Social Media and Electronic Health Records:

Connecting Patients & Providers

By

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Abstract

Can the technology and understanding developed from social networks improve patient outcomes by providing a more reliable, complete, and easier way for patients and providers to communicate with each other? What areas of patient-provider and provider-provider communications must be first addressed before attempting to implement the principles of social networking in health care?

This study provides preliminary answers to such questions by triangulating methods – including a web-based survey of providers, paper surveys of patients, in-depth interviews of elite stakeholders, and a systematic review of the literature – to generate a conceptual model of how to integrate social networking principles into current and future EMR systems. In all cases, I focused my questions on beliefs about social networking, the willingness on providers' and patients' parts to use alternative means of communicating about health, and the economic and political challenges associated with extending the use of electronic medical records (EMRs).

My main findings are that both patients and providers express an overall high interest in using EMR systems that utilize principles of social networking to help them communicate with each other and manage medications and track health measures. Providers are wary of traditional forms of social networking, likely because of privacy concerns, but are interested in new ways to communicate with their patients. Finally, although there are significant age and education differences among patients who use traditional Internet technologies, there is evidence that among those who do have Internet access, social networking may be a more equitable avenue of communication with patients.

I conclude by suggesting a conceptual model that provides a picture of how the principles of social networking could be applied to current and future expectations for EMRs.

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Introduction

People all over the world are experiencing a tremendous shift in the way they communicate. The ever-increasing affordability and availability of technology has created paths of communication that previous generations could not have even imagined. Whether it is parents texting to check in with their children, or an Egyptian using Facebook to ignite a revolution – the early years of this new information age are proving that its influence will reach every part of our lives.

In the United States, as of this writing (June 2011), the most visited web site is Facebook.com.[1] Here, anyone can keep track of a huge network of friends, their photos, what they are doing, and any other information they care to share. The data are organized, secure, real-time, mobile, and easy to use. However, when it comes to health care in the United States, much of the communication between doctors and their patients comes in the form of faxes, voicemails, and sticky notes. Despite strong recent pushes to adopt electronic health record systems, we still lack any specific standard, or even a dominant platform for unifying critical health data across providers. Even in large academic hospitals and wealthy group practices with expensive electronic medical records systems, communication between health care providers is too often disjointed and inefficient.

Why, then, is there such a lag in the communication technology of an industry that makes up over 17 percent of the nation's gross domestic product, consuming more than 2.5 trillion dollars a year?[2] The goal of this paper is to explore the history and current use of communications technology in the health care industry by reviewing the literature and engaging in a small, preliminary, triangulated query of stakeholders' desires and expectations – including in-depth interiviews with representatives of industry, and small pilot surveys of provider and

patient opinions about electronic health communication. These initial interview and survey findings, anchored by the context offered by the literature, generate a proposal for a new conceptual model, with which this paper concludes. The present study is neither all encompassing nor definitive; it will however provide a snapshot of the attitudes and opinions of North Carolina patients and their primary care providers regarding the integration of social networking tools into patient care. Additionally, in-depth interviews with elite stakeholders further bolster the literature investigation of EHR policy, while also providing information to gauge the contrast in desires and beliefs of patients and providers. The backgrounds of the stakeholders range from executives at EHR corporations, to hospital administrators, to researchers in the field of health information technology; the views of these stakeholders can provide a broader illustration of the current industry outlook on social media and health care.

The final aim of this paper will be to use data from all these sources to develop a conceptual model of how a socially connected EHR may operate in the context of a 'medical home.' Both medical homes and EHRs have been promised to improve efficiency and create cost savings, however, their true potential will only emerge when it is recognized that an entirely different paradigm for how providers and patients communicate with each other within the EHR and medical home must be developed. I apply a modified theoretical framework for social networking in education and training to social networking in medical practice. Just as social networking is shifting the way we as humans teach, train, and disseminate knowledge, this framework will provide a guide in which it to develop the policy, tools, and infrastructure needed to ensure that we may successfully apply similar tools to revolutionize the way patients interact with their providers and each other.

Theoretical Framework

The rise of online social networks, and the evolution of the Internet towards what is called "Web 2.0" is continuing to subtly but profoundly change the way we as humans are communicating, accessing information, and learning from each other. The rate in the development of these technologies and trends is incredible, quickly outpacing the development of theoretical frameworks for understanding their effect on various realms of social interactions.[3]

Recognizing this situation, Gunawardena et al developed a theoretical framework for 'building online communities of practice with social networking tools.'[3] This framework, although designed specifically to better understand social networking in the field of education, is perfectly suited to provide the foundation for developing a theoretical framework to investigate the role of social media in medicine. Much of medical practice, like the field of education, is about creating environments in which physicians can educate, inform, and instill the tools that a patient needs to better protect their own health. Also like education, those placed in the traditional roles of teaching (see: physicians) often have much to learn from those traditionally being taught (see: patients). This concept of omnidirectional information flow between actors in a shared learning environment is what lies at the core of the education model, "communities of practice" (CoP). As defined by Wenger, McDermott and Snyder, communities of practice are "groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis." [4 (p4)] This definition sounds like a paragon of how physicians and patients operating in a medical home practice should relate to one another. Given this obvious transferability, I will use the foundation laid by Gunawardena et al to develop my own framework within which can be applied the fundamentals of social networking, in the context of the model of a medical home.

The notion of the "medical home" is a relatively new one in the field of medicine -- one that has been derived to try and solve the growing problem of a disparate and confusing network of specialists and primary care physicians that are involved in an individual patient's care. In brief, the medical home seeks to give the responsibility of managing a patient's overall care and interaction with all of their specialists to one primary care office. This office would act as the "hub" of this patient's care -- a centralized area through which all of the information and data generated from patient care flows. It has been surmised that this organizational form will help end confusion among patients and providers regarding medication management, decrease duplication of services and tests, and create generally more efficient, safer care.

There is a general agreement that electronic health records will play a vital role in the implementation of any medical home. This paper takes as a given that EHRs will become the absolute most important part of any such endeavor. Indeed, with the proper development of an EHR system that utilizes social networking and the fundamentals of Web 2.0, such a system could act as a 'virtual' medical home. Leveraging open, secure, standardized forms of online communication, this system would seamlessly forward and direct the flows of information that come from the patient, her specialists, pharmacists, and other care providers directly to the primary care provider, and allow the proper types and amounts of the information from each of these sources to be available, in turn, to the others.

