "real" users. You can post bulletins around the office asking for volunteers or send out a letter or e-mail.

- *Test.* Run the test according to the materials and tasks, record video if possible and take field notes. Have the subjects think/read aloud so you know exactly what they're doing and thinking. When all the tests have concluded, summarize the data across all testers, making note of any tasks or issues that seemed to be significant problems. In our example, tests will be administered to several users at different times. You may set up a video camera to record their actions and the computer screen, and/or set up a voice recorder to document everything the user says. Also, take field notes during the test and write down anything you think is important or interesting. During the test, the subjects will talk aloud and say everything they are thinking and doing; if they aren't speaking much, prompt them to do so. Your user might say something like, "I'm looking on the screen for a place to click but I'm not sure where," or "I see the list of discussion forums, but I'm not sure which one the 'plantar fasciitis' one is under." Problems like these need to be documented and resolved before the real MISSION goes live.

- *Analyze.* Interpret the data, especially areas that may have given several testers problems. Draw conclusions from the findings and make recommendations on how to fix problems or improve issues. If many of the users had difficulty determining which forum to look under, perhaps the names of the forums need short descriptions. If they could not figure out where to click on the home page to find the discussion forums, that page should be re-designed. Take all the data you recorded in your notes, on video, and on audio, and pay close attention to the problems your users had; once you've summarized the problems and solved them, repeat the testing process. You can invite the same testers back to see if they like the changes, or new testers can be recruited to see if they have any problem with the system; their data can then be compared to the first iteration's data.

Card sorting. Participants are asked to organize website content in a way that makes sense to them. They review chunks of information and put them in order and in groups that make sense to them. This will be useful in the layout of the MISSION, especially when organizing resource information and support groups. For example, you could create cards with discussion forum topics and ask testers to put them in the order they prefer, asking them why they chose that method of organization. The navigation of the site can be determined in this way, too. Tell your testers to arrange cards in the order they'd like to see on the MISSION's homepage. Cards like "discussion," "contact us," and "resources" could then be organized how the users want them.

Contextual interview. Participants are observed in their regular environment doing tasks on their own. This can be combined with usability testing; during a test, the researcher can ask the tester questions as they observe what they are doing, or during a contextual interview the user may be given simple tasks to try. A user might search for information on a pre-existing website like WebMD® or DailyStrength while a researcher asks them questions about how they are searching for information or what they think about site characteristics. This is somewhat like think-aloud-protocol, except that the system being tested isn't the MISSION, and any tasks that are tested are usually spontaneous or small.

Focus group. This is a discussion among several (8-12) people representative of the MISSION's target audience, moderated by someone on the research team. Researchers can ascertain the users' general beliefs and attitudes about ideas or concepts, or they can conduct a focus group after users have undergone testing of the MISSION to get their opinions on the prototype. For example, gathering a group of ten 40-something-year-old women will allow them to discuss amongst themselves and with researchers things they think are most important for women their age and for their families. The social aspect of a focus group facilitates more opinions and open discussion among testers; by talking to homogeneous groups, the testers may feel more comfortable among people like them and open up more to each other and facilitators.

Heuristic evaluation. This is done early in the design process; a developer/evaluator checks their prototype against a list of usability principles to unmask potential problems before bringing in users to test it. These guidelines contain empirically-tested rules as well as traditional and cultural rules-of-thumb. Just a few of these principles are:

- Design not conducive to browsing will leave users frustrated and less likely to attempt to use the site again, so make sure there aren't any "dead end" pages with no way to backtrack but the browser's "back" button (Nielsen, 1998). Also, deep-rooted menus make it too hard for users to find what they're looking for; keep menus broad and shallow (Larson & Czerwinski, 1998; Shneiderman, 1998).
- The entire MISSION should be designed with the same color and design scheme, illustrating cohesiveness and eliminating confusion (Preece, 2000, p. 280).
- Avoid excessive use of color; use soft backgrounds and dark, contrasting text. Keep the audience' demographics in mind – if users are made of predominantly older people, bright, flashy colors will be more of a nuisance than an attention-getter (Preece, Rogers, Sharp, Benyon, Holland, & Carey, 1994).

