

The Rise of Health 2.0 and the Impact of User-Generated Content
on Pursuing Treatment Options

by

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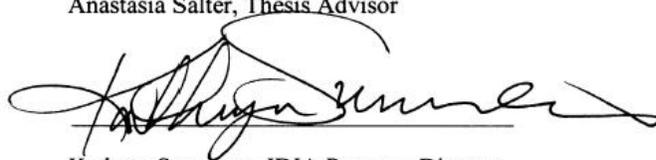
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Introduction

Prior to the birth of Web 2.0 the interpretation of health information was mainly left to those elite professionals who could interpret the medical jargon that filled journals and books. Over the years, a revolution has been building, changing the way health information and care is approached. Health 2.0, as it is often referred to, has revolutionized the doctor-patient relationship and has placed an established industry in a position to shift the traditional approach or risk being left behind. Technology has provided the ability to create and access millions of pages of health information, that range from academic to amateur, empowering consumers to seek more control over their health and challenge the conservative field of health care providers. Given the ability for individuals to access this type of information, Health 2.0 has shifted patient expectations. One survey showed that “60% of users agree that health information technology gives them a sense of control and empowerment in managing their health” (Bass, Ruzek, Gordon, Fleisher, McKeown-Conn & Moore, 2006). This newfound ability to access health information empowers patients to ask their doctors well-informed questions.

This paper examines the Health 2.0 revolution by utilizing survey and eye tracking data to identify the way in which individuals are searching for health information and what the potential impact the information they encounter has on their health decisions. It will outline the challenges and benefits of embracing the various types of online health information available to consumers, particularly user-generated content.

Building upon previous research and the research conducted in this study, this project will highlight the importance for healthcare organizations and professionals to embrace online communities in order to offer patients and caregivers the opportunity to provide a stronger

patient-centered health care experience.

Literature Review

Social Media

Social media is no longer a foreign concept to most. And “whether it is termed new media, participatory media, or Web 2.0, the way in which information is created, shared, and disseminated is changing dramatically” (Della, Eroglu, Bernhardt, Edgerton, & Nall, 2008). Containing elements of both *interpersonal* communication and *mass* communication, it “enables communicators to develop, send and deliver unique messages to many different people all at the same time” (Della et al., 2008). It also extends the definition of communicators in the traditional sense, meaning companies and the communications, public relations and marketing teams no longer control the message.

Web 2.0 emphasizes “conversations, interpersonal networking, personalization and individualism” (Boulos & Wheeler, 2007). Contrary to its predecessor Web 1.0, its’ content can be more easily generated and published by users, and the collective intelligence of users encourages more democratic use (Boulos & Wheeler, 2007). While this shift is powerful, the ability for users to be creators and readers vastly increases the amount of information available, which can also increase the noise that individuals must filter out.

Web 2.0 goes beyond user-generated content, it’s a revolutionary way that people can “collaborate, identify potential collaborators or friends, communicate with each other, and identify information that is relevant for them” (Eysenbach, 2008). It includes various types of networks, including blogs, podcasts and videos, and “encourages a more human approach to interactivity on the Web, better supports group interactivity and fosters a greater sense of

community in a potentially ‘cold’ social environment” (Boulos & Wheeler, 2007). It emphasizes the pre-eminence of content creation over content consumption. “Information is liberated from corporative control (traditional content owners or their intermediaries), allowing anyone to create, assemble, organize (tag), locate and share content to meet their own needs or the needs of clients” (Boulos & Wheeler, 2007). This revolution of social media has created a level of community, empowerment and ownership for users. With content being flexible and ever-changing, there are “several instances of amateur knowledge surpassing professional, when the right kind of systems and tools are available” (Boulos & Wheeler, 2007). Templated websites and free blog platforms are examples of tools that individuals can utilize to create content with very little web development or design knowledge.

The reason Web 2.0 has so quickly come to fruition is that it has the ability to “engender immediacy, online presence, mobility, ubiquity, and location sensitivity” (Boulos & Wheeler, 2007). To participate, people only need a common interest to tap into social networking services and create online communities, with a strong desire to interact with others.

Web 2.0 has revolutionized the way people communicate and access information on a day-to-day basis. Online communities will continue to become a mainstay for communication and interaction. According to Williams & Cothrel (2000), “before long, the ability to create and manage virtual communities will become a distinguishing feature of nearly every successful business.” Organizations that do not actively participate within their own virtual communities, or even those already in existence (e.g. Facebook), have no role in the production of knowledge surrounding it. The need to embrace these communities, and Web 2.0 as a whole, is especially paramount in the healthcare industry.

Health Information

Health information is perhaps facing the greatest shift with the changes Web 2.0 has afforded individuals in terms of access and communication. Health information is unique in that the “mechanisms for how and why individuals respond to health information in particular – and users’ subsequent behavior – are quite different from the mechanisms related to processing of news and other types of content” (Hu, Sundar, 2010). In a study by Hu & Sundar (2010), they discovered that individuals looking for health information often took actions based on the information they found, but were unable to determine what factors influenced them to make decisions based on what they found online.

Recent data shows the growing trend of individuals seeking health information outside of their physician’s office. According to a 2011 Pew Internet & American Life Project report, “eight in ten internet users look online for health information, which makes it the third most popular online pursuit among all those tracked by the Pew Internet Project, following email and using a search engine” (Fox, 2011c). Della et al. (2008) reported that “the first quarter of 2007 witnessed an overall 12% growth in the online health information category as compared with the first quarter 2006.” As people have grown more familiar with searching for information and have found that they have the ability to search through various types of information (e.g. communities, blogs, websites), the expectations of finding information related to health issues has increased.

Women significantly outpace men in “pursuit of information about specific diseases or medical problems, certain treatments or procedures, doctors or other health professionals, hospitals or other medical facilities, food safety or recalls, drug safety or recalls, and pregnancy

and childbirth” (Fox, 2011c). This data demonstrates that women either need to feel more control over the health of their family members, or are seeking to fill an emotional need by identifying with others.

Another group most likely to search online for health information are users who have experienced a recent medical emergency, their own or someone else’s. They prove to be voracious information consumers (Fox, 2011b) and are also more likely than other internet users to go online to try to find someone who shares their situation: 23% compared with 16% (Fox, 2011a). In fact, according to Pew Internet research, almost half of internet users who are searching for health information do so on behalf of another person. Thirty-six percent say their last search was on behalf of themselves, and 11% say it was both for themselves and someone else (Fox, 2011c).

The revolution of health information is bringing a shift in the way people are consuming this information. In the past, individuals relied heavily on receiving information from their physicians. However, studies show that health professionals, friends, family members, and fellow patients are all becoming part of the mix. Individuals are taking it upon themselves to consume as much information as possible about symptoms, diagnoses, and treatments—however, we don’t have a clear picture of how they choose which sources to value and avoid the many traps represented by drug-funded and poorly sourced information—a problem that my study will address.

Health 2.0

Health information is critical to health-related decisions, and the Internet has enabled users to get more involved and empowered with every aspect of their lives. These “Web 2.0

sociable technologies and social software are presented as enablers in health and health care, for organizations, clinicians, patients and laypersons” (Boulos, Wheeler, 2007). When concerning health information the Internet has “not only facilitated increased patients’ access to information, but it has also enabled new pathways for patients to find and help each other” (Fox, 2011a). This revolution has been named “Health 2.0.”

While the majority of health related conversations are happening offline: “Just 5% of adults say they received online information, care, or support from a health professional” (Fox, 2011a), more and more Americans are turning to friends and family for support and advice when they have a health problem. A recent Pew Internet & American Life Project study shows that people’s networks are expanding beyond that to include online peers, particularly in the crucible of rare disease (Fox, 2011a). The availability of social tools and the motivation, especially among people living with chronic conditions, to connect with each other are the driving forces behind the need to go online for conversations about health (Fox, 2011b). What recent research does not indicate is how much this interaction has impacted their treatment decisions. By making connections and establishing trust with others in similar situations, one might conclude that people seek second opinions more often or question their doctors more. They may also learn about new treatments, procedures or trials around the country that their doctors may be unaware of.

Health 2.0 introduces new opportunities that were inconceivable a few decades ago by promoting “user-centered design and interactivity, broad social connectivity, deeper understanding of what motivates behavior change beyond ‘risk,’ and the use of multimodal media that expand people’s access to health information and discourse across time, place, and

cultures” (Neuhauser & Kreps, 2010). Coupled with the trend toward more patient control of health information-seeking and decision-making, Health 2.0 is becoming quite powerful. By enhancing the user’s control of information searching, initiating connections with health providers, and linking with others in online spaces healthcare organizations are in an influential position to capitalize on providing health platforms that would further fuel the Health 2.0 revolution and empower patients.

Studies have examined how patients’ are seeking health information and found that the information discovered had affected their relationships with their health providers. A 2005 national survey showed that the majority of individuals were going to the Internet first, rather than to a provider, for health information (Neuhauser & Kreps, 2010). Even more telling is that “the vast majority of people under 30 years old prefer Internet to initial interactions with medical professionals, want to actively investigate their health options, and assertively put forth their ideas and connect with others about issues” (Neuhauser & Kreps, 2010). Physician’s exhibit mixed feelings about this shift. Neuhauser & Kreps (2010) outlined three typical outcomes:

The health professional feels threatened by patients who bring in information and react defensively by asserting an ‘expert opinion’ (professional-centered relationship); the health professional and patient work together to find and analyze the information (patient-centered relationship); or the health professional guides patients to reliable health websites (Internet prescription).

This study could be taken further to see if those doctors who are more accepting of social media’s presence and recommend sites to their patients saw better outcomes in treatment.

My study concentrates on the importance of patient communities and the impact the interaction has within those communities on treatment decisions. The amount of user-generated content regarding health content is growing, as well as the number of individuals who are interacting with this content. In 2009, “59% of US ‘e-patients’ accessed user-generated health content, and 20% had created such content; 53% had looked at Wikipedia for health information, and 39% had used a social networking site” (Neuhauser & Kreps, 2010). A recent Pew Internet & American Life Project study (Fox, 2011b) indicated that while social networks sites are not a significant source of health information for most people, they can be a source of encouragement and care.

Social networks, particularly patient communities, can fill a gap that cannot be found specifically reading health content or by visiting a doctor’s office. According to Johnson and Ambrose (2006), today’s healthcare system is “unable to support this approach as the demands for overall effectiveness, from the individual patient’s point of view tend to be sacrificed for the sake of efficiencies in the time and other resources of health care personnel.” Because the typical office visit is not able “to provide the patient with the continuous affective-cognitive, social-environment, or other support, which could result in optimal treatment outcomes (Johnson & Ambrose, 2006), patients are turning to online communities to meet their needs more completely.

One example of the benefits for virtual communities is based on the statistic that “100 million prescriptions go unfilled in the U.S. each year, and an estimated 125,000 Americans die each year from noncompliance, or failure to take their medicine as prescribed” (Johnson & Ambrose, 2006). Citing a lack of comprehension and a lack of information as a major reason for

noncompliance, Johnson and Ambrose (2006) believe that online communities help patients to comprehend their treatment to a greater extent, through information sharing with others suffering from the same ailments.

Comprehension involves assimilating adequate and relevant information from their environment and their communities, integrating it with their existing knowledge base, and interpreting the treatment as having desirable outcomes. If this cycle of information processing is complete and adequate, there is a much higher likelihood that the patient will then take the necessary actions to comply with dosage requirements (Johnson & Ambrose, 2006).

Combining the power of online communities with the ability to find reliable health information would allow healthcare organizations to offer patients, family members and caregivers a powerful health experience. An article written by Wyatt and Loder (2011) further supports this theory by exploring how “tools of the information revolution give patients more control over their own health and care, thereby enabling clinicians and health professionals to enter a more balanced health contract.” By allowing information to be organized around the patients, allowing patients to control aspects of their own data, and to contribute to research can only lead to better care.

Information plays a primary role in empowering the patient. “Even if the patient sees a healthcare professional on a weekly basis for one hour, they will still look after themselves 167/168 hours a week or 99% of the time” (Wyatt & Loder, 2011). Healthcare organizations must create a way to reduce this gap. Moving toward giving patients more control would allow an increased emphasis to be placed on a more proactive management of care approach, rather

than crisis management (Wyatt, Loder, 2011). Eysenbach (2008) agrees that there is a broader idea behind Health 2.0, which is “the notion that healthcare systems need to move away from hospital-based medicine, focus on promoting health, provide healthcare in people’s own homes, and empower consumers to take responsibility for their own health.” Patients are even being viewed as experts and – “according to the Web 2.0 philosophy – their collective wisdom can and should be harnessed: ‘the health professional is an expert in identifying disease, while the patient is an expert in experiencing it’” (Eysenbach, 2008). However, Wyatt and Loder, as well as Eysenbach, are missing one critical component to creating better information sources and access, by leaving out the need for information and interaction that caregivers and family members have when faced with a loved one’s health issues.

A 2011 Pew Internet & American Life Project study (Fox, 2011b) shows that more than a quarter of adults in the U.S. provide unpaid care to a loved one. Those ages 30-49 “are the most likely age group to be focused on other people, which is not surprising since two-thirds of this group have young children living at home and may also be looking for information on behalf of aging relatives” (Fox, 2011c). This finding is important when considering how healthcare organizations could better integrate social communities and health information to also incorporate areas for family members, friends and caregivers to access. This may prove particularly important for older individuals or those incapacitated by their health condition and rely on others to seek information or support.

Health 2.0 Challenges

Overview

With the manifestation of Health 2.0, there are many challenges that heed its adaptation among healthcare organizations, physicians, and individuals themselves. Not only can the

amount of health information online be overwhelming, but there are issues pertaining to the credibility of information, cost and security that need to be taken into consideration when recommending ways for healthcare organizations to embrace Health 2.0.

Credibility of Information

Della et al. (2008) acknowledged that “it is obvious that relentless connectivity to digital information is shaping the way in which health information is created, shared, and disseminated, as well as the way in which health information is sought, accessed, and consumed.” The low entry barriers for producing user-generated content, brings about challenges, particularly when health information is being created and shared at the rate it is today. “Sorting through the content overload created by professionals and amateurs alike will become an even more taxing exercise for American consumers” (Della et al., 2008). For individuals seeking health information, it may become even more challenging to obtain a complete picture of health behavior and health care recommendations than ever before, despite the unprecedented amount and availability of health information today (Della et al., 2008). Without the ability to assess the credibility of these health sites, “people will end up embracing bad information and unreliable services. This could have devastating effects” (Fogg, Soohoo & Danielson, 2002).

The results of a 2002 Consumer WebWatch survey (Fogg et al., 2002), revealed that people claimed that certain elements were crucial to a website’s credibility. To determine how individuals decipher how they trust the information they found on the Internet, they looked at “whether consumers actually perform the necessary credibility checks-and-balances while online that they said they did in an earlier national poll” (Fogg et al., 2002).