Wikis are a new fundamental construct that has emerged as part of the Web 2.0, and allow for the creation and editing of data in an online space collaboratively by a number of users. The edits made by these users are typically tracked and always linked to them, and allow for users to view and manage any and all revisions in the space. As shown in Figure 1 below,

Gunawardena et al places wikis at the base of a theoretical framework for social networking in teaching; similarly, we will put the EHR itself as the basis of the theoretical framework.
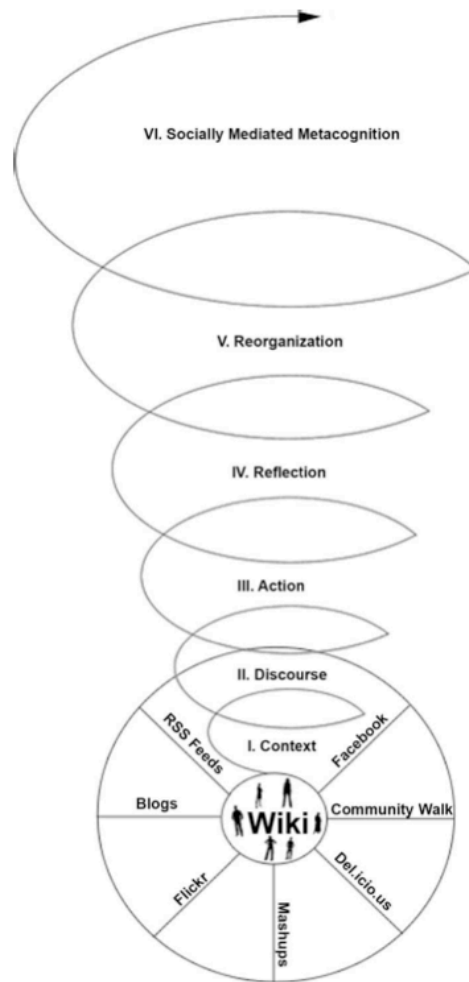
Figure 1 – Gunawardena's Theoretical Framework for Social Networking in Teaching[3(p12)]

Much like wikis, the EHR is a repository of knowledge that is constantly updated and changed by a variety of actors involved in the care of a patient. It is the foundation upon which all social tools should be integrated into the care of the patient. Therefore, centered on this foundation should be the various social tools that can allow both patients and providers to interact with each other and with the EHR. In the learning community, Gunawardena et al specify already existing tools, such as Facebook, blogs, and del.icio.us.[3] However, as discussed later in this paper, health care requires the development of tools that are uniquely sensitive to the

particular needs of providers and patients. The path upward from the base of the wiki and the connected social networking tools is one that Gunawardena et al use to illustrate the stages of learning in the 'communities of practice' theory.[3] This is the perfect parallel for the type of patient-centered education and care that takes place in a medical home. As patients become involved in their own care at a deeper level, their ability to learn about their conditions will continuously encourage proactivity in their actions to manage their health. As they continue to visit other specialists and providers who are also socially incorporated into their care, the group maintains a much higher level of "socially-mediated metacognition" in the understanding of a patient's care.

In this manner, we have now connected existing development of theoretical frameworks in the field of education and 'communities of practice' with the core fundamentals of the medical home, and we have recognized that at some level, the medical home will by necessity be a virtual entity that manages data and connections between individuals, much like todays already existing social networks.   Figure 2 below illustrates a framework for how social networking tools could interact in the medical home EHR. The tools are represented as distinct, yet connected, demonstrating that different actors in the medical home will have different levels of access to change and view a patient's medical data. At the center of the home is the patient, whom primarily communicates with a primary care provider, who has access to all of the patient's separate specialist data. The patient also has access to a limited subset of data that flows from all of her providers, along with the ability to insert new data into the stream.
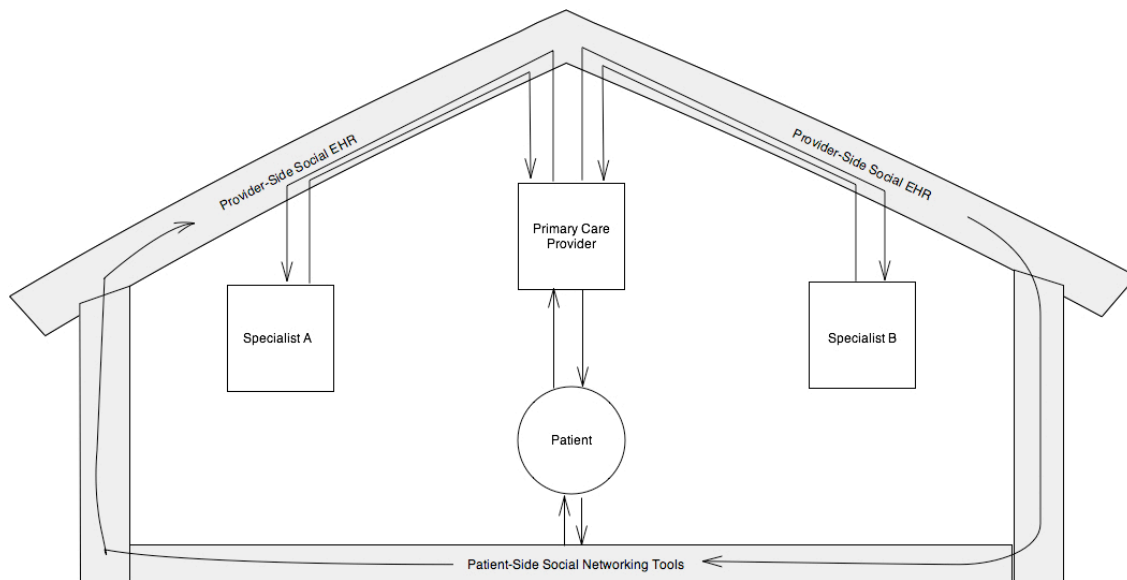
Figure 2 – Conceptual Representation of Data Flow in a Socially ConnectedMedical Home EHR

This is the basis from which to develop a new theoretical framework that will guide our understanding and research efforts in how new technologies and trends will shape the future of medical practice.

Time and resource constraints prevent this paper from making the full investigation of whether the implementation of such a change in patient-provider communication patterns will improve outcomes. Nevertheless, before such an investigation can take place, it is important to review the literature for any research that that already incorporates the Web 2.0 or social media principles that lie at the foundation of this framework. It is also important to investigate the likelihood that patients, providers, and stakeholders of current EHR technology would embrace and use such a system, and whether they are willing to devote the necessary time and resources to do so. The quantitative aim of this paper seeks to gather data to answer these questions, such that the findings can be applied to further developing a model for improved communication in the health care system.