- Don’t use graphics and animation for the sake of having something cute to look at. These media elements should only be used to exemplify behaviors or activities and very rarely should be used as decoration (Lynch & Horton, 1999).
- For downloadable documents or videos, state what technical requirements the user will need in order to view the documents on their own computer, and give directions on how to download and retrieve the file (Preece, 2000). While some younger users may be computer-savvy, older users may not be familiar with some web features like these.
- Tips like “use headings,” “chunk the text into manageable quantities,” and “user tables, bullets, and blank spaces to organize information” all increase the effectiveness of the MISSION information delivery. Pages should not be filled with huge blocks of texts lacking an organization scheme, and white space should be used deliberately, not overwhelmingly (Nielsen, 1998).

Individual interview. One participant is interviewed at a time, but they are not working or completing tasks during the interview. This method will reveal a lot of deep quality information about their attitudes, beliefs, desires, and experiences with applications similar to the MISSION before designing its features.

Parallel design. When beginning the design process of the MISSION, several developers create different versions of it while following the same list of requirements. This is done to explore many different ideas each may have, and the best features of each one are included in the final version. For example, if both a physician and an information architect were given the same requirements that a MISSION must have, they would most likely draw two very different prototypes based on their experiences and opinions about what elements are most important. By allowing several members on the design team to develop their own prototypes and then discussing their rationales, it will shed light onto ideas others may not have thought of before.

Personas. After conducting research to see who the MISSION’s users are and what they value (through interviews, focus groups, surveys, etc.), create fictitious characters who are representative of them. These characters belong to the demographics of their representative audiences and share features like age, education, and computer skill level. When designing aspects of the MISSION, the personas will be considered (“Would ‘Susan’ know what to click on?” “Will ‘Stuart’ be able to find what he’s looking for?”). By creating personas, developers personify the otherwise vague “user” and can better anticipate problems that might arise with the MISSION’s features.

Surveys. These can be done online or on paper several times throughout the design process. Early, they determine who the users are and what they want the MISSION to offer. Later, after testing early prototypes or almost-final versions of the MISSION, surveys reveal if users were able to find what they were looking for, how satisfied they were, what they liked or disliked, and if they can offer any suggestions for improvements.

Task analysis. This method, partnered with user analysis, allows researchers to learn more about the users' goals when they approach the MISSION and what they must do to reach those goals. This analysis finds out what the users are trying to do (find information on cancer? send private messages to the doctor or nurse?) and how they currently try to reach those goals (do they follow the architecture of the site or do they use the search function?). Through this analysis, researchers will get a better idea about what the MISSION should offer and how it should present that information or service.

Use cases. A use case describes a user and the steps they go through to complete a task. When considering cases, pick an actor or persona and define what they've come to the MISSION to do. Describe the steps they take to realize their goal, as well as any alternate courses of action. This gives a better understanding of how a user will use the site to reach a goal and the steps taken to do so.

REFERENCES

-----. (2007) PGP leads in secure email/data encryption. *Computer workstations, 20*(11). 2-5.

American Cancer Society (2007). *Cancer Facts & Figures2007*. Retrieved 15 March 2008 from <http://americancancersociety.org/downloads/STT/CAFF2007PWSecured.pdf>. Atlanta: American Cancer Society.

American Heart Association. (2008). Heart disease and stroke statistics. Retrieved 10 March 2008 from <http://www.americanheart.org/downloadable/heart/1200082005246HS_Stats%202008.final.pdf>. Dallas, TX: American Heart Association.

Aristotle. (1991) *On Rhetoric: A Theory of Civic Discourse*. (G.A. Kennedy, Trans.). New York: Oxford University Press.