The study conducted was the first to generate findings about what people notice when they evaluate a website for credibility. Previously other studies had looked at the judgments people made about website features. Key findings of the study showed that individuals rarely used the rigorous criteria when evaluating credibility (e.g. they almost never referred to a site's privacy policy), which was a contrast to the findings of Consumer WebWatch's earlier national survey (Fogg et al., 2002). Instead the data showed that the average consumer paid far more attention to the superficial aspects of a site, such as visual cues, than to its content (Fogg et al., 2002). For example, "nearly half of all consumers (46.1%) in the study assessed the credibility of sites based in part on the appeal of the overall visual design of a site, including layout, typography, font size and color schemes" (Fogg et al., 2002). The results of this research show that the design look of websites was clearly the most prominent issue when people evaluated website credibility. "Participants seemed to make their credibility-based decisions about the people or organization behind the site based upon the site's overall visual appeal" (Fogg et al., 2002). If this is true, does this mean that a pharmaceutical site can persuade people to think it is more reliable and trustworthy than a non-profit healthcare organization simply because it has more dollars to spend on web design, even when their intentions are different?

There is a growing concern about the extent to which consumers are getting their information from websites that are not trustworthy and do not have the appropriate qualifications to provide health information. According to Dutta-Bergman (2004), "experts argue that source credibility is important in consumer decision-making in a medical context because sources that are not believable are likely to mislead the consumer, impacting the quality of medical decision-making." A concern among medical professionals, with the combination of layperson and professional sources available, is that there may be a blurring line over the relative standing of

professional expertise and lay expertise in influencing user-evaluated information credibility. Essentially, the Internet has vastly increased the presence of patient expertise; but does that mean that individuals searching for health information use the two types of expertise differently? And is it such a bad thing to have both types of sources coexist?

Participants reported “significantly greater behavioral intentions toward information attributed to a Web site than to a blog, a home page, or the Internet, whereas there was no significant difference between a Web site and a bulletin board” (Hu & Sundar, 2010). Completion of the study, “produced a significant main effect for selecting source on behavior intentions, with means in the following order: Web site, bulletin board, blog, home page, and the Internet” (Hu & Sundar, 2010).

Findings revealed that “selecting sources on the Internet hold difference meanings for users depending on both the type of original source and the relevance of content” (Hu & Sundar, 2010). For example, a blog that is created by a layperson regarding their experience with a particular diagnosis and discusses a controversial treatment is perceived as more of an outlet than when a doctor uses it for the same purpose.

Perceived information completeness can potentially influence users’ psychological differences as a function of selecting source (Hu & Sundar, 2010).

The credibility of the individual or organization providing the information is threatened when the information in an online environment is not complete. Loss in the credibility of the source, in turn, is likely to impact future consumer evaluations of the source (individual or organization) as a health information provider (Dutta-Bergman, 2004).

Therefore, health information providers should check the completeness of each article offered on different platforms (Dutta-Bergman, 2004). Providing complete health information “had stronger effect on attitudes toward the information than incomplete health information, regardless of participants’ motivation” (Hu & Sundar, 2010). Those who receive complete health information showed greater behavioral intention than those receiving incomplete information (Hu & Sundar, 2010). Participants were inclined to believe that websites were controlled by editors more so than other types of online health sources and felt the added level of gatekeeping would lead to more credible information.

According to Dutta-Bergman (2004), the “completeness of health information refers to the extent to which the discussion of a health topic is comprehensive, balanced and adequate in its portrayal.” One could even argue that the more complete the information is the better equipped is the patient in making a decision based on the information (Dutta-Bergman, 2004). The downside of incomplete information is that it does not give the full picture, thereby missing necessary and relevant information that could be misleading the consumer (Dutta-Bergman, 2004). Research suggests that consumer trust in the information increases with increasing levels of completeness.

Source credibility extends beyond just a website. When individuals are searching for health information they can choose from thousands of sources. “Medical experts posit that health information provided by a source that is not believable is detrimental to consumer outcomes” (Dutta-Bergman, p 254). Hu and Sundar identify two types of source expertise that can craft health information. “One is professional expertise, possessed by medical professionals, and the other is patient expertise, grounded in patients’ or laypersons’ subjective experiences of health and illness” (Hu & Sundar, 2010).

Source Expertise

Some healthcare professionals worry about this addition of the layperson despite recent research showing that no matter what the level of internet access someone may have, “health professionals continue to play a central role in most people’s lives when it comes to being sick, getting well, and maintaining good health” (Fox, 2011a). However, research indicates a shift is occurring and that while health professionals continue to be the central source of information, ‘peer-to-peer healthcare’ is becoming a significant supplement (Fox, 2011a). In particular, when an issue involved technical issues related to a health issue, professionals held sway. “When the issue involved more personal issues of how to cope with a health issue or get quick relief, then non-professionals were preferred by most patients” (Fox, 2011a).

In addition to the advice and information given by health professionals, patients are using information and advice offered by other patients to help them actively participate in their own health care and make informed personal health decisions (Hartzler & Pratt, 2011). Hartzler and Pratt (2011) sought to understand how patients’ experiential expertise contrasts with the medical expertise of health professionals. They conducted an in-depth content analysis to explore how patient expertise and clinician expertise compare with respect to topics discussed and the types of recommendations offered” (Hartzler & Pratt, 2011). The results from the analysis “show that patient expertise differs significantly from clinician expertise in topic (medical, personal, or both), type of recommendation (action strategies, knowledge, perspectives, and information resources), and style of recommendation (narrative vs. prescriptive)” (Hartzler & Pratt, 2011).

Hartzler and Pratt (2011) found that patient expertise differs significantly from that of clinicians in topic, type and style. Even more so, the information provided by patients compliment the expertise provided by health professionals. This finding is encouraging, as

patient communities have the ability to combine both these sources and in doing so, share valuable information. There is a great opportunity for physicians to become “social enablers, providing situations that become positively ‘addictive’ and indispensable, so patients can gather, learn from, and support each other, improving health outcomes” (Boulos & Wheeler, 2007). Research has shown that those involved in online communities exhibited significantly less loneliness and withdrawn behavior, and improved patient compliance and treatment (Johnson & Ambrose, 2006). There was also less worry, anxiety, depression, and resistance to treatment (Johnson & Ambrose, 2006). Healthcare professionals need to accept the huge potential and opportunities the future of online patient communities holds in supporting patient care.

Their findings “suggest that experienced patients do not necessarily serve as ‘amateur doctors’ who offer more accessible but less comprehensive or detailed medical information” (Hartzler & Pratt, 2011), rather, they are able to offer valuable personal information that doctors cannot necessarily provide. My paper prototype will seek to place these two types of “experts” in the same community to increase the value of information, while being cognizant of providing accurate and credible information.

The healthcare industry is facing a mounting demand for flexible access to personal health information, which has been encouraged by technological trends and policies promoting patients’ rights (Frost & Massagli, 2008). The new concept of Personal Health Records 2.0 (PHR 2.0), which allows users to share part of their electronic health record with others introduces “unique and unprecedented opportunities for engaging patients in their health, health care, and health research, and for connecting patients with informal and formal caregivers, health professionals, and researchers” (Eysenbach, 2008). This new revolution concerns physicians

because of privacy issues, as some fear that individuals “may be unaware of the fact that web-information is often permanently archived and may be accessible long-term” (Eysenbach, 2008), putting out information that they may not realize is easily accessible.

There is also a major concern among physicians over the risk “that a collection of static medical information may be overly complex for the patient and therefore overwhelming” (Frost & Massagli, 2008). Physicians have also expressed concern about patients spreading misinformation or incorrect information through these communities. “This is a valid concern, and the only way to get around this problem is for participants to be aware of this potential problem, to crosscheck information with medical sources, and to become discerning users of such information” (Johnson & Ambrose, 2006). Healthcare organizations have a unique position to embrace Health 2.0 changes and be proactive in creating communities in which qualified health professionals can ensure accurate information is available within the communities and can provide discussions over the information shared.

While the adoption might be slower, physicians are beginning to pay more attention to the benefits that these patient communities might have. Almost “40% of these physicians say they already recommend patient communities to their patients and another 40% would consider recommending them” (Modahl & Moorhead, 2011). This is a positive trend, as it suggests that “online patient communicates may grow in acceptance by the medical community as more physicians become acquainted with them” (Modahl & Moorhead, 2011).

Another positive result shows that “about half of physicians say they would be comfortable with serving as a source of professional advice for an online patient community or engage anonymously to better understand these communities” (Modahl & Moorhead, 2011).

There is also solid interest in finding ways to monitor patients' health and behavior online.

“When asked about the benefits of online interactions with patients, clinicians most often cited improved access to care, supported by more – and more convenient – communication” (Modahl & Moorhead, 2011). These findings are positive in showing that physicians are starting to realize the benefits to Health 2.0 and those that do can serve as great resources for the communities healthcare organizations build.

Patient Communities

More than 90 million Americans, representing over 84% of Internet users, participate in online groups. Of these, almost 30% participate in medical or health-related groups (Johnson & Ambrose, 2006). This figure is astonishing and represents “attempts by patients and others to fill voids that exist in the current health system” (Johnson & Ambrose, 2006). Turning tradition on its side, online health communities are serving as supplements to the physician office visit to help satisfy patient needs.

Recent studies have revealed that the rise of ‘smarter patients,’ ‘expert patients,’ ‘informed patients,’ and ‘empowered patients,’ “who are able to challenge the authority of doctors, manage their own health problems by developing related knowledge, become empowered through information acquisition, and, as a consequence, reject the unequal doctor-patient relationship” (Hu & Sundar, 2010). Analyses of two health bulletin boards were “perceived as valuable venues of personal opinions, actionable suggestions, and concrete information” (Hu & Sundar, 2010). A focus-group conducted among mothers of young children, “expressed preference for online parenting advice that was presented by other parents in addition to information from clinical professionals” (Hu & Sundar, 2010). This could highlight the need

again for the ability to combine information provided by professionals, as well as from those that are able to share their real-life experiences.

There are several benefits to online patient communities. First, the “members of such a community have shared purposes, and they interact socially by adhering to tacit and explicit protocols, rituals, and roles using Internet technologies that support interaction” (Johnson & Ambrose, 2006). Second, online participation satisfies many of the needs of patients and their caregivers, such as the affective, spiritual, cognitive, and the behavioral, in ways that the traditional health care infrastructure fails to accomplish (Johnson & Ambrose, 2006). Patient communities are also beneficial because participants can ask questions (i.e. “can anyone help...?”; “does anybody know...?”), pose problems, and provide answers and solutions through their storytelling (Johnson & Ambrose, 2006). A 2007 study of the Association of Cancer Online Resources found that information exchange, not simply emotional support, was the primary driver for community members (Fox, 2011a).

In the last few years, “patient expertise has continued to gain visibility as Web-based social software (e.g., forums, social networking, tools, blogs, and wikis) helps patients to readily exchange information and advice with others who are facing similar health situations” (Hartzler & Pratt, 2011). Patients find that it is easier to confide to others in these extended networks in ways that are sometimes hard to confide to their closest family members and friends (Fox, 2011a). Online communities need to be designed with both patient, family members and caregivers in mind, as they have very different information and support needs.

Today there are hundreds of online patient communities that exist and range from small patient-run communities to those started by healthcare or nonprofit organizations (e.g.

Livestrong, Mayo Clinic). They have been “shown to support reciprocal information sharing and help move participants from information gathering to positive behavioral change and to provide a venue for patients to discuss morality and medical ethics” (Frost & Massagli, 2008).

In 1997, the HMO Kaiser Permanente launched *Kaiser Permanente Online*, a free, members-only website combining services such as online appointments and access to nursing staff, as well as information such as a health encyclopedia and moderator-led discussion groups (Williams & Cothrel, 2000). They sought to parallel the organization’s effort to provide coordinated and integrated customer care by creating a seamless interface and weave together discussion groups with other online offerings (Williams & Cothrel, 2000). A key to their success has been a careful approach to online moderation, with each discussion group assigned a moderator from among the ranks of Kaiser’s health-care providers – doctors, pharmacists, nurses and educators (Williams & Cothrel, 2000). While this type of community begins to show the power that online communities can hold for healthcare organizations, there is still the lack of information being exchanged and the ability to communicate regarding that information. There is also no separate area for family members or caregivers.

Online Cancer Communities

Good education combined with good information can make dealing with a condition a bit easier. Locating peers and attending physical support communities can be difficult, so online communities can provide a good alternative (Preece & Ghazati, 2001). Research shows a heightened need for those with rare diseases to be able to connect with others across the globe, making it a viable start for healthcare organizations to begin creating online communities. Cancer communities are emerging at a rapid rate making it more important to understand how people are searching for information and what type of information matters to them most.

Based on the knowledge that certain types of cancer involve different prognoses and treatment options, Ginossar (2008) looked to find if there were differences in individuals' communication needs and differences in the content of the e-mail messages that they post. Previous studies reported that online cancer communities (OCCs) were used for (a) exchange of information, (b) exchange of emotional support, (c) advocacy, and (d) concerns regarding conflicts (Ginossar, 2008). Even though the study found the differences were smaller and less reliable, findings revealed that women provided more expressive, emotion-focused support, while men tended to provide more task-focused support (Ginossar, 2008).

Ginossar's study was the first to examine how family members of cancer patients use OCCs. The study revealed that family members tend to utilize these communities differently than patients. "Family members who posted e-mail messages to these groups were almost twice as likely as patients to seek information, and utilized the OCCs to a lesser degree than patients for information provision and exchange of emotional support" (Ginossar, 2008). Ginossar found that family members did not share much information with other members of the groups, signaling that "family members of patients rely more on OCCs as information sources, whereas patients tend to utilize other channels for information seeking, in which they obtain the information they later share with the group" (Ginossar, 2008).

Rutten, Arora, Bakos, Aziz & Rowland (2005) felt there was great importance in understanding what cancer patients need to know and from whom receive information during the course of care, as it is essential to ensuring quality care. Their research led them to discover that the benefits of information for cancer patients included "increased patient involvement in decision-making and greater satisfaction with treatment choices; improved ability to cope during

the diagnosis, treatment and post-treatment phases; reductions in anxiety and mood disturbances; and improved communication with family members” (Rutten et al., 2005). Reviewing literature published over the past 20 years, they primarily addressed patients’ information needs and sources during diagnosis and treatment (Rutten et al., 2005).

A focus of this paper is on the amount of health information on the web and the ways in which people are using the information they discover. “Most patients seek explanatory information about their cancer or treatment, especially just after their diagnosis and before starting treatment” (Eysenbach, 2003). Health professionals are unable to meet the patient demands for information, indicating that a combination approach of patient and healthcare professional knowledge would be highly successful. Two surveys reported that “87% of patients stated that they want as much information as possible, and almost 54% of these patients did not feel that their physicians and other health care workers provided them with adequate information” (Eysenbach, 2003). However, dissatisfaction with the amount of information health providers were providing is not the only reason why patients turn to the Internet, searching for information has also been described as a coping strategy (Eysenbach, 2003). There are people living with cancer that are satisfied with the amount of information they have received, but want to reassure themselves that they have every bit of information available (Eysenbach, 2003).

While some challenges exist, the benefits for creating online communities for patients and their caregivers, far outweighs the risks. Healthcare organizations have a unique opportunity to harness the power of online communities and engage with patients and caregivers on a deeper level, allowing them to provide a new layer of care.

Methodology

Information found within online communities can have the ability to introduce new treatment options or experiences that ultimately effects a patient's treatment decisions, whether it encourages them to seek a second opinion or provides them with knowledge and confidence necessary to discuss other options with their doctor. I hypothesize that individuals searching for health information will have the need to search various websites in order to become more educated and may rely more on online communities to provide experience-based anecdotes that would have a greater impact than straight forward health information (e.g. WebMD).