Weighing the Evidence: Review of the Medical Literature

Background

Electronic health records (EHRs) are computerized medical information systems that collect, store, and display patient information.[5] Over the past ten years, the development and implementation of EHRs has been rapid. However, when compared to the spread of other information technology shifts of the past few decades, such as email and social networking, its acceptance and implementation has been slower, more difficult, and more fragmented. The idea of combining the principles of social networking and the Web 2.0 is relatively new, but examples in the literature of efforts to do so have become more prevalent over the past two years. Indeed many such research endeavors have done so without specifically stating that goal.

Social networking is part of a broad change in the way people are communicating over the Internet that is encompassed in the term "Web 2.0." In the most general sense, Web 2.0 is used to describe a broad shift in how people are communicating via the Internet from a way that has traditionally been relegated to just consuming information, to a much more interactive way that involves creation, collaboration, and sharing. By shifting the amount of information and the ability to put that information onto the Internet from the hands of a few, to anyone with an Internet connection, Web 2.0 has given anyone in the world the ability to become an influence on the collective global consciousness.

Certain technologies and principles that have made this shift possible. Going from an Internet that required significant time and resources to publish content and attain a following, to one that simply requires a cell phone, required changes in both technology and the way information is collected, defined, and shared. Some of the most important changes in technology that have catalyzed this shift in the way people are communicating are:

- The shift to wireless Internet using Wi-Fi and cell phone networks

- Improvements in battery, processor, camera, and display technology to allow the mobile access to the Internet using smartphones, netbooks, and tablets.

- Lower cost Internet connected devices

- Open web standards and protocols such as XML, Javascript, and HTML5.

Also, a new set of principles have emerged among successful online services that have changed not only the business models of digital communications, but the way in which people interact, discover, and share information. Many companies and services such as Google, Facebook, Twitter, YouTube, and Digg and are leaders in creating this change. From personal research and study in Lackey and Glassman's lectures[6], some of these principles include

- Free services provided with or without advertisements

- Using an individual's actual identity and confirming it

- "Tagging" data – using user info, metadata

- Wikis - collaboration on a single website with author and history tracking

- Online service application programming interfaces (APIs)

- Curating data for quality and integrity

- Mobile "apps" for various Internet connected services

- Location-aware services

- Harnessing the power of large group input to push info up or down in its online visibility

- Storing personal data in the "cloud" and not on a personal device.

- Customizability of web presences and profiles

- Subscriptions to data feeds and pushing relevant data

- Commenting on other users data and comments.

The purpose of this literature review is to find instances where the technologies and principles described above have been studied in conjunction with health care. The emerging status of social media along with the fluidity of how its principles may be applied in the health care setting made this systematic review an especially challenging one. Therefore, the review was carried out more specifically to understand the various methods and results that have been found from applying the principles of social networking to an electronic health record, or another form of electronic communication, in regards to the communication between health care providers and patients in an ambulatory care setting.

Search Strategy

The first step in developing a search strategy for this review was to create a list of synonyms for what is actually being studied. Because the field of electronic health information technology is still very much emerging, there are several synonyms being used to describe the same or very similar systems. Electronic Medical Records (EMRs) and Electronic Health Records (EHRs) have become interchangeable terms in most health informatics.[5(p1)] The Office of the National Coordinator for Health Information Technology (ONC) agrees that although these terms are being used interchangeably, the term electronic *health* record goes much further in expanding the scope of the term to include a focus on the total health of the patient.[7(p2)] Additionally, they see EHRs as broader than EMRs in that they are designed to create a flow of information that is much more patient oriented, allowing medical information to be shared between all providers involved in a patient's care, and including the patients themselves.[7(p2)] The term EHR, as ONC defines it, is a much more appropriate term for what this paper seeks to study

because it takes the perspective that the patient and their health care providers are a team, and that they are connected socially, and should therefore be connected electronically.

Another term that often misunderstood is the Personal Health Record (PHR). A PHR is simply a patient's personal record of their health information, whether it is paper or computerized. However, with the advent of web portals that access EMRs and allow patients to access and store their personal health information, PHRs are increasingly becoming synonymous with such web portals. The online linking of a PHR via a web portal to an EMR is actually where the lines begin to blur between all of these definitions. Based on the ONC's definition of the EHR, one could say that a PHR that gives a patient access to their personal health data in the EMR as well as a way for them to communicate with all of their health providers actually *is* and EHR. Therefore the searches that I used for this systematic review used the terms EMR, EHR, and PHR tied together with OR statements to gather the broadest set of health information systems that may allow patient-provider interactions.

After determining the synonyms for the systems to be studied, the next step was to determine what sets of technologies and principles from social networking to add to the search so as to generate a relevant, yet empirical set of research to review. After much preliminary searching through the literature, I found that although there are many articles that tout social media and social networking as important in the future of health care, there are few to none that actually represent and empirical, quantitative, research study on how such changes in communication between patients and providers may affect health outcomes. Instead, I often found studies that analyzed certain technologies or principles that lie under the general shift to a more "Web 2.0" way of communication between patients and providers. Perhaps most common among these was using new mobile technologies, such as smartphones and SMS messaging to

relay small bits of data between patients and providers. Another common theme was using

online interfaces, not only as a PHR to store and view patient data, but as a place where patients

can communicate with their providers, upload data, and be a contributor to the online

conversation. This difference between passively viewing data online and actively contributing is

the fundamental difference between "Web 1.0" and "Web 2.0" and is most often embodied

through services like Facebook and Twitter. Therefore, the search strategy sought to tie together

the synonyms for electronic health information systems with those of mobile technologies and

social networking to find instances in research where such modalities have come together. This

led to the following search strategy in PubMed:

(("electronic health record" OR "EHR" OR "electronic medical record" OR "EMR" OR

"personal health record" OR "PHR" OR "health communication") AND ("social media"

OR "social network" OR "social networking" OR "facebook" OR "twitter" OR "tweet"

OR "mobile communication" OR "mobile device" OR "smartphone" OR "iPhone" OR

"text message" OR "SMS" OR "Web 2.0")) OR (("Patient-Centered Care"[Mesh] OR

"Ambulatory Care"[Mesh] OR "medical home") AND ("social media" OR "social

network" OR "social networking" OR "facebook" OR "twitter" OR "tweet" OR "mobile

communication" OR "mobile device" OR "smartphone" OR "iPhone" OR "text message"

OR "SMS" OR "Web 2.0"))

This search method used a strategic set of terms designed to gather studies that had

incorporated the most popular social networking outlets, such as Facebook and Twitter, as well

as studies that may have centered on mobile communications or personal health records. These

terms were then combined with terms that represent EHRs to find where such principles had been integrated into patient-provider communications regarding the health record. Finally, an "OR" statement including the MeSH terms: "patient centered care," "ambulatory care," and "medical home" were included because the utilization of EHR technology is a central tenet of the medical home and the push for better patient-centered care. Finally, an additional search was performed of the electronic database of the Journal of the American Medical Informatics Association (JAMIA) using the term "social network OR PHR" to retrieve additional articles that may have been recently published but not yet deposited into PubMed.