Aristotle. (2001). *On Rhetoric*. In Bizzell, P. and Herzberg, B. *The Rhetorical Tradition: Readings from Classical Times to the Present*, 2nd ed (179-240). Bedford/St Martin's.

Ball-Rokeach, S., & DeFleur, M. (1976). A dependency model of mass media effects. *Communication Research, 3,* 3–21

Bandura, A. (2001). Social cognitive theory of mass communication. *Mediapsychology, 3,* 265-299.

Barth, J., Schumacher, M., & Herrmann-Lingen, C. (2004). Depression as a risk factor for mortality in patients with coronary heart disease: A meta-analysis. *Psychosomatic Medicine, 66,* 802-813.

Berger, M., Wagner, T.H., & Baker, L.C. (2005). "Internet use and stigmatized illness." *Social Science & Medicine 61,* 1821-1827.

Carroll, A.E., Marrero, D.G., & Downs, S.M. (2007). The HealthPia GlucoPack™ Diabetes phone: A usability study. *Diabetes technology and therapeutics 9*(2), 158-164.

CDC Media Relations. (2003). 11 August Press Release: Aging boomers drive up doctor visits. Retrieved 3 December 2007 from CDC Media Relations Web site: <http://www.cdc.gov/od/oc/media/pressrel/r030811.htm>.

CDC (2007) *Health, United States*. Retrieved 14 February 2008 from <http://www.cdc.gov/nchs/hus.htm>.

Coe, M. (1996). *Human factors for technical communicators*. New York: Wiley.

Collmann, J., Johnathan, C., Sostrom, K., & Wright, W. (2004). Organizing safety: Conditions for successful information assurance programs. *Telemedicine Journal and e-Health*; 10(3), 311-320.

Constant, D., Sproull, L., & Kiesler, S. (1996). The kindness of strangers: The usefulness of electronic weak ties for technical advice. *Organization Science*, 7(2), 119-135.

DailyStrength. (2008). January 29 Press Release: CDC and DailyStrength partner to bring CDC's health expertise to DailyStrength. <http://static.dailystrength.org/images/promo/CDC_DS.pdf>.

Demiris, G. (2006). The diffusion of virtual communities in health care: Concepts and challenges. *Patient Education and Counseling. 62,* 178-188.

Dictionary.com (2008a) Retrieved 14 February 2008 from <http://dictionary.reference.com/browse/network>. Lexico Publishing Group.

Dictionary.com (2008b) Retrieved 8 March 2008 from <http://dictionary.reference.com/browse/sociability>. Lexico Publishing Group.

DHHS. (n.d.) Usability.gov: Your guide for developing usable & useful Web sites. Retrieved 1 April 2008 from <http://www.usability.gov/>.

DHHS. (2003). Federal Register: 45 CFR Parts 160, 162, and 164, Health Insurance Reform: Security Standards; Final Rule; 68(34), 8332-8381.

DHHS. (2007a). Security 101 for covered entities. Retrieved 6 January 2008 from < http://www.cms.hhs.gov/EducationMaterials/Downloads/Security101forCoveredEntities.pdf>. Vol 2. Paper 1.

DHHS. (2007b). Security standards: Administrative safeguards. *HIPAA Security Series.* Vol 2, Paper 2. Revised March 2007. Retrieved 6 January 2008 from <http://www.cms.hhs.gov/EducationMaterials/04_SecurityMaterials.asp>.

Eason, K.D. (1988). *Information Technology and Organisational Change.* London: Taylor Francis.

Eddy, D.M. (1990). Screening for Cervical Cancer. *Annals of Internal Medicine 113*(3), 214-226.

Eng, T.R., Maxfield, A., Patrick, K., Deering, M.J., Ratzan, S.C., & Gustafson, D.H. (1998). Access to health information and support: A public highway or a private road? *JAMA*; 280(15), 1371-1375.