While information and source credibility have been identified as important factors and may cause users to stay on a website to read more content, I propose that users who connect with others via online communities are influenced by emotional and psychological factors that play a role in their decisions to seek second opinions or different treatment options. My research will look to determine what patterns of action might exist for people that have obtained health information online, particularly treatment information, and how it might impact their decision.

In making recommendations for health care providers to better utilize online communities, my research will pay close attention to individuals who have been faced with a cancer diagnosis or a close family member's diagnosis. By seeking to determine how those particular individuals react to the various types of health information and if they are drawn specifically to online communities for more information or simply support, will help guide the final recommendations for the prototype.

There is also the need to identify the impact of caregivers, or even family members and friends, and how they interact with health information. They most likely serve as strong

influencers on the patient when deciding treatment information, and in some cases, particularly if a patient is incapacitated, they could be the main seeker for health information. This is important to recognize as there may be needs they have that are not being met by visiting patient-focused groups for information. .

The current methodologies used in studying users approach to searching for health information and determining the importance of the information found has been quite varied. Some studies have looked purely at the messaging of public health campaigns and the effect on self-efficacy, while others dig deeper into how users determine credibility. Researchers have used surveys, focus groups, and user studies to determine the outcomes.

Using a combination of survey questions and eye tracking studies, my study seeks to determine the impact health information has on participants, looking particularly at the role online communities' play. Pretests and pilot studies were conducted to fine-tune the questions and sequence. Those participating in the eye tracking study were also asked to participate in a paper prototype study that showcased a potential online cancer community.

Survey

Design Overview

The survey consisted of 21 questions (Appendix B). Six of those questions were focused on gathering demographic information. The remaining focused on garnering survey takers Internet usage and the type of health information searching they do, if any. The initial demographic questions were important to collect in order to determine if there were any identifiable patterns to how people searched and used the health information they found. The main questions focused on whether respondents sought health information for themselves, their

friends, family or both. These questions were intended to assess how many individuals might be looking on behalf of others, supporting the hypothesis that health care organizations should attempt to support family members and friends within their online communities. The health information behavior questions were designed to gauge the types of information respondents turn to (e.g. WebMD vs. Discussion Boards) and what they did with the information found. Questions also sought to determine how respondents felt they valued or determined the credibility of health information they found. Based on the response to a question focused on cancer diagnosis and if they had been personally been diagnosed or if someone close to them (e.g. family or friend) had been diagnosed, logic was set up through Survey Monkey to show two additional questions. They were then asked specific questions pertaining to cancer and health information. A question pertaining to uploading mobile health applications was chosen to see if there might be an increase in need to have easier access or reliance on health information.

The purpose of this component was to identify on a larger scale any patterns to how individuals are searching for health information, particularly when it comes to social media and online communities, and what they tend to do with the information.

Participants

The survey had a 90% completion rate, with 90 individuals starting the survey and 81 completing all questions. Respondents were recruited through social network channels, such as Twitter and Facebook. Hashtags (e.g. #cancer) were used to attract respondents that potentially had personal experience with a cancer diagnosis. Few respondents were known personally to have had varying types of cancer diagnoses and were contacted directly to participate if they desired, several of the individuals passed on the survey to those who had also been affected by the disease.

Survey respondents varied in basic demographic information, which included age, gender, educational background, community and work status. All respondents indicated they were over 18 years of age: seven (8.6%) were between the ages of 18-24, forty-seven (58.0%) participants were between the ages 25-34, thirteen (16.0%) were between the ages of 35-44, four (4.9%) were between the ages 45-54, seven (8.6%) were between the ages 55-64 and three (3.7%) were over the age of 65. The majority of respondents were female (74.1%), while males made up 25.9% of survey respondents. Age and gender are important demographics as they may identify, when paired with the other responses, if there are major gaps between users (e.g. male vs. female) that need to be taken into consideration when developing an online community. The large representation of the 25-34 age range over the others may skew results, as that particular age range tends to be more socially connected than the others. Having had more representation, particularly with the 18-24 age group and the 55+ may have identified different patterns related to the information sources they use.

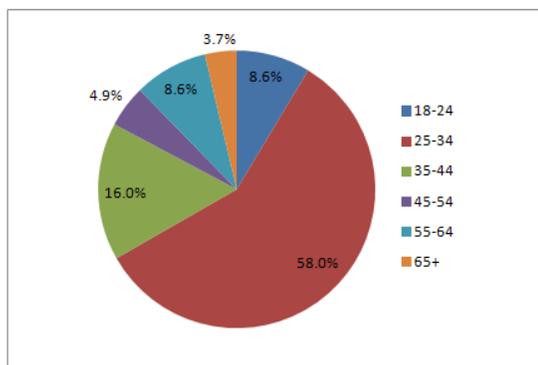


Figure 1. Respondents by Age

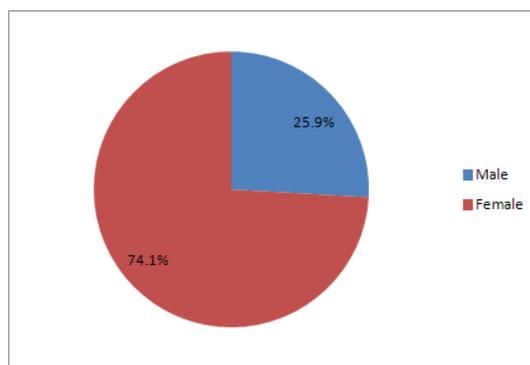


Figure 2. Respondents by Gender

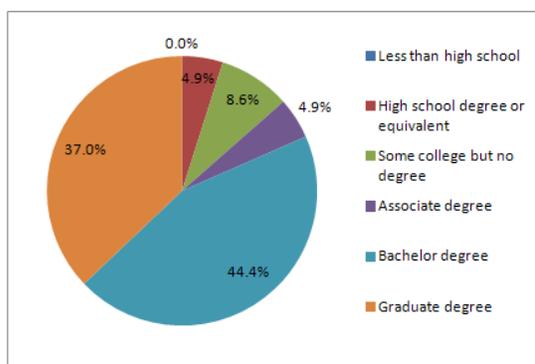


Figure 3. Respondents by Education Level

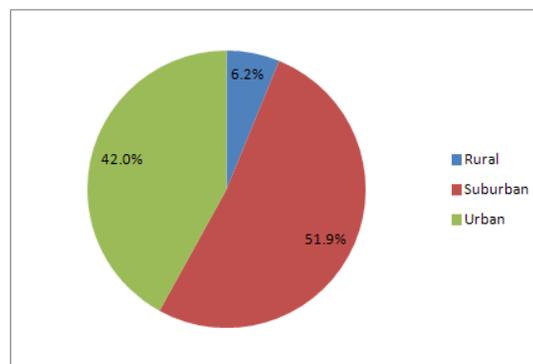


Figure 4. Respondents by Area

Most respondents have degrees in higher education. Seventy respondents have completed college with an Associate's degree (4.9%), a Bachelors degree (44.4%), or a graduate degree (37.0%). Those with higher education levels said that the use of references (bachelors: 75.0%; graduate: 93.3%) and content completeness (bachelors: 80.6%; graduate 83.3%) were most important in determining credibility.

Out of the 81 respondents, a majority lived in suburban and urban communities. Five (6.2%) individuals lived in rural areas, while 42 (51.9%) lived in the suburbs and 34 (42%) lived in urban areas. The lack of rural respondents may hinder the ability to fully identify the potential for these areas, as rural respondents tend to have lower education levels and less access to Internet. Sixty-four respondents (79.0%) are currently employed, while nine (11.1%) marked unemployed. Three respondents (3.7%) were on leave and five (6.2%) were retired. Most likely tied to employment numbers, 90.1% respondents have health coverage, while only 9.9% of respondents do not.

Almost all of the respondents (90.1%) use the Internet several times a day. Respondents were asked if during the past 12 months if they participated in any of the following activities: Participated in a social network (i.e. Facebook, Twitter), read a blog or visited a review site, and/or clicked on an advertisement.

Table 1

Respondents Internet Use

N=81	Several Times a Day	About Once a Day	3-5 Days a Week
Weekly Internet Use	90.1%	8.0%	1.1%

Almost all respondents (98.9%) said they had visited a social networking site in the past 12 months. Eighty-seven percent of respondents had read a blog or visited a review site and 44.3% clicked on an advertisement. These results align with industry trends of social media usage where age is not a limitation for those who access social networks, but factors such as location and education are.

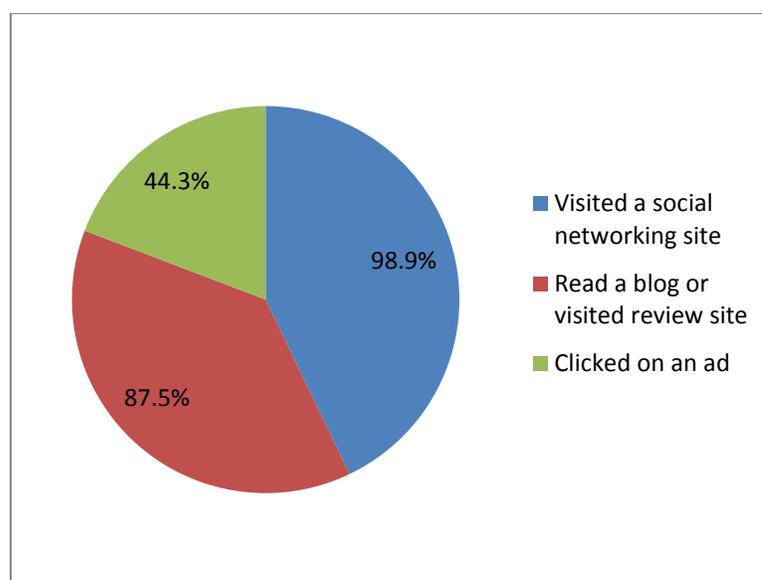


Figure 5. Respondents Internet Use

Regarding searching for health information, 90.4% of survey respondents have used the Internet for seeking health information pertaining to themselves, while 86.8% of respondents have researched health information on behalf of a family member or friend. A majority of individuals have visited health information websites (e.g. WebMD) versus patient community websites, alternative medicine websites, blogs/videos/podcasts, and mobile applications.

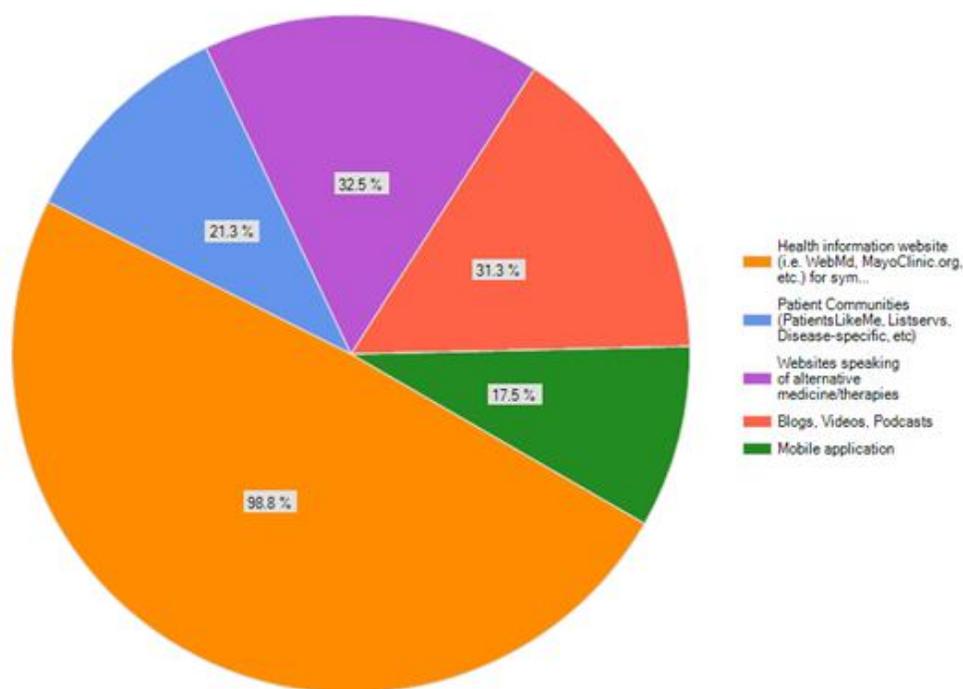


Figure 6. Health Related Websites Visited

Survey data showing that 92.8% of respondents who said they had not participated in an online support group for people with similar health issues, raised more questions about how people were searching for information and selecting the sources they visited. If almost all respondents (98.9%) had visited a social networking site in the past 12 months and if a majority of respondents had searched for health information, why then might there be such a low number of people participating in online support groups?

Survey results led to the desire to gain deeper insight into how users perceived the health information they found. If the majority of respondents used social networks and searched for health information, what might be causing users to overlook online support groups in their search for health information? And with the majority of respondents indicating that they searched for

health information for both themselves and others, is there a difference in how they perceived the information depending on who it was for? An eye tracking study would provide direct insight into the ways in which users viewed the various types of health information they came across.

Eye Tracking

Design Overview

The eye tracking component was then conducted in order to observe firsthand how individuals search for health information and whether they act according to what the online survey results illustrate. It also investigates what impact the information found on pharmaceutical websites versus those on other health sites (e.g. .org, .gov).

Dutta-Bergman (2004) had categorized web-based behavior into two distinct styles of navigation: goal-directed and experiential.

Although browsing is characterized by its exploratory nature and absence of planning, goals, or objectives, searching is goal-directed and the user looks for specific information to solve a problem or to fulfill specific information needs. Whereas the browser is not particularly attentive to specific issue-relevant information objects, the searcher is driven by his or her very specific interest in the search topic (Dutta-Bergman, 2004).

For this study, web use motivation was concentrated on searching. Respondents were asked to imagine a scenario where a loved one had been diagnosed with a particular type of cancer and then were asked to search the Internet for treatment options. This created a high level of goal-directedness with the respondent focusing his or her attention toward the particular diagnosis.

The eye tracking study consisted of 6 participants who were asked to complete 5 tasks. The study looked at the way individuals searched for health information and how they deemed the information credible. After taking the questionnaire, participants began the eye tracking test. Tasks were outlined on the computer and users were asked to press F10 to proceed to the next screen. The first task had participants conduct a free search for ‘stage 2 breast cancer’ with the objective to find information about what types of treatment options are available. After participants felt they had completed their task, they moved on to task 2, which had them move through 4 websites: WebMD (www.webmd.com); Mayo Clinic (www.mayoclinic.com); Johns Hopkins Medicine (www.hopkinsmedicine.org/healthlibrary); and the National Institute of Health (www.nih.gov). During this task, participants were to seek treatment options for colorectal cancer. The third task had users search for ‘bone marrow support,’ with the instructions to select two online support groups and articulate what their thoughts were on the content and credibility of the sites they came across. The fourth task asked participants to look at a chemotherapy treatment drug and visit the pharmaceutical company’s website and another website of their choice. The final task had participants search for alternative cancer treatments for breast cancer. Participants were allowed to freely search and visit any website.

Participants

The eye tracking study consisted of 6 participants who were asked to complete 5 tasks. Respondents were recruited through social network channels, such as Twitter and Facebook. A pre-test questionnaire was given prior to the testing to collect demographic information, as well as information on their current use of the Internet for seeking health information.