Selection Criteria

Studies identified using the above strategy had to meet the following additional selection criteria to be included in the literature review:

- articles written in English ,
- articles accessible using the UNC libraries journal subscriptions,
- article focused on electronic patient-provider communications that could be feasibly incorporated into an EHR, and
- articles produced empirical data (either qualitative or quantitative) regarding the findings of their study.

Articles that only focused on EMR/EHR research among health care providers were excluded. Further, articles that were non-empirical or editorial in nature, or only discussed patient education or individual patient management of health data were excluded.

Search Results

This PubMed search above yielded 83 articles. After reviewing the titles and abstracts of each of these articles, five met the selection criteria above for full review. Additionally, the JAMIA search yielded 67 articles, and after a close review of all of the titles and abstracts, two met the selection criteria and were added to the review. An overview of the seven articles is presented in Table 1.

Table 1 - Summary of Systematic Review Articles

Author / Location of Data Collection	Description & Principle(s) Studied	Type of Research (Qualitative / Quantitative)	If qualitative		If quantitative		Overall Conclusions	Quality (good, fair, poor)
			Number of cases	Data Collection Methods	Sample size	Data Collection Methods		
Slagle et al.[8] **U.S.A**	Child-centered medication management. 1) Online patient data storage and access 2) Mobile messaging via SMS	Quantitative / Qualitative	202 parents of children who had chronic medication needs	Online quiz	202 parents of children who had chronic medication needs	Open ended questionnaire	Initial pilot yielded a strong endorsement from parents. No evidence to show superior to traditional medication management.	Fair
Wangberg et al.[9] **Norway**	Three Internet-based studies: Diabetes self management, smoking cessation, online PHR 1) Online patient data storage and access 2) Mobile messaging via SMS 3) Tailored online content	Quantitative			Study 1 (diabetes) – 90 registrants Study 2 (smoking cessation) – 2884 registrants Study 3 (PHR) – 410 registrants	Questionnaires	High attrition rates among internet-based interventions. Self-efficacy is an important factor for engaging and maintaining health behaviors. Use of tailored emails and website content increased adherence. Emailed post-assessment reminders increased intervention use.	Poor

Table 1 continued - Summary of Systematic Review Articles

Author / Location of Data Collection	Description & Principle(s) Studied	Type of Research (Qualitative / Quantitative)	If qualitative		If quantitative		Overall Conclusions	Quality (good, fair, poor)
			Number of cases	Data Collection Methods	Sample size	Data Collection Methods		
Lyles et al.[10] U.S.A. Washington	Collaborative care diabetes management 1) Online patient data storage and access 2) Multi-platform (smartphone & game console) 3) Mobile messaging via push email 4) Tailored online content	Qualitative	8 enrolled diabetic patients	Thematic analysis of semi-structured interviews.			Patients found value in tracking glucose trends, better communication, and increased health awareness. However, the technology was often frustrating or difficult to use. Online communications should support an existing relationship.	Fair
Winkelman et al.[11] Canada Toronto	EMR integrated PHR for patients with IBD 1) Online patient data storage and access 2) Personalized support and online content 3) Patient-driven online communication 4) Patient customizable interface	Qualitative	12 patients with IBD of at least one-year duration	In-depth interviews and focus groups.			The patient involvement with the EMR must be more broad and involved than just a "web portal" – four themes emerged from the data that encompassed patient-perceived usefulness: illness ownership, patient-driven communication, personalized support, and mutual trust between patients & physicians.	Good

Table 1 continued - Summary of Systematic Review Articles

Author / Location of Data Collection	Description & Principle(s) Studied	Type of Research (Qualitative / Quantitative)	If qualitative		If quantitative		Overall Conclusions	Quality (good, fair, poor)
			Number of cases	Data Collection Methods	Sample size	Data Collection Methods		
Do et al.[12] U.S.A	A PHR tethered to the Military Health System leveraging either Google Health or Microsoft HealthVault. 1) Online patient data storage and access 2) Used standardized formats (CCD & CCR) for patient data. 3) Patient-driven online communication	Qualitative	From 250 patients total, 20 active duty military, 20 of their family members, and 20 retirees. Plus 10 providers.	Telephone interviews and a panel of 10 patients and 10 providers			Patients desire the convenience of health record access, but also desire functions such as secure messaging, appointments, medication renewal, and health reminders. There are technical challenges and conflicting beliefs on how information should pass between patients and providers.	Fair
Downer et al.[13] Australia Melbourne	Cohort study of SMS messaging to improve outpatient attendance 1) Mobile technology 2) Pushing relevant and custom data to patients.	Quantitative			Trial group: 1382 patients who had a Sept. appointment & gave a mobile number	Patient attendance data extracted from outpatient scheduling system	Overall failure to attend was significantly reduced by SMS messaging (14.2% vs. 23.4%; P<0.001). Although similar to other reminders, this method is more custom, low-cost, and efficient.	Fair
Chou et al.[14] U.S.A	Analysis of HINTS survey data 1) Social networking 2) Blogging 3) Online support groups	Quantitative			Internet users who completed the HINTS 2007 survey N = 5078	Extracted from publicly available HINTS 2007 survey data	Use of social media is not uniformly distributed across age strata (65% between ages 18-24). People with lower health status more likely to use online health tools.	Fair

As many hospitals, health care systems, and EHR vendors are developing personal health records (PHRs) as online web "portals" for patient access to medical records, this study sought develop and test some distinctly "Web 2.0" features that are designed to aid with parents and their children in the management of complex medication regiments. Some of these features included: medication-specific business logic, which automatically imported info such as the minimum allowable time between two doses of a medication; SMS alerts that were customizable and contained a URL that allowed the patient to mark the medication as taken or not; and personalized scheduling that allowed for modifiers such as "with a snack" or "as needed."