Eysenbach G., Diepgan TL. (1998). Responses to unsolicited patient email requests for medical advice on the World Wide Web. JAMA; 280, 1333-1335.

Federal Register (2000). Rules and regulations. *65(250),* 82461-82510.

Felkey, B.G., Fox, B.I., & Thrower, M.R. (2006). *Health care informatics: A skills-based resource.* American Pharmacists Association: Washington, DC.

Fonseca, J.A., Costa-Pereira, A., Delgado, L., Fernandes, L., & Castel-Branco, M.G. (2006) Asthma patients are willing to use mobile and web technologies to support self-management. *Allergy 61*(3), 389-390.

Garretson, C. (2007) *Network world 24*(43), 28.

Garton, L., Haythornthwaite, C., & Wellmann, B. (1999). Studying online social networks. In S. Jones (Ed.), *Doing Internet Research*. London: Sage Publications.

Greenbaum, J., & King, M.E. (1991). *Design at Work: Cooperative Design of Computer Systems.* Hillsdale, NJ: Lawrence Erlbaum.

Greenberg, M.A., & Stone, A.A. (1992). Emotional disclosure about traumas and its relation to health: Effects of previous disclosure and trauma severity. *Journal of Personality and Social Psychology, 63,* 75-84.

Gunter, B. (2005). *Digital health: Meeting patient and professional needs online.* Lawrence Erlbaum Associates: Mahwah, NJ.

Hackos, J.T. (2002) *Content management for dynamic web delivery.* New York, NY: Wiley & Sons.

Hamilton, A. (2007) Is Facebook overrated? *Time 170(3),* 48.

Hemingway, H., & Marmot, M. (1999). Evidence-based cardiology: Psychosocial factors in the aetiology and prognosis of coronary heart disease. Systematic review of prospective cohort studies. *British Medical Journal, 318,* 1460-1467.

Hillery, G. (1955). Definitions of community: Areas of agreement. *Rural Sociology 20,* 111-123.

Hillery, G. (1959). A critique of selected community concepts. *Social Forces 37,* 237-242.

Howard, T.W. (forthcoming). What are the RIBS of successful online social networks? In J. Swartz (Ed.) *New information technology spaces*. (forthcoming).

Howard, T.W. (1997). *A Rhetoric of Electronic Communities.* Greenwich, CT: Ablex.

http://www.honcode.ch. (2007). HON Code of Conduct (HONcode) for medical and health web sites. Retrieved 29 December 2007 from <http://www.hon.ch/HONcode/Conduct.html>.

Huntington, S.R. (2003). “Web site liability: how your organization can avoid some common risks.” *Healthcare Executive.* Sept/Oct, 70-71.

Kelly, A., Haddix, A.C., Scanlon, K., Helmick, C.G., & Mulinare, J. (1996). Cost-effectiveness of strategies to prevent neural tube defects. In: Gold, M.R., Siegel, J.E., Russell, L.B., Weinstein, M.C. (Eds.) *Cost-effectiveness in health and medicine (313-348).* New York: Oxford University Press.

Kokka, S. (1998). Property rights on an Internet. *Journal of technology law & policy, 3*(2), 24-35.

Lange, A., Schoutrop, M., Schrieken, B., & van de Ven, J.P. (2002). Interapy: A model for therapeutic writing on the Internet. In S.J. Lepore & J.M. Smyth (Eds.), *The writing cure: How expressive writing promotes health and emotional well-being* (215-237). Washington, DC: American Psychological Association.

Larson, K., & Czerwinski, M. (1998). Web page design: Implications of memory, structure, and scent for information retrieval. Paper presented at the CHI ’98, Human Factors in Computing Systems, Los Angeles.