The participants were not as varied as the survey takers, as 5 (83.3%) fell in the 25-34 age range and 1 (16.7%) were in the 35-44 age range. The majority of participants were female

(66.7%). Most had received their bachelor's degree and lived in the suburbs. One hundred percent were employed and had health care coverage; this could affect results because it does not incorporate individuals that are unemployed and those that do not have health coverage.

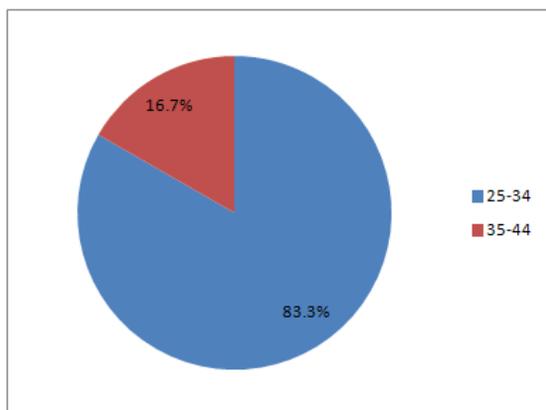


Figure 7. Age of Eye-Tracking Participants

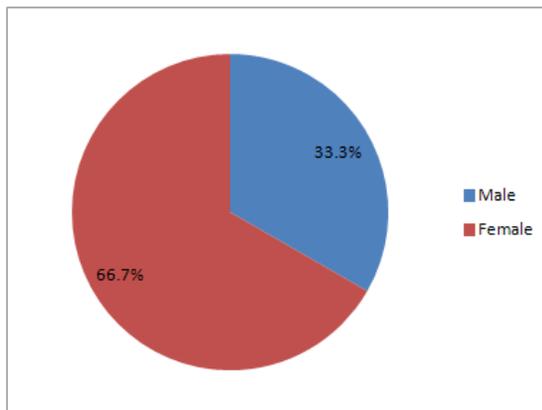


Figure 8. Gender of Eye-Tracking Participants

Paper Prototype

Design Overview

In order to determine how individuals would interact with a trusted online patient community model to provide a basis for recommendations for healthcare organizations, the same participants that participated in the eye tracking study were also asked to partake in a paper prototype test. Demographic information was collected during the questionnaire given before the eye tracking study.

The paper prototype was initially developed based off of previous research and current work in a healthcare organization. The cancer community was chosen for the initial prototype in order to start with a focused illness. It utilizes various social networking elements, such as sharing capabilities, ratings, discussion forums, chat functionality, and videos in an environment that both patients and healthcare professionals could participate in safely. The prototype also

acknowledges both the need for individuals to seek health information and the concern among healthcare professionals over accurate information, since it enables content to be monitored and commented on. It also recognizes the need to give caregivers and family members a separate place to meet their needs in terms of seeking information and reaching out to others in similar situations. Overall, the prototype seeks to be an extension of care, providing support to patients and caregivers during the off-hours they are not face-to-face with their physician.

Participants were given the background of the paper prototype and told that it was an interface being developed to provide support and information to patients, family members and caregivers that were dealing with a cancer diagnosis. It was explained that any patient, family member or caregiver would be given access if they were associated with the healthcare organization that was hosting the community.

The first task participants were asked to complete was to learn more about the staging of cancer. This required users to start at the homepage and go through the registration process. Once participants were registered, they were lead to the patient homepage and were to locate more information about cancer staging. For the second task, participants were asked to contact a nurse through the website to ask a question regarding over-the-counter medications during chemotherapy treatments. Ultimately, users would use the 'Live Chat' functionality to complete the task. The third task asked participants to rate an article within the community. For the fourth task, participants were asked to track a symptom to save for their next doctor appointment.

Results

Eye Tracking

Analysis of the eye tracking study revealed certain patterns and behaviors that affected the way people searched and selected specific health information. Credibility of information; design, content completeness, education, and search behavior play a sizable role in searching for health information.

Credibility of Information

Name recognition and reputation proved to be the driving force behind the participant's selection when searching. Most participants looked carefully at the domain name and who it belonged to. The domain name seemed to draw in participants, particularly if it contained a highly recognizable name (www.mayoclinic.com or www.webmd.com), which further confirmed the credibility of the site once they arrived. Those who selected the American Cancer Society (www.cancer.org) noted how they trusted the Cancer Society, and therefore felt the website content was just as trustworthy. Depending on the domain name (.org, .gov, .com) users expectations were different. One participant visiting a .gov site mentioned, "because it's from the government...it would be at least reviewed for accuracy...flaws can happen, but I would expect them to have a standard or process for reviewing content before it goes on the page."

WebMD proved to be a highly trusted source for 5 out of the 6 participants at one point of the study or another. Although most could not explain the reasoning for the trust: "I always go to WebMD, I don't know why I just always do." "I find WebMD to be a reliable and trustworthy source, I don't know if that's irresponsible or not and I don't know why I feel that way..." Two participants specifically commented that they trusted WebMD because it has a lot of information

and appears to be thorough. Mayo Clinic (www.MayoClinic.com) is another website that was highly respected by users. One participant commented that for cancer-related information, the Mayo Clinic would be a top choice to find information. Consequently, the fact that it is a trusted hospital led one participant to go as far as believing that all content on the website was written by doctors.

Only one participant actually checked for references, which is a stark contrast with the online survey, where 65 respondents (80.2%) said that references were the most important part of determining the credibility of a website. Similar to the response that associated Mayo Clinic content as being written by doctors, perhaps respondents create assumptions that confuse the presence of cited content with brand identity. For example, Mayo Clinic is a hospital, therefore content must be written by doctors. Or perhaps survey respondents not faced with browsing websites believe that references would be important to them and make a site more credible.

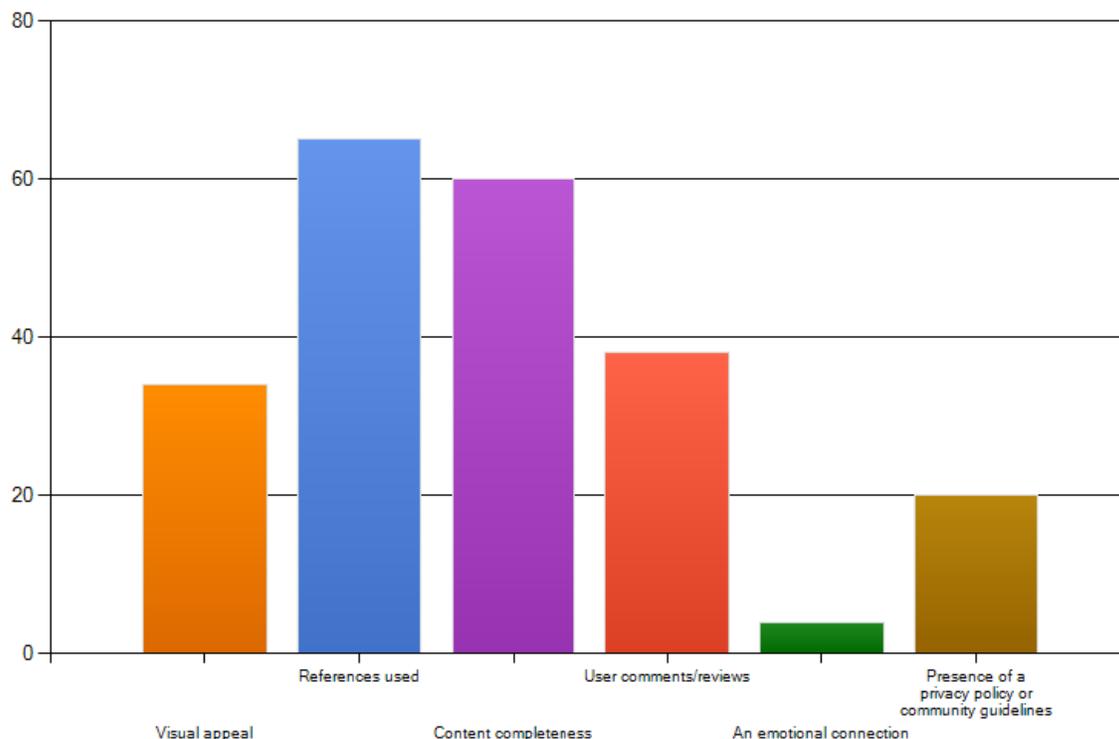


Figure 9.

Following closely behind the use of references, 60 (74.1%) online survey respondents indicated that content completion was important in determining the credibility of a website. Yet, the eye tracking study showed that reputation of the source itself seems to have a larger role in determining website credibility. For example, the Mayo Clinic and Johns Hopkins Medicine were considered reputable from the start based solely on brand reputation. These sites, including WebMD, have very thorough content. The more information a website provided, the more credible participants noted it being. WebMD and Mayo Clinic's health information is very in depth providing links to more information and a layout that seems to go through all aspects (symptoms, treatment, etc.). There were, however, instances in which Johns Hopkins Medicine search results did not return the most accurate search information, most participants struggled to find the relevant information they were tasked with finding. However, because they trusted the

source, they seemed to overlook the fact that they were unable to easily find the information they were seeking.

It proved to be exceptionally easy to lose a person's trust if a site did not meet certain standards. While the online survey reported 42.0% of respondents relying on visual appeal for determining credibility, the eye tracking study showed that the appeal of design had a much larger impact on people's trustworthiness and likelihood to use that information. As much as domain names played an important part in attracting users to click on the site, visual appeal was the main deterrent for staying on the website and establishing trust. Therefore, when participants were tasked with looking for online support communities, they were not well received. Visual design comments were immediately made by the 5 out of 6 participants who visited the BMTSupport.org (bone marrow transplant online community) site. Comments included: "kind of looks like a homemade website..." and "This site looks immaturely made, doesn't seem like as professional as I'd want it to be if I was sharing very personal information..." This shows the value of creating websites that not only focus on the appropriate goals and objectives, but incorporate solid design and user experience elements throughout the website.

The same pattern emerged on the last task, which asked participants to visit an alternative cancer treatment website for breast cancer treatments. The caliber of website design was much lower than those of Mayo Clinic or WebMD, and immediately participants became skeptical and distrusted the websites. One participant noted that it was "another homemade website...just looks like all advertisements trying to get my email to send me junk mail." Another participant noted that the content effects (i.e. crossed out content) was not professional and did not appeal to

her. She also noted that it looked like a website that she could create herself. When participants detected lower design quality and felt as though they could build the website or write the content themselves, the website lost all credibility. Only one participant said, while visiting BMTSupport.org that the website could have been designed by “mom and pop” who were just trying to connect with others, however she was hesitant because of the colored font to want to stay on the website. Interestingly, when design quality was lower, links and email address signups quickly became perceived to be schemes that either lead them to other websites or would send them junk mail.

Along with domain names, titles and descriptions played a significant role in grabbing user's attention, particularly when visiting online communities. Fifty percent of participants had a hard time choosing an online community because the descriptions were inaccurate. Some listings pulled random content through for the description, which did not allow the user to make the connection with what the keyword they were searching with the description content. Outdated date stamps were also shown in the descriptions, making the decision hard for individuals to pick. One participant did not even want to attempt to click on any results because the dates were so old, but chose the first one anyway because "it didn't matter." Two participants visited the Daily Strength website and were immediately drawn to the outdated posting dates within the forums. One participant went to a different bone marrow transplant support site and was shown a message that said the oldest and newest message available was December 31, 1969. This inaccuracy immediately lost the user's desire to continue staying on the website.

The screenshot shows the website header for the Bone Marrow Donor Support Network, with the tagline "Bone Marrow Donor Awareness & Patient Support". Below the header is a navigation menu with links: why donate?, how donation is performed, donor preparation, donor recovery, about transplantation, F.A.Q., donor journals, discussion forum, chat room, join the registry, news, links, about BMDSN, and contact us. A "[Return to Index]" link is also present.

The main heading is "Bone Marrow Donor Support Network Discussion Forum" followed by "Message Index Keyword Search". Below this is a search instruction: "Use the form below to search for specific messages. You can search either for messages containing a certain keyword or keywords, or for messages posted by a specific individual. (All searches are based on partial-string matches and are case-insensitive.)"

The search form includes a "Search messages:" section with two radio buttons. The first is selected: "Posted within the last 1 Year(s)". The second is "Posted between 31 December 1969 and 31 December 1969". Below these options, a yellow box displays the error: "Oldest available message: 31 December 1969" and "Newest available message: 31 December 1969".

The "Search for:" section has two radio buttons. The first is selected: "Messages containing Any of the following keywords:" with an empty text input field below it. The second is "Messages posted by:" with an empty text input field below it.

A "Search Messages" button is located at the bottom of the form.

Figure 10. Bone Marrow Donor Support Network Date Errors

Education

An interesting trend that emerged from the eye tracking study was how participants utilized health information to educate themselves and continue searching, refining their search along the way. Participants considered the initial search they were asked to complete in the task to be a good starting point, but did not provide enough information. This goes to support findings that individuals are avid seekers of health information and are willing to spend time educating themselves and searching for more information. Several participants stated that they would educate themselves on the condition and treatment options and grab keywords to continue searching based on what they had learned. One participant said that she would continue reading beyond the specific diagnosis. During the first task, the user was asked to search for “stage 2 breast cancer treatment.” She commented that she would “look at the next stage to see what would happen if the diagnosis was wrong...or cancer advanced.” The main reason she cited was to mentally prepare for worst case scenarios.

Education showed its benefits. It not only lead individuals to cross reference data, essentially conducting their own ‘check and balances’ system on the information they found, but it also empowered them to want to speak with their physicians more openly. For example, while the pharmaceutical site seemed to provide accurate information and was built within a professional website design, two participants would cross-reference the data with the government website to make sure that there was no “hidden agenda.” And one participate said that if his doctor had conducted one screening and during research it was found that there were other screening options, he would not hesitate to seek a second opinion. Several instances showed that while a participant might not trust the site, they are still willing to browse the site for information that might further their own research.

Seventy-three percent of online survey respondents that used the Internet to seek information on treatment options said that they found the information to be somewhat reliable. The two male participants, in particular, seemed to be less tolerant of health information not coming from reliable sources. One male individual stated that he would collect information from several sites (even ones he deemed untrustworthy) and run it by his health care provider. Another male individual said that at times he visits Wikipedia, and that while “you can’t trust the stuff on here, it might give you a keyword that sends you in a new direction.” The female participants tended to believe the information they found as long as they had deemed the site “credible,” which typically was by design look and feel or brand name recognition.