The most significant finding in this study was that among the 202 parents of children who had chronic medication needs, a very high number of them were able effectively utilize the online tools. Their ability to use the program was tested with a variety of online quizzes and medication scheduling scenarios that assessed whether they could successfully perform the tasks, how many attempts until success, and their perceived difficulty of the tasks. The overall quiz score, without prior training was $89 \pm 5\%$ SD. They were also asked for feedback based on Nielsen's conceptual model for usability based on the functionality, ease of use, interface layout, aesthetics, intuitiveness and usefulness of the program. The majority agreed that the scheduler was easy (91%); that the scheduler did not take too long (90%); and that the options for creating a schedule were comprehensive (74%). Additionally, with a smaller arm of twenty children aged 6-12 with cystic fibrosis who were given pagers that received medication alerts, it was found that 85% of the children were actively telling caregivers about their medication reminders.

The most significant threat to the validity of this study is the unique nature of the study participants. The study population represents a fairly narrow group of parents and children who are accustomed to managing a chronic illness. This may have biased the results favorably

towards usage of the tool because these groups are typically more engaged with their health care. Additionally, there was no demographic data collected, so it is difficult to determine the degree of selection bias in how factors such as education, economic status, age, and race may have affected comprehension and usage of the tools. Finally, the tools developed for this particular program illustrate the importance of specific principles such as mobile messaging and user customizability and demonstrate that patients and their caregivers desire them and can use them, but the study did not even attempt to illustrate any effect on health outcomes such as improved medication compliance or fewer adverse events from better medication management.

Wangberg et al.[9]

This study utilized three arms to test adherence various types of Internet-based health interventions: diabetes management (N=90), smoking cessation (N=2884), and maintaining a personal health record (N=410). The most significant findings of this study were in the smoking cessation arm, as it was the only one powered to generate statistically significant findings. Specifically, they found very high rates of attrition in usage of the intervention website, which followed a logarithmic trend demonstrating usage decreasing about 25% every month of the intervention. Similar, non-significant rates of attrition were seen in the other arms. This finding, while concerning, was tempered by the finding that user tailored mobile text messaging actually increased usage of the tool in the diabetes arm and prevented attrition in the smoking cessation arm. This demonstrates that the type of mobile engagement seen in "Web 2.0" type communications may have a beneficial effect on patients' self-efficacy.

A potential threat to the internal validity of this study is that the researchers used the number of logins to the online tool as a measure of adherence to the interventions. They mention that there was a correlation between number of logins and time spent on the site, however, time

spent on the intervention site does not give any indication that it is more or less successful in producing improved adherence to the actual intervention than more traditional means of communication. Additionally, there was no way for them to understand the reasons behind the high rates of attrition – participants stopping use of the site could just as likely represent a success in the intervention (e.g. smoking cessation) as a failure.

Lyles et al.[10]

Like the diabetes arm of the Wangberg et al. study, Lyles and associates saw diabetes management as a potential testing ground for new methods of web-based patient-provider communication. They recognized specifically that "recent literature has discussed the effectiveness of mobile devices for regular health behavior reminders or a means for uploading clinical information for more continuous health monitoring."[10] They went beyond simply providing and online interface by developing software that allowed patients to access and upload pertinent diabetes information using glucometers paired wirelessly via Bluetooth with smartphones and a unique interface that utilized the Nintendo Wii for patients to access their medical records.

The most important findings of this study were summarized in five qualitative themes that were uncovered during in-depth interviews with the eight patients that participated. These themes were: 'connecting with the nurse practitioner is valuable, uploading data from glucose monitors is easy, smartphones are frustrating, the program helps me focus on taking care of myself, and accessing the web features through the Wii was not useful.'[10] Three of these themes deal with the particular implementation of the technology incorporated by the study and may reflect either poor user interface design or troubles with technical glitches. Patients did find using the wireless Bluetooth glucose monitor to be easy, illustrating that certain technologies,

when implemented well can be easy for patients to use and useful. Most importantly, despite the

technical problems, this study shows that some patients are receptive to web-based and mobile

communications, and that they find them to improve a connection with their health care

providers and give them better focus on taking care of themselves.

The most serious limitation of this study was the very small size of the study population,

which prevented the researchers from gathering the full spectrum of potential user experience,

and prevented them from comparing experiences between age groups, levels of technical

literacy, or other demographic characteristics. Additionally, like other studies mentioned in this

review, this one was unable to assess any effect of this new intervention on health outcomes

related to better management of care.

Winkelman et al.[11]

Like the previously mentioned studies that focused on diabetes, Winkelman and

associates recognize that the long time frame and 'high attendant costs' of chronic illnesses over

time lend them to be well fitted to electronically mediated self-management tools.[11] This study

focused on IBD patients because of the researchers' convenience of access to these patients and

because IBD fit the characteristics of a prototypical chronic illness. Twelve patients with at least

a one-year history of chronic IBD participated in either in-depth interviews or focus groups that

collected information on their current health self-management strategies, their attitudes toward

electronic health information, and their thoughts on an Internet-based patient access to an EHR

system.

The authors used a three-stage analysis of the transcript data from the interviews and

focus groups that involved coding component key words and phrases, which were then grouped

into a loos framework of idea – a procedure known as "axial" coding. Grouping into higher-

level themes followed – called "selective" coding. The major findings of this qualitative study are in line with the others, revealing a similar set of desires and outcomes among patients when discussing online access to medical records. These themes included: useful information access promotes increased illness-ownership and self-efficacy; online tools encourage patient driven communication with providers; patients desire and feel positive when personalized support is integrated into the system; and patients find that accessing and participating in their health information fosters a greater sense of mutual trust and engagement with their provider.

Like the other qualitative studies in this review, this study is most limited by the size of the sample, and also by the qualitative nature of the data analysis. This study is more firmly grounded in a theoretical framework for analyzing and coding the qualitative interviews, however, the results are still subject to the researchers' interpretations, and thus limit the generalizability of the study.

Downer et al.[13]

This study is different from the other studies in this review in that it was a quantitative, controlled cohort study that sought to measure the effect of a single intervention on a single variable. The researchers sought to answer the question of whether the use of SMS text messaging could improve outpatient attendance. With a study population of 1382 patients who gave their mobile numbers and were scheduled to attend a clinic in September, the study detected a significant difference in rates of 'failure to attend' (FTA) when compared to the control group of 1482 patients. The overall FTA rate in the trial group was 14.2% compared to 23.4% (P<0.001) for the control group, indicating a significant reduction in missed appointments among those who received SMS reminder messages.