Lett, H.S., Blumenthal, J.A., Babyak, M.A., Catellier, D.J., Carney, R.M., Berkman, L.F., Berg, M.M., Mitchell, P., Jaffe, A.S., & Schneiderman, N. (2007). Social support and prognosis in patients at increased psychosocial risk recovering from myocardial infarction. *Health Psychology, 26,* 418-427.

Lett, H., Blumenthal, J., Babyak, M., Sherwood, A., Strauman, T., & Robbins, C. (2004). Depression as a risk factor for coronary heart disease: Evidence, mechanisms, and treatment. *Psychosomatic Medicine, 66,* 305-315.

Lett, H., Blumenthal, J., Babyak, M., Strauman, T., Robbins, C., & Sherwood, A. (2005). Social support and coronary heart disease: Epidemiologic evidence and implications for treatment. *Psychosomatic Medicine, 67,* 869-878.

Locke, L. (2007). The future of Facebook. *Time Magazine.* July 17. Retrieved 6 March 2008 from <http://www.time.com/time/business/article/0,8599,1644040,00.html>.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Jr., Bandura, A., Ritter, P., Gonzales, V.M., Laurent, D.D., & Holman, H.R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care 37*, 5-14.

Lynch, P.J., & Horton, S. (1999). *Web style guide (Preliminary version).* New Haven, CT: Yale University Press.Mack, J. "Beyond HIPAA: ethics in the e-health arena." *Healthcare Executive.* Sept/Oct 2004, 32-33.

Margolis, H.S., Coleman, P.J., Brown, R.E., Mast, E.E., Sheingold, S.H., & Arevalo, J.A. (1995). Prevention of Hepatitis B virus transmission by immunization. An economic analysis of current recommendations. *Journal of the American Medical Association 274*(15), 1201-1208.

Mayhew, D.J. (1999). *The usability engineering lifecycle.* San Francisco, CA: Morgan Kaufmann Publishers, Inc.

McCarthy, C. (2008). ComScore: Facebook is beating MySpace worldwide. *CNET.* Retrieved 15 July 2008 from <http://news.cnet.com/8301-13577_3-9973826-36.html>.

Mills, M.E. & Sullivan, K. (1999). The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *Journal of Clinical Nursing; 8,* 631-642.

Muller, M.J. (1992) Retrospective on a year of participatory design using the PICTIVE technique. Paper presented at the Proc. CHI '92 Human Factors in Computing Systems, Monterey, CA.

Mumford, E. (1983). *Designing Participatively*. Manchester, UK: Manchester Business School.

MSNBC. (2008). Weighing the high cost of cancer care. Retrieved 2 April 2008 from <http://www.msnbc.msn.com/id/23783216/>.

National Research Council: Computer Science and Telecommunications Board. (2000). *Networking health: prescriptions for the internet.* National Academy Press: Washington, DC.

Navarro, A., Voetsch, K., Liburd, L., Bezold, C., & Rhea, M. (2006). Recommendations for future efforts in community health promotion: report of the National Expert Panel on Community Health Promotion. Atlanta (GA): Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion.

Nelson, L. (1948). *Rural Sociology*. New York: American Book Co.

Nielsen, J. (1998). *Jakob Nielsen.* Retrieved 6 March 2008 from *<http://www.useit.com>.*

Pennebaker, J.W., & Beall, S.K. (1986). Confronting a traumatic event: Toward an understanding of inhibition and disease. *Journal of Abnormal Psychology, 95,* 274-281.

Pennebaker, J.W., Colder, M., & Sharp, L.K. (1990). Accelerating the coping process. *Journal of Personality and Social Psychology, 58,* 528-537.

Pennebaker, J.W. (1991). “Self-expressive writing: Implications for health, education, and welfare.” In P. Belanoff, P. Elbow, and S.I. Fontaine (Eds.), *Nothing begins with N: New investigations of freewriting* 157-170*.* Southern Illinois University Press.

Petrie, K.J., Booth, R., Pennebaker, J.W., Davidson, K.P., & Thomas, M. (1995). Disclosure of trauma and immune response to hepatitis B vaccination program. *Journal of Consulting and Clinical Psychology, 63,* 787-792.