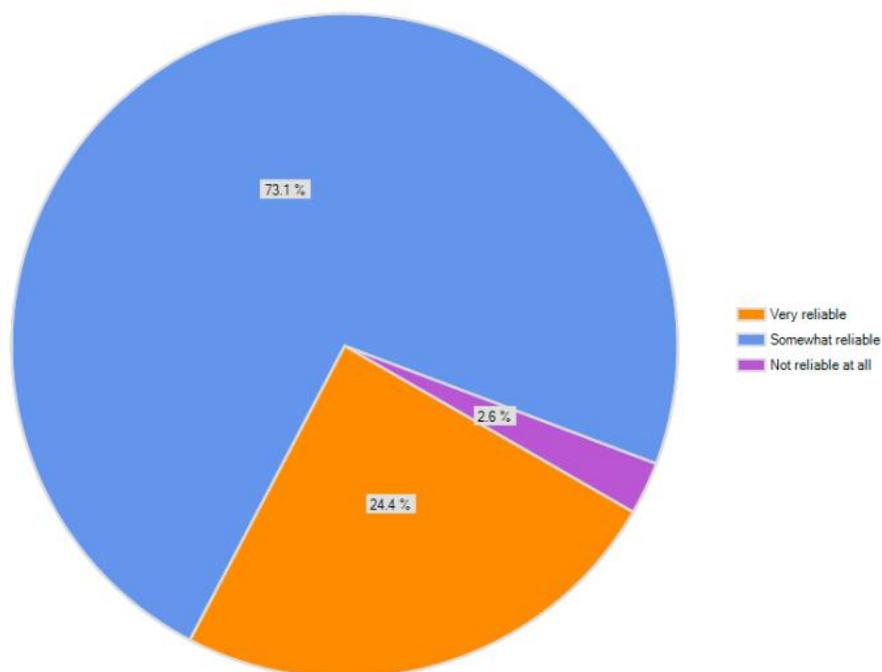


Figure 11. Reliability of Information

Taking a closer look at how males and females determine credible information, survey data was cross tabulated. Females surveyed indicated that references used and content completeness was important, however no female eye tracking participants looked for any

reference data. Females also indicated that user comments and reviews were important. Not shown in the cross tab data is the option to choose emotional connection, which had no male respondents answer, but several females said yes. This indicates that seeing what others think or have experienced is an important factor for females.

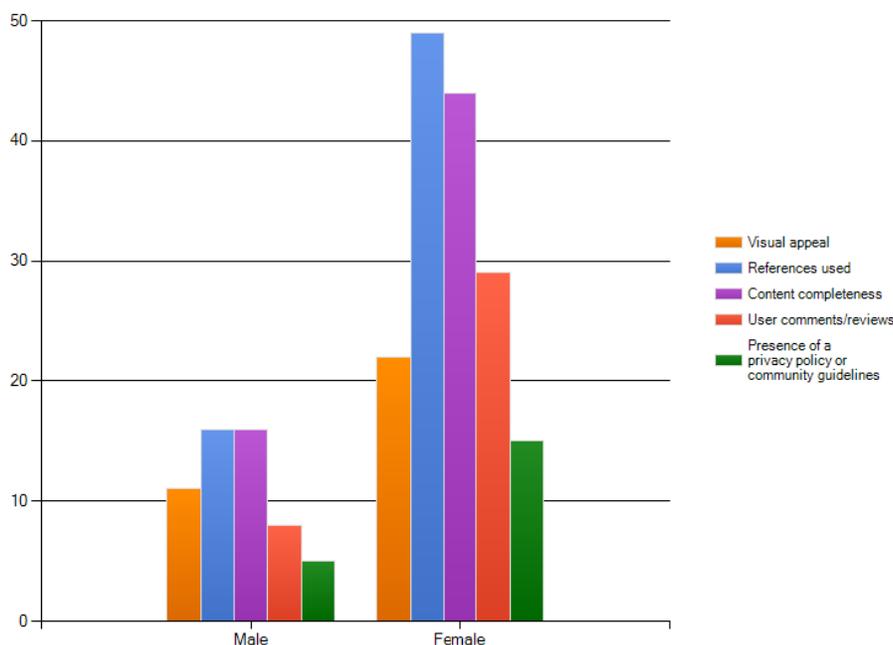


Figure 12. Determining Credibility Factors by Gender

Search Behavior

During the initial task, which was a free search conducted by participants, only two participants selected the same site (www.cancer.org). The others were driven by familiarity (WebMD), domain name trust (www.cancer.org), and intriguing description (www.cancercenter.com, www.whathealth.com, www.mybreastcancertreatment.org (sponsored listing)).

Each participant got to the search rankings using different keyword combinations. Only one participant typed in the task's suggested keyword 'stage 2 breast cancer,' while four

participants were guided by the Google suggestion tool. One participant conducted a long tail search for ‘treatment options for stage 2 breast cancer.’ This variation from the tasks suggested keyword (‘stage 2 breast cancer’) lead to the user seeing a different list of results, providing her with different options to choose from.

Table 2

Searches conducted for Task 1: ‘stage 2 breast cancer treatment’

Participant	Keyword Searched
1	‘stage 2 breast cancer’
2	‘stage 2 breast cancer treatment’ (used suggested)
3	‘stage 2 breast cancer treatment’ (used suggested)
4	Diverted on own: ‘treatment options stage 2 breast cancer’
5	‘stage 2 breast cancer,’ selected suggestion – ‘stage 2 breast cancer prognosis.’ Later refines search to switch ‘prognosis’ to ‘treatment’
6	‘stage 2 breast cancer treatment’ used suggestions box

All six participants read titles and descriptions very carefully and used the URLs to make most of their selections.

The reasons people believe search listings to be produced can have great influence on their selections, as well as their perceptions of credibility. There was an assumption by participants that higher listings were more trustworthy. Not one participant looked beyond the first page, and rarely did anyone look below the third result. One participant commented, “I usually choose the first organic search, just because I know it’s probably been visited the

most...so I would tend to think it has better information.” There was one instance where that participant refined her search term and noticed the same listing appeared near the top and said, “obviously that this is here twice, shows me that a lot of people have visited this,” and then proceeded to visit that site and in a way mentally mark it as trustworthy.

When people are in research mode for health information and feel as though content is written with a marketing focus, they were quickly turned off. During Task 2 participants were asked to find information about ‘colorectal cancer treatments’ and were given four separate websites (WebMD, Mayo Clinic, Johns Hopkins Medicine, and the NIH) to complete the same task. Interestingly, when users were dropped on the Mayo Clinic’s homepage, only one participant came across the actual health content written by Mayo that included symptoms, diagnosis, treatment, etc. The other 5 participants ended up using the search box to immediately conduct a search, leading them to the patient care content. Those participants, who landed within the patient care section, were not settled with the content, as they felt it was trying to persuade them or give a sales pitch instead of providing unbiased information. Once participants searched, whether it was from the search box or with the drop down, participants were unaware of the cues Mayo Clinic had established to let them know where they were in the site. This brings up an important lesson from this study that highlights the importance of properly classifying health information content. Several organizations use “Health Information” as main navigation labels to contain their information on symptoms, diagnoses, conditions, treatments and more. However, there seemed to be confusion around what the term meant and several participants did not seem to make the connection that “Health Information” was an easy way to access the information they were looking for. Therefore, healthcare organizations should carefully consider how to label health information and make it easier for users to identify with.

User testing is also recommended to determine that users are finding the information in an easy manner.

Online Communities

A majority of the survey respondents specify that they visit a variety of health information resources online, particularly health information websites like WebMD or Mayo Clinic. And while online communities have grown rapidly, they still comprise a smaller portion of sites visited, with only 21.3% of online survey respondents claiming to have visited a patient community in the last 12 months.

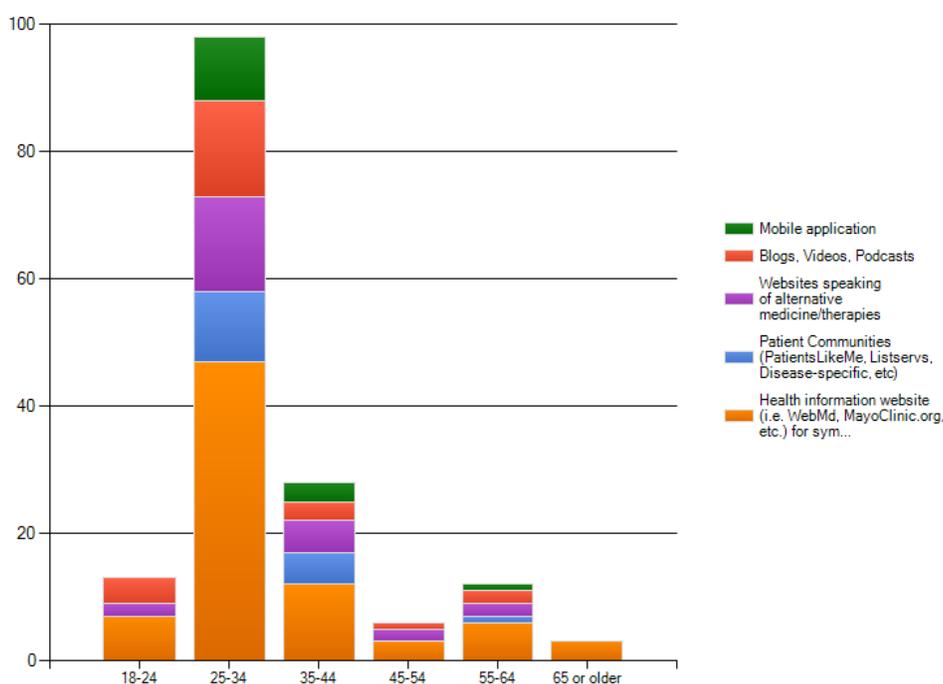


Figure 13. Age Groups Cross Tabulated with Health Information Channels Accessed in Last 12 Months

Eye tracking participants shared that online communities do have their value, but serve more of an anecdotal purpose and are not reliable for medical advice. One female participant said that “WebMD would just give me the facts, but a support forum would tell me exactly what I’d experience more so than...it would tell me the pain, mentally and physically I am going to

have.” Both male participants were more reluctant of these communities, claiming them to be arbitrary and were more judgmental of the lack of professional design elements.

Online survey respondents who indicated that they had visited online communities indicated that the top three reasons were to read others comments/stories (65.5%); seek information on treatments, diagnosis and symptoms (40.0%) and; gather information or find resources (23.6%). Less than 22% indicated that they participated in online communities.

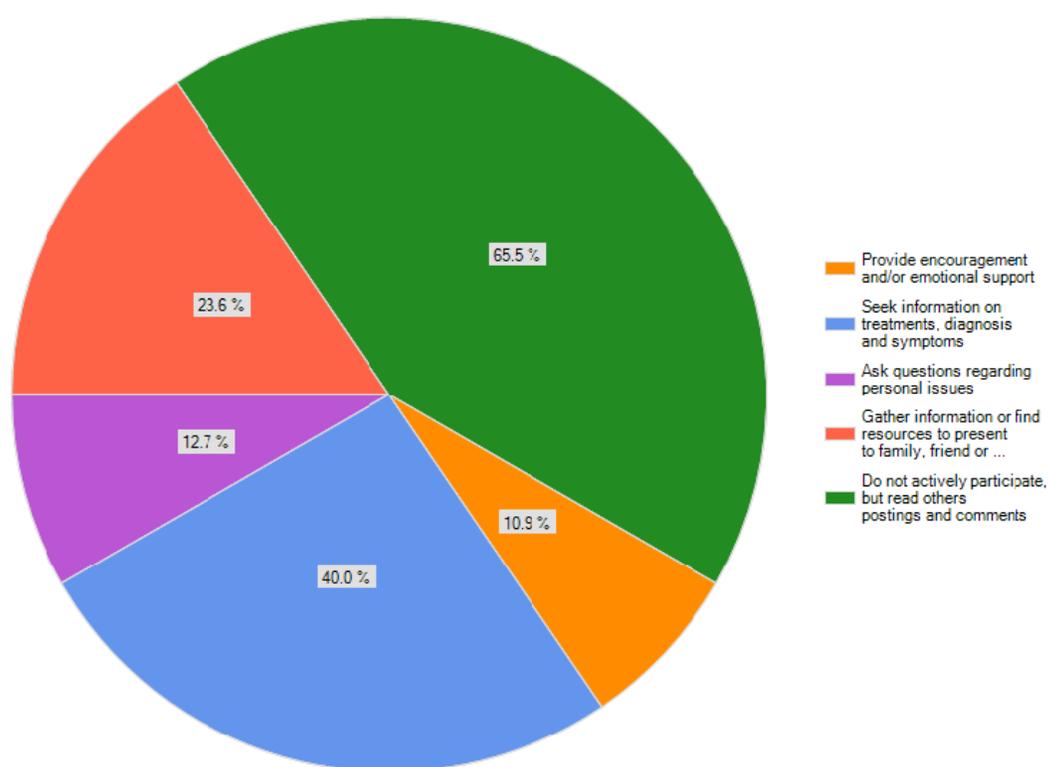


Figure 14. Participation in Online Communities

Seven percent of survey respondents have had a personal cancer diagnosis; 69.5% have had a family member diagnosed with cancer; 35.4% had a close friend who had been diagnosed with cancer and 19.5% of respondents had no experience with a cancer diagnosis. When asked what the most influential factor was when determining treatment options, physicians were heavily favored by 86.7% of respondents. Interestingly, those (3.3%) that had faced a cancer

diagnosis, either personally or by a family member or friend, identified patient communities, blogs or social networks as being more influential than health information websites (1.7%). This differed from the search behaviors of the eye tracking participants. And respondents also noted that information obtained from books and journals (6.7%) were ranked higher than the patient communities and health information websites combined.

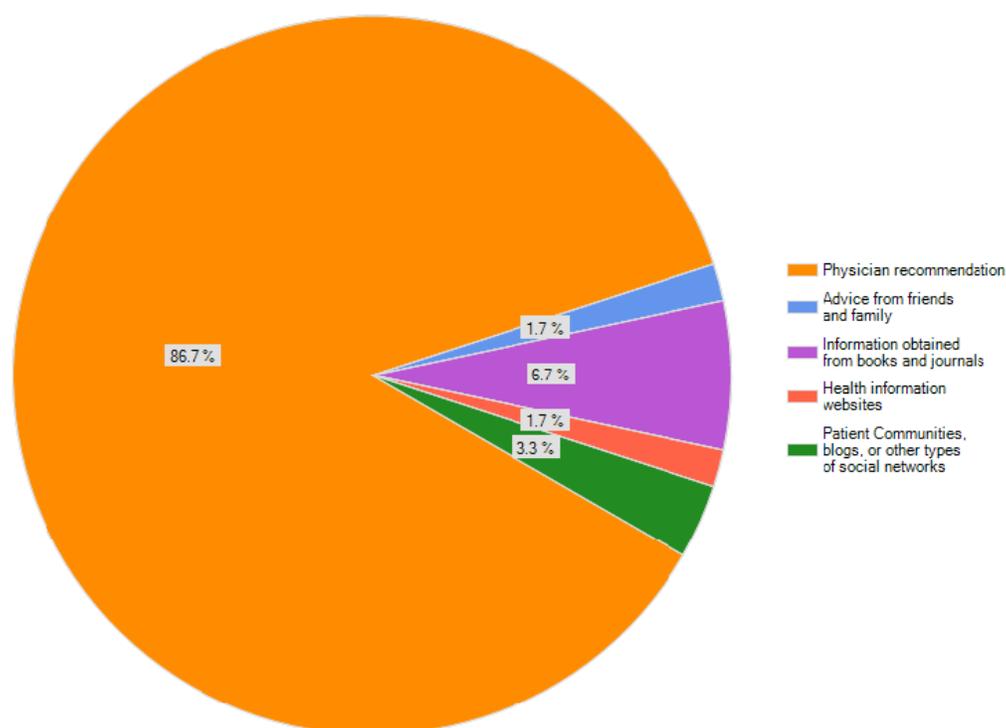


Figure 15. Influential factors when determining treatment options.

Paper Prototype

As mentioned in the methodology, the paper prototype was developed based on previous research and working in a healthcare organization. In an effort to serve as an extension of patient care, the paper prototype was created around the concept of combining social network capabilities with access to accurate health information. The purpose of the online community prototype would ultimately be to serve healthcare systems or professionals. While cancer was

the focus of this prototype, other diagnoses (e.g. transplant groups) could easily benefit from this type of community.