The most significant threat to the validity of this study is that it used a historical control group of patients from a different month of the year. Thus, the difference in FTA could have been the result of seasonal differences in attendance rates or difference for that particular month.

Do et al.[12]

This qualitative study of a PHR pilot developed for the military health system demonstrated the use of patient access to their medical records using standards-based models of Continuity of Care Documents (CCD) and Continuity of Care Records (CCR) combined with the private data brokers Google Health and Microsoft HealthVault to create an example of how future PHRs could embrace standards to allow the interface of various private and public health systems.

The study enlisted a total of 250 patients under the care of the military health system, including active duty members, family of active duty members and retirees. For the qualitative data collection, 60 patients from each of these three groups were interviewed regarding their experience with the new system. 50 of the 60 interviewees indicated no challenges with using the PHR, while all 60 said they were satisfied with the convenience of the record access. Some of the challenges that were indicated included complex clinical terms, some appointment dates seemed wrong, missing clinical notes, and difficulty with data entry and sorting. When asked, at least 55 of the 60 members of the interview group desired the following features: secure messaging feature, appointment scheduling functions, medication renewal, and health reminders such as immunizations and preventive care.

Unlike the other studies mentioned, this study also sought the providers' input on the process of providing a PHR to patients, and illustrated some disconnect between certain desires of the providers and their patients. The provider panel requested a 7-day delay in the release of

clinical results to allow sufficient time for the provider to contact the patient to explain the results, while patients that they wanted instant access to their health data. Additionally, providers found that accessing the PHR to provide patient results could be disruptive to their clinical workflow.

The major limitations of this study are its qualitative nature and specific patient population. Differences in the general population of the military, such as young age, could have skewed the satisfaction with this online PHR, limiting its external validity. Do and associates' contribute to previous research that patients desire and are able to use new online methods of health communication while adding to the conversation the emerging tension between the desires of providers and their patients in how to handle health care information.

Chou et al.[14]

One of the major concerns when discussing the feasibility of implementing new communication technologies in health care is that such changes may create difficulties for certain patient populations and thus create further disadvantages for already disadvantaged groups. Chou and associates sought to identify any socio-demographic and health-related factors associated with social media users in the United States by analyzing data from the 2007 Health Information National Trends Study (HINTS, N = 7674).

According to the HINTS data, about 69% of US adults reported having access to the Internet in 2007. Among these Internet users, 23% had used a social networking site, with younger age being the only significant predictor of such use, showing a linear relationship. The key finding of this study was that *among those with Internet access*, racial/ethnic and health-status disparities did not seem to affect social media use; in fact, non-white Americans who accessed the Internet were more likely to use social media than white Americans.

This finding seems encouraging in that it demonstrates that new technologies and trends in online communications such as social media are being adopted and used by people independent of socio-demographic and health-related factors. However, the biggest limitation of this study is that it only studied the trends among those who were reported Internet users, and thus there are likely important economic and health differences among those who are not Internet users that would change these results. Additionally, this study did not contain data specifically about health-related use of these technologies, and therefore could not make any conclusions about whether people desire to use them in conjunction with their health care. Finally, as the technologies are evolving so rapidly, this study was unable to capture usage among newer websites such as Twitter and Facebook, as well as the rapid increase in usage of mobile devices tethered to such services.

Conclusions

The studies presented in this systematic review generally used only a few of the previously described technologies and principles of Web 2.0 and social media. Most often, researchers have looked for ways to create and improve online personal health records and their interfaces, as well as ways to utilize mobile messaging systems to remind patients and gather chronic disease information. Since most of these studies were assessments of pilot programs using only a few principles and features, there is still very much room for continuing research. Those involved in health information technology policy, research and design should broaden their notions about what is possible using the EHR and the PHR by incorporating technologies and principles that have been widely successful in other spheres of information technology.

Among the studies that qualitatively analyzed patient responses to various types of PHRs and messaging systems, there was a tremendously positive response and desire to use such tools. Patients want better and easier ways to view and understand their health information, as well as easier and more personalized methods of communicating with their health providers. Several studies indicated that such personalization of digital health communication contributed to patients' illness ownership and self-efficacy. Patients who used these tools also felt more engaged with their health care providers. The pitfalls to these positive findings were evident in the research by Wangberg et al. and Lyles et al. Wangberg et al demonstrated that it may be difficult to keep patients engaged with online tools over time.[9] Lyles et al demonstrated that if the technology is not easy, user-friendly, and well designed, patients will become frustrated and disenfranchised. Although several studies showed that personalizing health communications (an important principle of social media) reduced attrition of online interventions, more research must be done to understand what parts of health information technology are most important to patients, what keeps them engaged over time, and how to continue to develop tools that are easy to use and understand.

Finally, the qualitative nature of much of the research, especially when each study centered on very different systems of patient communication, makes any finding very difficult to generalize. None of the studies sought to demonstrate a positive effect on actual health outcomes, with only some demonstrating a positive effect on behaviors that may lead to better health outcomes, such as tracking personal health data, engaging more frequently with health care providers, and improving attendance to clinic appointments. Regardless, these studies indicate the tremendous potential for not only expanding the application of new Web 2.0 and social media technologies in patient care and communications, but that such implementations

may improve patients' illness ownership, self-efficacy, engagement with their providers,

medication management, and perhaps eventually improve their overall health.

Methods

Because of the ever-changing nature of information technology, it is difficult to gauge people's interactions with specific technologies over any certain length of time. Additionally, because of the broad emergence of social networking in the past few years, researchers are still grasping to understand how this shift in communication may alter the health care industry. Survey research is a standard method that can be used not only to discover the opinions of people about technology, but can be repeated so as to track any trends over time. Some surveys have measured patients' use of social media and technology in their health care[6], but no study has sought to measure and correlate dyadic data from patients and their own providers.

To advance my understanding of the current state of communication technology and health care, as well as where it may be headed, I designed a three-pronged data collection scheme for this study. This scheme sought to gather data from the most prominent interests in health care communications: patients, providers, and stakeholders in the health care IT industry. I deployed surveys in primary care clinics across North Carolina to gauge attitudes about technology of both patients and providers in the same setting. This allowed not only for a general understanding of both of these groups, but the ability to compare where there may be differences in ideals and usage of information technology, although it must be said that because both surveys were entirely anonymous, I could not construct true patient-provider dyads; rather, I simply have data from patients and providers in similar settings. In-depth interviews with prominent figures in health information technology sought to provide a qualitative angle from which to approach the quantitative survey data and give additional insight into how these various groups of individuals interacting in the health care world may differ in their thoughts and usage of technology.