Preece, J. (2000). *Online communities: Designing usability, supporting sociability.* West Sussex, England: Wiley & Sons.

Preece, J., Rogers, Y., Sharp, H., Benyon, D., Holland, S., & Carey, T. (1994). *Human-computer interaction*. Wokingham, UK: Addison-Wesley.

Public Broadcasting System. (2001). March. The Hippocratic Oath - Modern Version. Retrieved 2 February 2008 from NOVA Online | Survivor M.D. Web site: <http://www.pbs.org/wgbh/nova/doctors/oath_modern.html>.

Quittner, J., Hempel, J., & Blakely, L.. (2007). “The battle for your social circle.” *Fortune. 156(11),* 29.

Rheingold, Howard. (2000). *The Virtual Community: Homesteading on the Electronic Frontier*. Revised. Cambridge, MA: MIT Press.

Ricks v. Budge. (1937). 64 P2d 208. Utah.

Robertson, T. S. (1971). *Innovative behavior and communication.* New York: Holt.

Rogers, E. M. (1995). *Diffusion of innovations* (4th ed.). New York: Free Press.

Rogers, E. M., & Kincaid, D. L. (1981). *Communication networks: Toward a new paradigm for research.* New York: Free Press.

Shneiderman, B. (1998). *Designing the user interface: Strategies for effective human-computer interaction (Third Ed.).* Reading, MA: Addison-Wesley.

Spielberg, A.R. (1998). On call and online: Sociohistorical, legal, and ethical implications of e-mail for the patient-physician relationship. *Journal of the American Medical Association; 280(15)*, 1353-1359.

Spielberg, A.R. (1999). Online without a net: physician-patient communication by electronic mail. *American Journal of Law & Medicine*; 25, 267-295.

Schuler, D. & Namioka, A.E. (1993). *Participatory design: Principles and practices.* Mahwah, NJ: Lawrence Erlbaum.

Taylor, M. (1982). *Community, anarchy, and liberty.* Cambridge, MA: Cambridge University Press.

van Brunt, D., & Salehizadeh, B. (2001). Ethical guidance in web site development. *Healthcare Executive* Sept/Oct, 68-69.

Van Melle, J., de Jonge, P., Spijkerman, T., Tijssen, O., Ormel, J., van Veldhuisen, D., van den Brink, R.H.S., & van den Berg, M.P. (2004). Prognostic association of depression following myocardial infarction with mortality and cardiovascular events: A meta-analysis. *Psychosomatic Medicine, 66,* 814-822.

Wagner, E. H., Bennett, S. M., Austin, B. T., Greene, S. M., Schaefer, J. K., & Vonkorff, M. (2005). Finding common ground: Patient-centeredness and evidence-based chronic illness care. Journal of Alternative and Complementary Medicine, 11(Suppl. 1), S7-S15.

Weiss, N. (2004). Email consultation: Clinical, financial, legal, and ethical implications. *Surg Neurol.* 61, 455-459.

Wellman, B. (1997). An electronic group is virtually a social network. In S. Kiesler (Ed.), *Culture of the Internet* (179-205). Mahwah, NJ: Lawrence Erlbaum.

The White House. (2008) Retrieved 2 April 2008 from <http://www.whitehouse.gov /infocus/healthcare/>.

Tracy, T. Doctors say they know best: Lay off the WebMD. Retrieved 1 July 2008 from Columbia News Service. Web site: <http://jscms.jrn.columbia.edu/cns/2007-03-13/tracy-medicalparanoia>.

Zahlmann, G., Obermaier, M. & Mertz, M. (2000). Real applications of patient-related telemedical services. In Marsh A., Grandinetti, L, and Kauranne, T. *Advanced infrastructures for future healthcare* (20-37). IOS Press: Amsterdam.