Participants showed favorable responses to the paper prototype portion of the testing. Several participants liked the private, closed aspect and felt comforted that it would be maintained by a healthcare organization. Participants were able to register and login to the prototype with no issues.

From the research and testing, a recommended approach to online communities for healthcare organizations would be to enable patients, family members and caregivers that are under the care of a particular healthcare organization to experience a one-stop-shop of health information. The community would allow individuals the ability to search academic articles, layperson articles and various types of resources (e.g. medical glossary) and assure individuals that the information found within this site is accurate and trustworthy. Individuals would be able to introduce new articles into the database that interested them and would have the ability to rate articles that they found helpful. The same democracy that exists as the backbone of Web 2.0 would exist within this community.

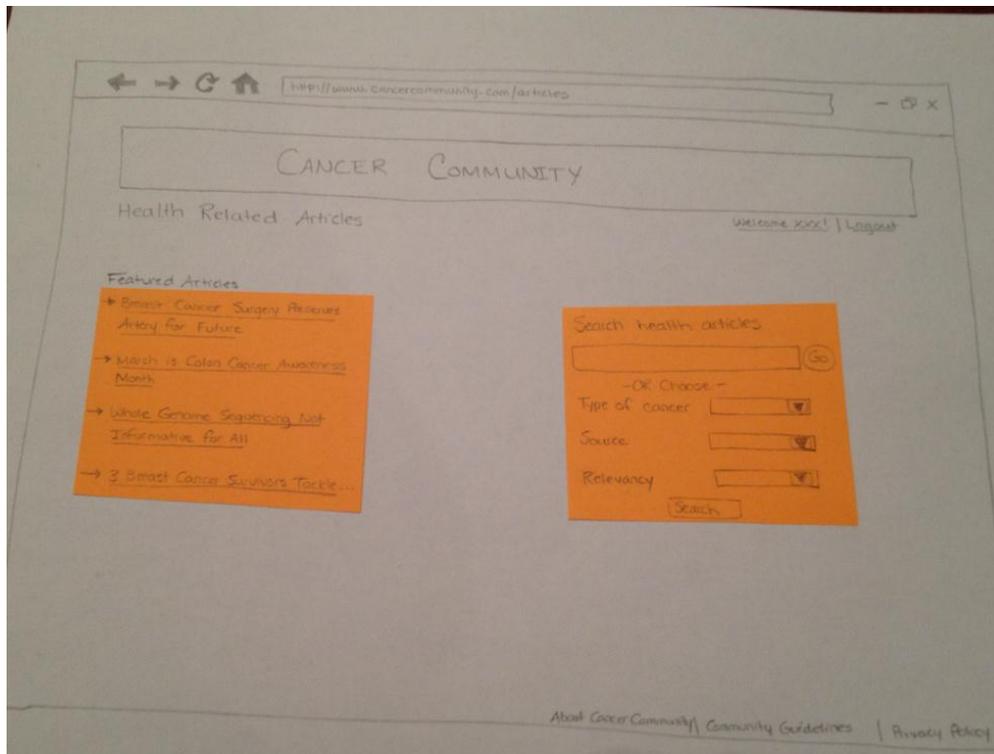


Figure 16. Articles Page

The article search and rating section of the prototype lead to discussions about the ability to incorporate comments along with the star rating system and how it would be helpful to sort through information. This component was added to the prototype to enable users to hold discussions about the content being shared and allow healthcare professionals to share their thoughts and opinions.

Articles should not be biased in any way towards the particular healthcare organization, but rather include an assortment of information from various sources so that individuals can gather information and become more educated about their diagnosis and the treatment options that exist. By providing unbiased and various types of information, this online community would allow individuals to quench their need to gather a plethora of reliable information. Ultimately, the resources should enable individuals to educate themselves, ultimately empowering

themselves to understand their needs and treatment options.

Along with a database of health information articles and resources, social networking elements will exist throughout the community to allow individuals to connect in a safe environment and ask questions, as well as share their personal experiences with others. Based on research done by Rutten et al. (2005), discussion groups should align with the ten information need categories:

1. Cancer-specific information
2. Treatment-related information
3. Prognosis information
4. Rehabilitation information
5. Surveillance and health information
6. Coping information
7. Interpersonal information
8. Financial/legal information
9. Medical system information
10. Body image/sexuality information

And while staff members ought to moderate discussion forums, it is important to allow natural conversations and the ability to share experience-based anecdotes to take place.

Since individuals only see their healthcare professionals for the allotted appointment times and may have questions after, the online community would provide the ability to chat with an advice nurse, or a staff member who is on call to moderate the community during certain time

periods. That way an individual can feel connected to an expert outside of the office. This provides healthcare organizations' with the ability to extend patient care and essentially strengthens patient loyalty. Weekly chats based on relevant topics (e.g. 'managing the side effects of chemotherapy') would also build upon this connection, as doctors would have the opportunity to be available to patients and answer questions. Doctors could also participate within the discussion forums.

During user testing three participants noted that it would be important to them to be able to know who they were speaking with. For example, if they were using the live chat functionality to speak with an advice nurse, they would feel more comfortable if they could see a picture and read background information on the person they are speaking with. This component could easily be featured within the online community for whichever advice nurse or doctor is online.

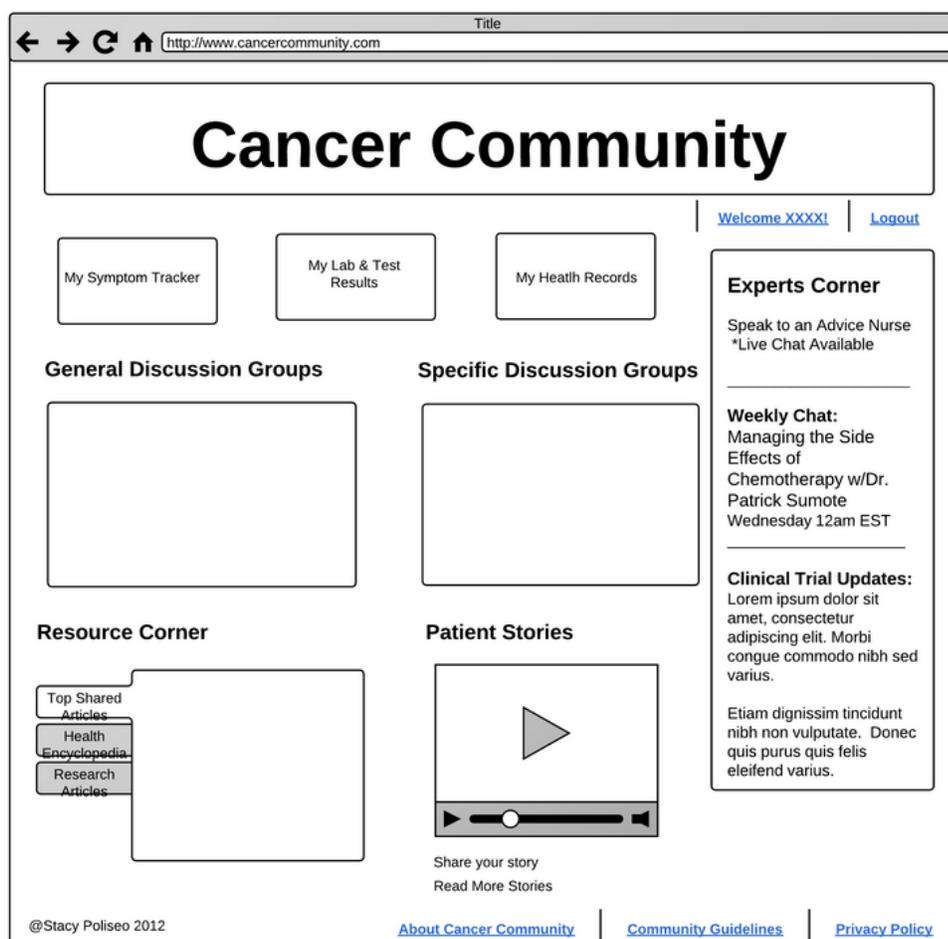


Figure 17. Logged In Page of Cancer Community

While health information and social networking elements are essential to this community, the ability for patients to access their own health records is vital. Electronic health records (EHR) are becoming the standard for healthcare organizations and professionals to have available. In fact, there are laws that will require patient health records to become available electronically to all patients in the next few years. Incorporating a patient's EHR to the online community would enable individuals to access their records, as well as get lab or other test results in a timely manner. This information would be secure and unable to be viewed by others.

To build off the one-stop-shop concept, a symptom tracker would help patients track

symptoms in a place that would be easy to maintain. Symptoms recorded could be printed or emailed, so that they are easily accessible for the next appointment. Users could also share their symptoms within the community if they desired to do so. Sharing symptoms, similar to PatientsLikeMe, could help patients connect with others who are experiencing comparable situations. Test participants liked the option to track their symptoms, but some were more reluctant than others to share among the community. During testing, one user commented that the pain scale on the symptom tracker should be reworded, as not all symptoms are painful. This adjustment would be reflected in the final design.

It would be important for users to understand that this is not a requirement and that their personal information (health records, test results, or symptoms) is stored securely and could not be viewed by anyone within the community. Individuals will have control over their own profile, with the ability to provide as much information as they wish. The option to disclose a patient's condition (e.g. stage 2 breast cancer patient) would be entirely up to them, however in doing so would provide the ability to connect with other patients with a similar diagnosis.

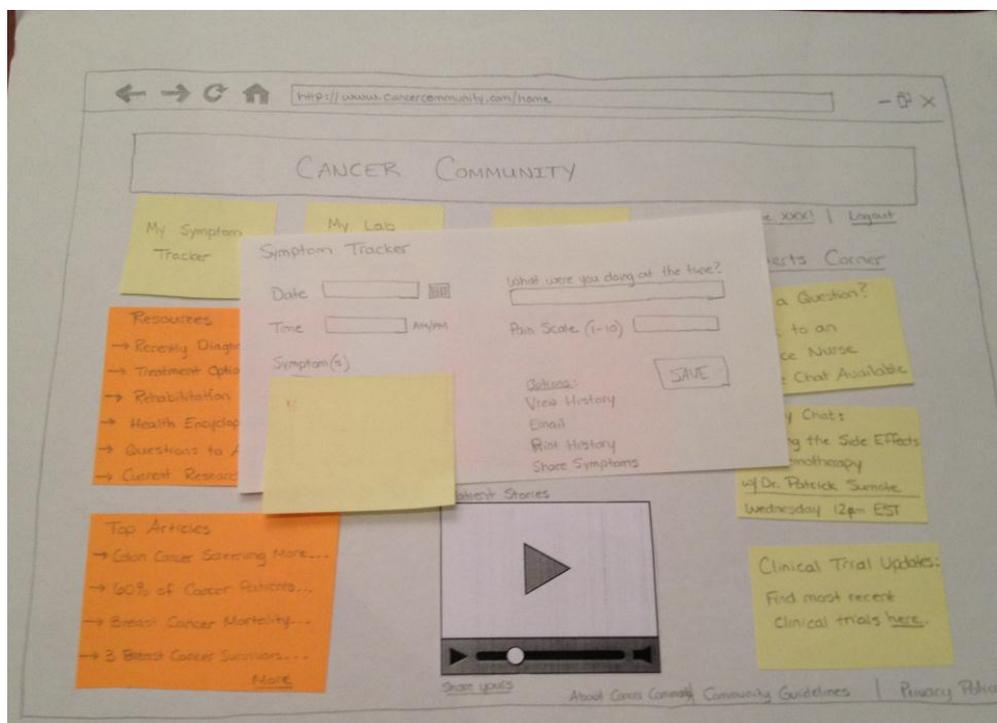


Figure 18. Symptom Tracker

Caregivers and family members can be incredibly influential when dealing with a loved one's diagnosis. Several individuals expressed their desire to gather as much information as possible, since they did not want to burden their loved one with asking too many questions or taking up the doctors' time during a loved one's visit. When participants were asked to seek information for a loved one, a majority of participants wanted to become as educated as possible, one person would even read beyond the current diagnosis to prepare them for the worst if their loved one's condition worsened or treatment failed.

Often times, the caregiver is the main seeker of information and exhibits different needs than patients. They currently have to utilize patient-focused online communities for information, which does not meet all of their needs, especially in terms of support. They, too, need a safe environment to discuss with others who are experiencing similar situations in having to care for a loved one. There may be sensitive issues or topics that they do not want a loved one to read or

know they are feeling. By providing similar resources as the patient community mentioned above (e.g. same resources, articles, etc.) but access to different discussion groups will help satisfy a group that is often left to fend for themselves. It allows both the caregiver and patient to have a safe environment to discuss topics that are important to them.

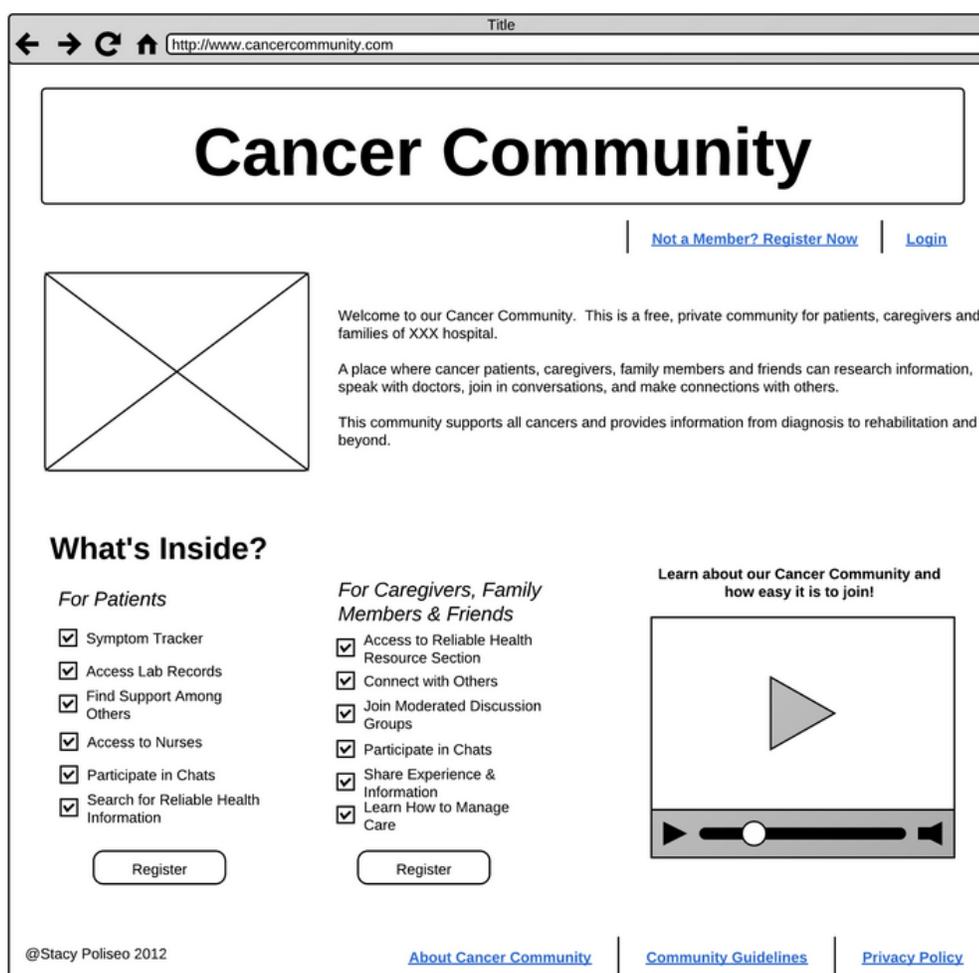


Figure 19. Cancer Community Main Page

Conclusion

Although sample size is somewhat small, this study supports several ideas about how individuals search for and perceive health information online. It reveals the need for individuals

to be scrupulous in their information gathering, particularly when they are seeking health information relating to the health of loved ones, as well as themselves. Ultimately, my research supports the opportunity healthcare organizations have to capitalize on the need to provide in-depth, accurate health information; more contact with healthcare professionals; and a safe environment to connect with others who are experiencing similar diagnoses, particularly those with cancer.