Patient Survey

The patient survey, approved by the UNC IRB, consisted of a brief set of questions designed to gauge an individual patient's knowledge and use of various technologies, as well as his/her willingness to use such tools to communicate with a health care provider. Questions were designed in groups and arranged in groups to gradually gauge patients' feelings towards ultimately using new technologies in communicating with their providers. The first group was designed to better understand the patient's overall Internet use as well as use in active and contributory online activities, such as email, social networking, paying bills, and looking up information about health. The second group sought to understand the patient's needs and desires in communicating with their health care providers, and the final group asked directly about their interest in using new technologies in communicating information about medicine, appointments, and labs with their providers.

The survey was administered at the family medicine primary care clinics at UNC as well as three other primary care practices that generally host medical student rotations. These clinics were Eagle Family Medicine in Greensboro, NC; LeBauer Health Care in Greensboro, NC and Signet Health Care in Whiteville, NC. All clinic participation was dependent on the agreement of the clinic owners and/or managing partners. See Appendix 1 for the letter requesting their participation in the study.

On or shortly after June 3, 2011, I provided clinics that agreed to participate with printed patient surveys. I asked that they hand out a survey to each of their adult patients at check-in, with the instructions to ask patients if they would simply fill out this *optional* survey and place it in the labeled box of the waiting room. If clinics were not willing to hand out the surveys to each adult patient, I asked them to put the surveys, along with the provided small sign, in a

prominent location in the waiting room for patients to see and decide if they would like to participate. Because the survey was anonymous and taken in a public, non-controlled environment, there was no way to control whether minors will fill out the survey either on their own or behalf of an adult in the waiting room. This caveat existed because of the necessity to administer the survey with little to no clinic staff involvement, and was necessary to collect a sufficient number of surveys. Because completion of the survey posed no obvious risk to respondents, and because it does not seek personal health information of any kind, the possibility that minors might fill it out was deemed acceptable. I gave each practice a sealed box with a slot in which patients were to deposit completed surveys. I briefed the administrative staff in person about the survey and how to respond to any questions posed by patients, and I also provided a survey administration guide for each clinic. The patient survey collected general demographic information but it asked for absolutely NO patient identifying information or personal health information. Although in some circumstances it would have been beneficial to gather data about specific health conditions as they relate to health information technology, for example, using a mobile phone to send diabetic glucose monitoring data to a provider, it was deemed necessary to exclude such questions to expedite the IRB approval process Therefore, these survey results are only an exploratory study of patients' likely willingness to use social networking-style methods of tracking their own health records. The survey and the survey administration guide are included in Appendix 1.

On or shortly after June 17, 2011, I personally collected the survey boxes (except for the Whiteville, NC clinic, whose distance from Chapel Hill necessitated my providing the clinic with a FedEx shipping order and shipping materials. I then hand-coded the anonymous surveys in an Excel spreadsheet before importing them to Stata 11; my faculty advisor downloaded the same

Excel spreadsheet into SPSS 19 as a backup and data analysis monitoring assurance strategy. After coding, the original paper surveys will be kept in my advisor's secure office.

I analyzed the aggregate patient data for overall levels of attitudes towards social networking tools in health care, while also assessing similarities in aggregate patient responses and the aggregated responses of providers. The anonymous patient surveys were NOT designed to be linked in any way to the anonymous provider surveys, in order to avoid creating any additional source of identifying either patients or providers, and also in order to permit statistical analysis that is not dependent on large numbers of linked individual pairs.

Provider Survey

Included in the letter to providers and clinic administrators requesting their participation in the patient portion of this study was a section asking them to participate in a web-based survey of their own beliefs about awareness and use of social networking tools, as well as their willingness to use such tools to communicate with their patients. I hoped that a web-based survey, created in Qualtrics, the UNC survey tool based at the Odum Institute, would generate a higher response rate among providers.

Because web-based surveys often have long and difficult URLs, I used the URL shortening service, "TinyURL" (www.tinyurl.com) to provide the clinics with a short, easy to type URL that redirected them to the Qualtrics survey. The short URLs provided by TinyURL can be custom specified, and do not expire. On June 26th, I ended the Qualtrics survey to prevent it from being accessed via the TinyURL link.

It was made clear to the providers that their responses would be kept anonymous and secure, and that the data would only be analyzed in the aggregate. The original study design intended to collect demographic data regarding the providers' years of practice, and degrees, e.g.

MD, NP, RN, DO, and PA. However, due to a technical glitch, the shortened URL link directed

providers to an older version of the survey that did not yet have demographic questions. In

recognition that in certain instances (where there is only one MD in a clinic for example) the

survey response data could be identified with a particular individual, I chose not to collect any

identifying information about the individual clinics, so that any given MD's responses could not

be inferred. Although this prevented me from analyzing the response rate of different clinics as

well as comparing the responses of providers to their own patients on a per-clinic basis, it was

deemed necessary to maintain the anonymity of the survey. A print version of the on-line survey

appears in Appendix 1.

In-Depth Interviews

The original design of the study sought to complete the data triangulation to the patient

and provider surveys by incorporating a systematic qualitative analysis of several in-depth

interviews with elite stakeholders in the health information technology industry. However, only

two of the ten stakeholders responded and agreed to be interviewed, therefore the data collected

from the interviews was instead digested and incorporated as valuable resource to guide the

discussion of the results of the patient and provider surveys, as well as the policy implications of

their findings.

Individuals who responded to the initial recruitment email (provided in Appendix 2) or

subsequent emails and phone calls requesting interviews were be asked to provide verbal consent

to be interviewed and audio recorded before proceeding with any such interview. A copy of the

verbal script was also provided electronically if the interviewee so desired. The interview script,

including the request for consent and the interview questions is provided in Appendix 2.

I conducted two interviews by telephone. The interview consisted of several open-ended questions, designed to allow the respondents to guide the conversation and also to allow me to ask reasonable follow-up questions depending on the interviewee's responses. If the stakeholder gave permission, the entire interview was recorded using an audio-recording device, which I transcribed into a Microsoft Word document. If respondents did not give permission to be audio-recorded, I took handwritten notes during the interview. Immediately after the interview was transcribed, a copy of the audio transcription or hand-written notes was sent to the interviewee. The responses were then stored digitally in a secure and encrypted file for analysis and reference during the course of writing this paper.