With the increasing availability of health information, there is a notable shift away from traditional health communication that emphasized one-size-fits-all messaging that did not particularly cater to people's personal characteristics or social settings (Neuhauser & Kreps, 2010). In fact, the one-size-fits-all messaging may "provoke negative feelings of fear, embarrassment, and guilt, rather than empowerment (Neuhauser & Kreps, 2010)" and that encouraging a transaction between the sender and receiver is highly beneficial. Taking that into consideration it is important for healthcare organizations to develop communities that consider the individual as a whole and provide them a safe place to communicate and access accurate information.

There seems to be great benefits in having access to information for individuals with cancer. It has been shown "to help patients gain control, reduce anxiety, improve compliance, create realistic expectations, promote self-care and participation, and generate feelings of safety and security (Eysenbach, p 365)." My research shows that the increased number in individuals seeking health information for their loved ones also identifies the potential healthcare organizations have to reach out to family members and caregivers to provide better care and empower them to participate in and support their loved ones treatment and lifestyle choices.

The best health communication approaches are “designed to match the unique characteristics, interests, and cultural orientations of intended target audiences, which means that effective interventions must be strategically designed for clearly segmented, homogenous groups of people (Neuhauser & Kreps, 2010).” Gaining a true understanding about the support needs of patients and caregivers, along with the role of online communities to support them is essential to providing a heightened health care experience. Online communities have been developing at a rapid rate, particularly for those with rare diseases or chronic conditions. Organizations have been created (e.g. PatientsLikeMe) to support this growing trend. And those communities that have been around for awhile continue to thrive, for example, as of August 2003, Yahoo!Groups listed 22,000 support groups in the Health & Wellness section, among them at least 280 cancer groups (Eysenbach, 2003). Today, that number has grown to over 53,500 support groups in the Health & Wellness section, with more than 800 cancer groups.

My study highlights valuable guidelines that healthcare organizations should take into consideration when developing online communities. First, it is evident from this research, as well as previous studies, that visual appeal is crucial. “It’s important to note that *looking* good is often interpreted as *being* good – and being credible (Fogg et al., 2002).” Designers should strive to maintain a professional look for health information, whether it is a website, discussion forum, blog, or patient community. Despite my online survey results where respondents cited references and content completeness as the most important in determining credibility, individuals rely heavily on visual appeal when determining the trustworthiness of a website.

It is recommended that healthcare organizations should strive to build online cancer communities that combine several elements of Health 2.0. This would mean building an environment that provided a combination of accurate health information, a connection to doctors

and nurses in the center (e.g. live chat functionality and weekly discussions with specialists), and the ability to collaborate and connect with others. The ultimate community would enable users to create their own safeguarding methods for protecting against inaccurate information. As the paper prototype identified, users should be given the ability to rate information they read, as well as share and comment on their findings. Essentially, the community would also give patients access to their health records and provide tracking abilities, such as test results and a symptom tracker.

Interfaces should be designed with patient-centered tools that would enable patients to easily find other patients who have similar health experiences, so that they may easily share and exchange information based on their own experiences. “Designers should explore enhancements that will make the expertise of patients more important, explicit, and accessible (Hartzler & Pratt, 2011).” Efforts should be made to facilitate what patient-expertise sharing can offer patients the opportunities to interact with these collaborative technologies in ways that extend beyond the traditional, text-based message boards of the past (Hartzler & Pratt, 2011). Collaboration, sharing and opportunities for discussion should be encouraged throughout the community.

With the online survey results, combined with the eye tracking study, it is apparent that more individuals are seeking health information online and that they are developing methods to filter out the noise. Source credibility is a pivotal factor in determining the quality of digital information. The ability to leverage brand names (e.g. Johns Hopkins or Mayo Clinic), combined with solid visual cues can create a trusted community that healthcare organizations can offer patients, family members and caregivers. Those healthcare organizations that embrace Health 2.0 and move to create communities of this caliber will not only improve patient-doctor

relationships and brand loyalty, but will have the opportunity to take patient-centered care to the next level and become leaders in their industry.

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Appendix

Appendix A: Online Survey Consent Form

Informed Consent Form

Purpose of the Study:

This study is being conducted by Stacy Poliseo, a graduate student at the University of Baltimore. The purpose of this study is to examine how individuals are searching for and utilizing health information (i.e. does it impact treatment decisions?).

What will be done:

You will complete a survey, which will take 10-15 minutes to complete. The survey includes questions about your online behavior regarding health information. It also will ask for some demographic information (e.g., age, marital status, education level) so that we can accurately describe the general traits of the group who participate in the study.

Risks or discomforts:

No risks or discomforts are anticipated from taking part in this study. If you feel uncomfortable with a question, you can skip that question or withdraw from the study altogether. If you decide to quit at any time before you have finished the survey, your answers will NOT be recorded.

Confidentiality:

Your responses will be kept completely confidential. Your IP address will not be recorded when you respond to the Internet survey.

All data collected will be anonymous.

Decision to quit at any time:

Your participation is voluntary; you are free to withdraw your participation from this study at any time. If you do not want to continue, you can simply leave this website. If you do not click on the "submit" button at the end of the survey, your answers and participation will not be recorded.

How the findings will be used:

The results of the study will be used for scholarly purposes only. The results from the study will be published for the completion of a Master's degree.

Contact information:

If you have concerns or questions about this study, please contact Stacy Poliseo at stacy.poliseo@ubalt.edu or Dr. Anastasia Salter at asalter@ubalt.edu.

For questions about rights as a participant in this research study, contact the UB IRB Chair: Dr. Eric Easton, Chair, University of Baltimore Institutional Review Board, [410-837-4874](tel:410-837-4874), eeaston@ubalt.edu.

By beginning the survey, you acknowledge that you are at least 18 years of age, have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time without penalty.

Appendix B: Online Survey Questions

Control variables

- Demographics – age, gender, marital status, level of education
 - Age
 - 18-24
 - 25-34
 - 35-44
 - 45-54
 - 55-64
 - 65+
 - Gender
 - Male
 - Female
 - Education
 - Some high school
 - High school
 - Some college
 - College graduate
 - Professional graduate
 - Community Type
 - Rural
 - Suburban
 - Urban
 - Work Status
 - Employed
 - Unemployed
 - On Leave
 - Retired
 - Do you have a regular health care provider?
 - Yes
 - No
- How often do you use the Internet or email?
 - Several times a day

- About once a day
 - 3-5 days a week
 - 1-2 days a week
 - Every few weeks
 - Less often
 - Never
- In the past 12 months have you use the Internet to do the following activity:
 - Visited a social networking site such as Facebook, Twitter or LinkedIn
 - Read a blog or visited a review site
 - Clicked on an advertisement within a website

Health Information Behavior

1. In the past 12 months have you used the Internet to search for health information pertaining to yourself?
 - a. Yes
 - b. No

2. In the past 12 months, have you researched health information on behalf of a friend or family member?
 - a. On behalf of a family member
 - b. On behalf of a friend
 - c. Neither

3. In the past 12 months, have you looked up health information on one or more of the following health-related websites:
 - a. Health information website (i.e. WebMd, MayoClinic.org, etc.) for symptoms, treatments and more information
 - b. Patient Communities (PatientsLikeMe, Listservs, Disease-specific, etc)
 - c. Websites speaking of alternative medicine/therapies
 - d. Blogs, Videos, Podcasts
 - e. Mobile application

4. In the past 12 months have you participated in an online support group for people with similar health issues?
 - a. Yes
 - b. No

5. If you have visited patient communities, is your participation to (Check all that apply)
 - a. Provide encouragement and/or emotional support
 - b. Seek information on treatments, diagnosis and symptoms

- c. Ask questions regarding personal issues
 - d. Gather information or find resources to present to family, friend or physician
 - e. Do not actively participate, but read others postings and comments
6. After searching for health information, what did you do with the information you found?
 - a. Shared with friend or family member
 - b. Shared with physician
 - c. Decided treatment path
 - d. Changed treatment path
 - e. Nothing
7. If the Internet was used for seeking information on treatment decisions, how reliable did you find that information?
 - a. Very reliable
 - b. Somewhat reliable
 - c. Not reliable at all
8. When browsing the Internet for health information, how do you determine the credibility of a site?
 - a. Visual appeal
 - b. References used
 - c. Content completeness
 - d. User comments/reviews
 - e. An emotional connection
 - f. Presence of a privacy policy or community guidelines
9. Has anyone close to you been diagnosed with cancer?
 - a. Have had a personal diagnosis of cancer
 - b. Have had a family member diagnosed with cancer
 - c. Have had a close friend diagnosed with cancer
 - d. Have had no personal experience or family member with cancer
10. When it comes to making important treatment decisions in cancer what was the most important factor influencing treatment decision?
 - a. Physician recommendation
 - b. Advice from friends and family
 - c. Information obtained from books and journals
 - d. Health information websites
 - e. Patient Communities, blogs, or other types of social networks
11. If your doctor recommended a social network site to join for caregivers or patients pertaining to a specific diagnosis, would you join?

- a. Strongly agree
 - b. Agree
 - c. Undecided
 - d. Disagree
 - e. Strongly disagree
12. In the past 12 months have you downloaded a mobile application(s) pertaining to health information?
- a. Yes
 - b. No

Appendix C: Informed Consent Form

Purpose of the Study:

This study is being conducted by Stacy Poliseo, a graduate student at the University of Baltimore. The purpose of this study is to examine how individuals are searching for and utilizing health information (i.e. does it impact treatment decisions?).

What will be done:

In this session, you will complete a short pre-test survey, which will ask for some demographic information (e.g., age, marital status, education level) as well as your current Internet use. This information is collected so that we can accurately describe the general traits of the group who participate in the study.

The next phase will be to participate in a 15-20 minute eyetracking study, which will explore how users search for health information. The session will be recorded to assess how you interact with different types of health information. For this session, your face, actions and voice will be recorded to assess how you interact with different types of health information.

At the end of the test participants will work with a paper prototype of a patient social networking website. This session will be videotaped capturing your voice, hands and interaction with the "computer."

Check if images or video are recorded during the research study:

- Yes, I give permission to use my image in scientific publications or presentations.
- No, I do not give permission to use my image in scientific publications or presentations

Check if voice recordings are used during the research study:

- Yes, I give permission to use my voice in scientific publications or presentations.

No, I do not give permission to use my voice in scientific publications or presentations

Risks or discomforts:

No risks or discomforts are anticipated from taking part in this study. If you feel uncomfortable with a question, you can skip that question or withdraw from the study altogether. If you decide to quit at any time before you have finished, your answers will NOT be recorded.

How the findings will be used:

The data collected during this session including photos, videos and audio will primarily be used for the purpose of improving patient communities for my thesis project.

The results of the study will be used for scholarly purposes only. The results from the study will be published for the completion of a Master's degree.

Contact information:

If you have concerns or questions about this study, please contact Stacy Poliseo at stacy.poliseo@ubalt.edu or Dr. Anastasia Salter at asalter@ubalt.edu.

For questions about rights as a participant in this research study, contact the UB IRB Chair: Dr. Eric Easton, Chair, University of Baltimore Institutional Review Board, [410-837-4874](tel:410-837-4874), eeaston@ubalt.edu.

By signing below, you acknowledge that you are at least 18 years of age, have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time without penalty.

Signature

Printed Name/Date _____

Address

City, State & Zip _____

Email Address _____

Appendix D: Pre-Test Questionnaire

Name (Last Name, First Name): _____

What category below fits your age?

- 18-24

- 25-34
- 35-44
- 45-54
- 55-64
- 65 or older

What is your gender?

- Male
- Female

What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree
- High school degree or equivalent (i.e. GED)
- Some college but no degree
- Associate degree
- Bachelor degree
- Graduate degree

What type of community do you live in?

- Rural
- Suburban
- Urban

What is your current work status?

- Employed
- Unemployed
- On Leave
- Retired

Do you have a regular health care provider?

- Yes
- No

How many hours per week do you use the Internet?

- Several times a day
- About once a day
- 3-5 days a week
- 1-2 days a week
- Every few weeks

- Less often
- Never

In the past 12 months have you used the Internet to do the following activity: (Circle all that apply)

- Visited a social networking site such as Facebook, Twitter or LinkedIn
- Read a blog or visited a review site
- Clicked on an advertisement within a website

In the past 12 months have you used the Internet to search for health information pertaining to yourself?

- Yes
- No

In the past 12 months, have you researched health information on behalf of a friend or family member?

- On behalf of a family member
- On behalf of a friend
- Neither

In the past 12 months, have you looked up health information on one or more of the following health-related websites:

- c. Health information website (i.e. WebMd, MayoClinic.org, etc.) for symptoms, treatments and more information
- d. Patient Communities (PatientsLikeMe, Listservs, Disease-specific, etc)
- e. Websites speaking of alternative medicine/therapies
- f. Blogs, Videos, Podcasts
- g. Mobile application
- h. Other _____

Appendix E: Test Script

User Testing Script

“Thank you for coming. I’m Stacy Poliseo, a graduate student at the University of Baltimore. I am currently conducting research on user-generated content and its impact on how individuals find and search health information.

We will be going through two phases of this test. The first will last about 15-20 minutes and will consist of an eye-tracking study. During this session, I will give you some tasks that might be representative of what people might do in real life. These tasks will be recorded.

The second phase will last about 10-15 minutes. We will be working with a paper prototype. I will be “playing the computer,” but the interface has the same functionality as a regular computer.

The interface we are testing today is an online community for individuals diagnosed with cancer, as well as their caregivers. Keep in mind that it is the interface being tested, not you!

The purpose of today’s session is for you to help us figure out how to make this interface more user-friendly before we move to the next steps of developing.

Similar to the eye-tracking study, I will give you some tasks that might be representative of what people might do in real life. Your job is to tell us what you think – does it make sense, does it do what you’d expect it to?

With your consent, I will be recording this session. For the eye-tracking portion your face, actions, as well as your voice will be recorded. During the paper prototype, videotaping will capture your voice, hands and your interaction with the “computer.”

Do you have any questions about what we’ll be doing today?

Eye-tracking Tasks

Task #1: Free Search

Goal:

To determine what site a user will go to when given no guidance as to what type of content to search for.

Steps:

- Start at Google.com
- Conduct search as determined by user

Instructions for Users: “Your mother was recently diagnosed with Stage 2 Breast Cancer. You want to determine what types of treatment options are available. Conduct a Google search.”

Task #2: Health Information Websites

Goal:

Learn more about treatment for Colorectal Cancer.

Steps:

- WebMd - <http://www.webmd.com/default.htm>
- Mayo Clinic - <http://www.mayoclinic.com/>
- Johns Hopkins Medicine - <http://www.hopkinsmedicine.org/healthlibrary/>

- NIH - <http://www.nih.gov/>

Instructions for Users: “This task will look at four different websites containing health information. You are looking to learn more about treatment options for colorectal cancer within each site. As you search, please share your thoughts about the information you come across.”

Task #3: Patient Communities

Goal:

Familiarize with several patient communities for bone marrow transplant patients

Steps:

- Search for ‘Bone Marrow Support’
- Choose two different online communities
- Discuss differences/credibility

Instructions for Users: “You are trying to connect with others who have had bone marrow transplants. Google the term ‘bone marrow support’ and select an online community. Peruse the community. What do you think? Is this a trustworthy site? Would you participate in a community like this? Why? Revisit your search and select a second online community. Answer the same questions.”

Task #4: Pharmaceutical Website

Goal:

Steps:

- Google search “Neulasta”
- Visit: <http://www.neulasta.com/>
- Choose one other site to visit

Instructions for Users: “Your father is just about to start chemotherapy treatments. You want to learn more about the drug he will be taking, called Neulasta. Conduct a Google search on “Neulasta” – visit both the pharmaceutical site: <http://www.neulasta.com/> and choose another site of your choice to learn more about the drug. Which site are you more likely to trust?”

Task #5: Homeopathic Website

Goal:

Identify alternative cancer treatments.

Steps:

- Google ‘Alternative cancer treatments’

- Browse search options

Instructions for Users: “A friend has told you about a success story she once heard about someone using alternative cancer treatments. Your mother was just diagnosed with breast cancer. Google ‘alternative cancer treatments’ and determine if you would recommend any of these treatments to your mother.”

Paper Prototype Tasks

Task #1: First time on site

Goal:

Learn about how the staging of cancer is decided

Steps:

- Click “Patients”
- Register/Log in
- Select ‘New to Cancer’
- Click on ‘Staging’

Instructions for Users: “You have recently been diagnosed with liver cancer and want to learn more about how the staging of your diagnosis was determined. Since you are new to this site, you will need to begin at the home page.”

Task #2: Medication Question

Goal:

To ask a nurse on-call if allergy medication can be taken during chemotherapy treatments.

Assumptions:

User is already logged in

Steps:

- Click on ‘Experts Corner’
- Click ‘Ask an advice nurse’
- Ask question via live chat functionality

Instructions for Users: “With spring arriving, your allergies have kicked into high gear. In the past, you’ve always taken Claritin. However, you have just started chemotherapy treatments and can’t remember if the doctor or nurse had advised against taking any over-the-counter medications. You want to ask a nurse on call.”

Task #3: Rate an article

Goal:

Rate a medical article you found useful.

Assumptions:

User is already logged in

Steps:

- Starting on home page, find resource section
- Search medical articles
- Choose a medical article
- Rate article

Instructions for Users: “You were given a few treatment options for combating brain cancer and want to learn more about them. You turn to medical articles and want to let others know if you found one in particular helpful.”

Task #4: Track a new symptom**Goal:**

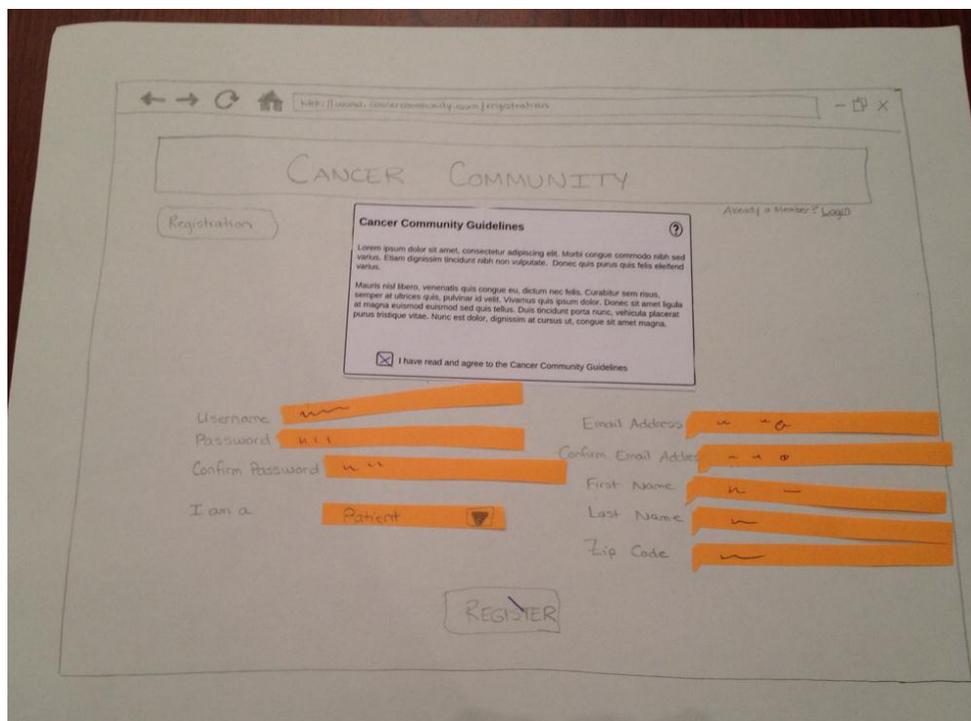
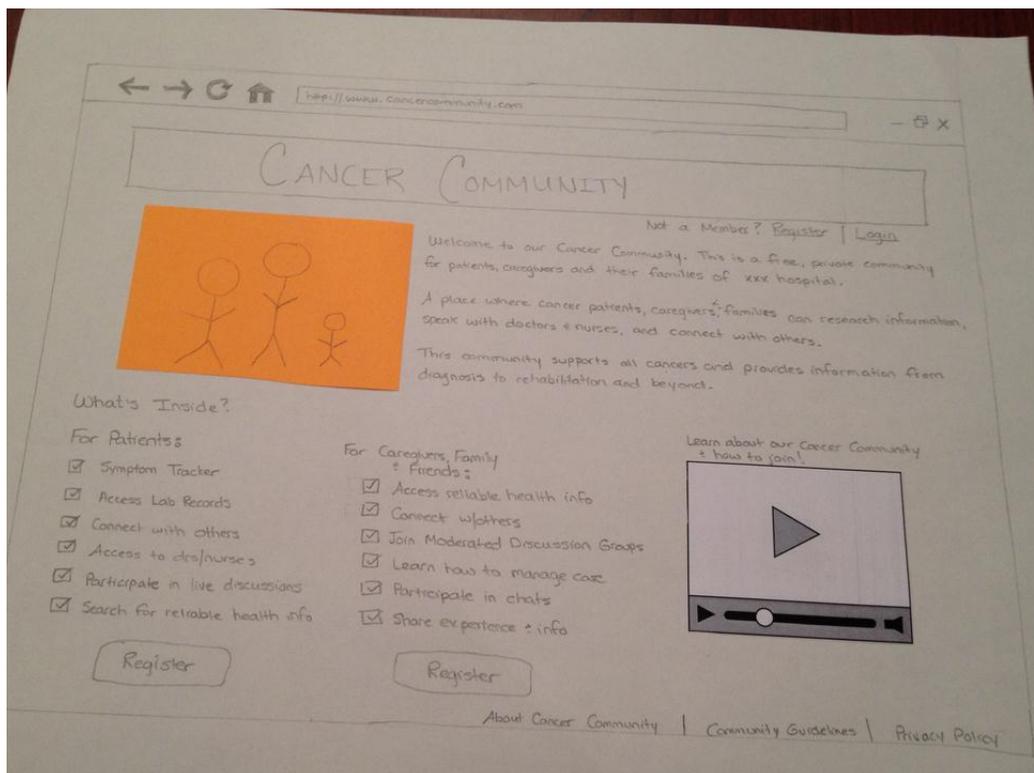
To track a new symptom for your next appointment

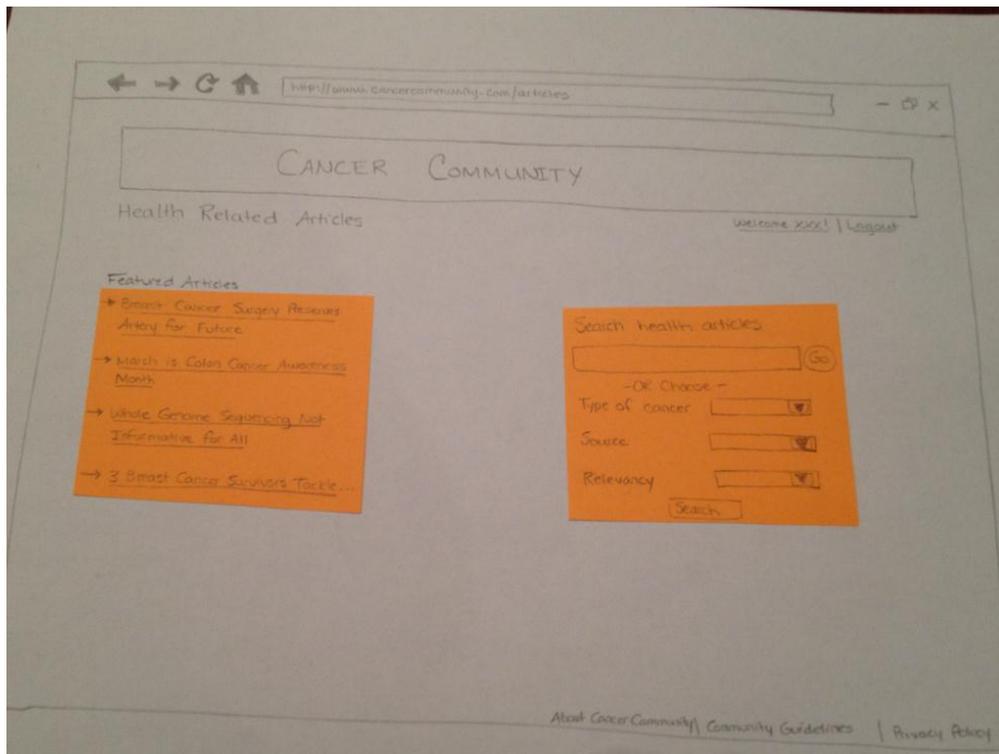
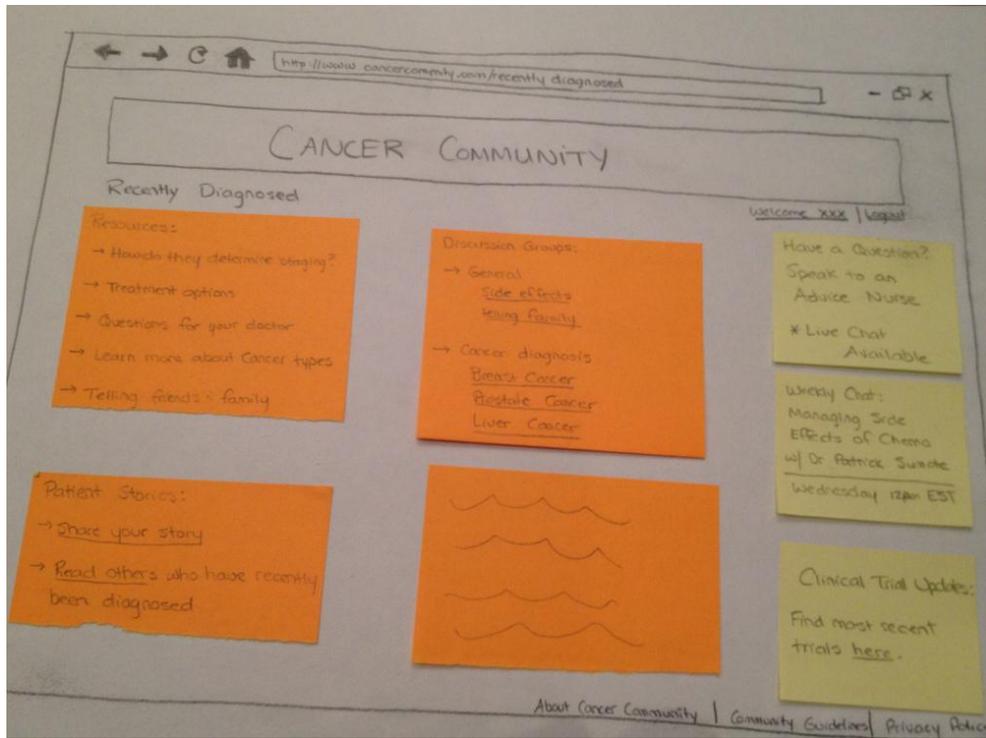
Steps:

- Click “My Corner”
- Click ‘Symptom Tracker’
- Record newest symptom

Instructions for Users: “You woke up with an incredibly dry mouth and want to make sure you let your doctor know at your next appointment. Use the symptom tracker to record this symptom.”

Appendix F: Paper Prototype



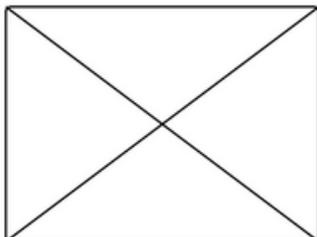


Appendix G: Wireframes

Title
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Cancer Community

[Not a Member? Register Now](#)
[Login](#)



Welcome to our Cancer Community. This is a free, private community for patients, caregivers and families of XXX hospital.

A place where cancer patients, caregivers, family members and friends can research information, speak with doctors, join in conversations, and make connections with others.

This community supports all cancers and provides information from diagnosis to rehabilitation and beyond.

What's Inside?

For Patients

- Symptom Tracker
- Access Lab Records
- Find Support Among Others
- Access to Nurses
- Participate in Chats
- Search for Reliable Health Information

Register

For Caregivers, Family Members & Friends

- Access to Reliable Health Resource Section
- Connect with Others
- Join Moderated Discussion Groups
- Participate in Chats
- Share Experience & Information
- Learn How to Manage Care

Register

Learn about our Cancer Community and how easy it is to join!



▶▶

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[About Cancer Community](#)
[Community Guidelines](#)
[Privacy Policy](#)

Title
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Cancer Community

Registration

[Already a Member? Login](#)

Cancer Community Guidelines ?

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I have read and agree to the Cancer Community Guidelines

Username

Password

Confirm Password

I am a

Email Address

Confirm Email Address

First Name

Last Name

Zip Code

@Stacy Poliseo 2012

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 [Community Guidelines](#) |
 [Privacy Policy](#)

← → ↻ ⤴ <http://www.cancercommunity.com> Title

Cancer Community

[Welcome XXXX!](#) | [Logout](#)

My Symptom Tracker

My Lab & Test Results

My Health Records

General Discussion Groups

Specific Discussion Groups

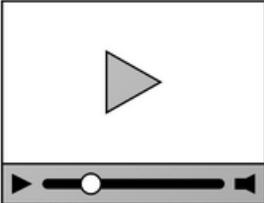
Resource Corner

Top Shared Articles

Health Encyclopedia

Research Articles

Patient Stories



Share your story
Read More Stories

Experts Corner

Speak to an Advice Nurse
*Live Chat Available

Weekly Chat:
Managing the Side Effects of Chemotherapy w/Dr. Patrick Sumote
Wednesday 12am EST

Clinical Trial Updates:
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