Results

Patient Survey

  The patient survey had a total of 106 responses, 104 of which were adult patients (aged 18 and older) who were included in the analysis. Age of respondents was normally distributed, with a mean age of 47 ± 16.9 years. The sample is disproportionately (68%) female, but this is not uncharacteristic of the relatively greater consumption of health services by women than by men.. The majority of patients who answered the survey were well educated, with 84% reporting 12 or more years of education. Table X displays overall demographic characteristics along with bivariate analyses of selected survey questions.

Internet & Technology Use

  Among the adult respondents, 92.3% (± 26.7) reported using the Internet in some form. This is higher than previous prevalence surveys of adult Internet use in the United States, which have estimated numbers closer to 70% in recent years.[14,15] Overall Internet use was significantly different within age and education groups. As shown in Table 2, approximately 68% of the 65+ age group reported Internet use, compared to more than 92% among younger age groups. No more than 75% of those with less than 12 years of education reported Internet use, while 95% or more of those with more than 12 years of education use the Internet. The prevalence and trends for overall email use were very similar to those for Internet use. Among the Internet users, 33.6% (± 47.5) reported using the Internet on their mobile phones, with the most popular platforms among mobile Internet users being Apple's iOS (iPhone, iPad, iPod Touch) at 34% followed closely by Google's Android at 26% and RIM's Blackberry at 24%.

When asked about interactive, online social networking services such as Facebook, Twitter, MySpace, and LinkedIn, over 66% (± 47.5) of all patients reported using at least one of these services. Facebook was by far the most popular, with 63% of patients reported using the service, followed by LinkedIn at 14%, Twitter at 13% and MySpace at 8%. Using social media varied significantly only among age groups, with almost 95% of the youngest respondents using some form of social media, while use drops steeply as age increases: 82% for ages 30-49, 48% for ages 50-64, and 32% for ages 65 and above. On average, patients reported that they use such services between "many times per week" and "every day." Like overall usage, the frequency of use of these services decreased as age increased, with the oldest patients (65+) who use these services using them on average once a week, while the youngest group (18-29) use them on average almost daily. Although Internet and email use were correlated with patients' education levels, neither social media use nor frequency were significantly different among education groups.

Activities that require active online engagement were also surveyed to understand how those usage patterns might translate to activities related to managing health care. Using the Internet to pay bills is an interesting correlate for Internet-based health communication, because it involves managing secure accounts and private data. About 73% (± 44.6) of all patients reported using the Internet to pay their bills. There were significant differences within age and education groups; however, unlike with Internet, email, and social media use, the most likely groups to pay bills online were not the youngest, but those aged 30-49 years (88.6%), who are at the intersection of being old enough to have bills to pay but young enough to expect to be "wired." Curiously, patients with 12-14 years of education were slightly more likely to pay bills online than were the most educated group, 82.6% vs. 79.0%, although this difference at the upper

end of education is probably not what is driving significance – rather, the vast difference between lesser and more educated people is the finding of note.

Two questions sought to gauge patients' comfort with privacy and security issues. They asked patients to rank their comfort level with "privacy on the Internet" and "medications stored online that all your doctors can see." Their responses were limited to a 4-part scale graded (1-4): "very comfortable, somewhat comfortable, somewhat uncomfortable, and very uncomfortable." The overall average comfort level for both of the above questions fell close to the "somewhat comfortable" level at 2.20 (±0.91) and 1.85 (±0.95), respectively.

Communicating With Providers

Nearly all of the patients who responded to the survey felt that "reminders are helpful" (96% ± 19.6), but some differences appeared among the types of reminders that patients preferred. When asked, "What kinds of reminders would you like?" approximately 64% of patients chose "email or text message," 34.6% chose "appointment card," 31.7% chose "automated call," 18.3% chose personal call, and 4.8% chose "website like Facebook, Twitter, etc." Statistically significant differences among demographic characteristics in this category were rare, but included the finding that patients in lower education groups preferred personal calls (41-50%) and did not prefer email / text messages (0-25%). Also, younger groups significantly preferred email / text messages, with 81% of the youngest group (18-29) choosing this option, compared to only 26% of the oldest group (65+) and the middle groups falling between (56-80%).

The above data demonstrate some patterns among patients when they are asked about conventional communication methods versus newer technologies. In order to probe people's

willingness to use such technology a little further, we encouraged patients to evaluate which technologies are *most* acceptable to them by giving them a set of four communication types (email, website, smartphone, and texting) and asking them to rank on a scale from 1-5 their likelihood of using them to communicate with their doctor, with 1 being "Unlikely" and 5 being "Likely." On average, patients said they were more likely than not to use all these methods, with each method receiving a mean of more than 3. Email had the highest ranking, with 4.40 ± 1.26, and was also the only method that differed among the demographic groups. Patients in the younger three age groups, total age ranging 18-64, ranked email between 4.46 and 4.83 on the likelihood scale, where the oldest age group, 65+ ranked email on average at a 3.00. The differences in likelihood to use email driven by education were more striking, as patients with less than 12 years of education scored email between 1.00 and 2.73, whereas patients with 12 or more years of education ranked email very favorably, between 4.75 and 4.80.

Table 2 – Bivariate analysis of patient technology survey

	Overall	Age Group				p value	Sex		p value	Years of Education				p value
		18-29	30-49	50-64	65+		M	F		<10	10-12	12-14	>14	
N	*104*	*16*	*44*	*25*	*19*		*32*	*69*		*4*	*12*	*23*	*62*	
% Use the Internet	92.3 ± 26.7	100	100	92.0	68.4	**<0.001**	87.5	94.2	0.2502	25.0	75.0	95.6	98.4	**<0.001**
% Use Internet on phone	33.6 ± 47.5	43.8	47.7	20	10.5	**0.0092**	31.2	34.8	0.7299	25	25	34.8	35.5	0.8913
% Use social media (Facebook, Twitter, MySpace, LinkedIn)	66.4 ± 47.5	94.8	81.8	48.0	31.6	**<0.001**	62.5	68.1	0.5829	25.0	41.7	73.9	71.0	0.5829
Mean freq. of social media use (1-5) *	3.5 ± 1.3	3.75	3.83	3.16	2.00	**0.0030**	3.43	3.60	0.6181	5	3.60	3.85	3.41	0.4040
% Use email	93.3 ± 25.2	100	97.7	92.0	78.9	**0.0306**	87.5	95.6	0.1361	50.0	66.7	100	98.4	**<0.001**
Mean freq. of email use (0-5) **	4.01 ± 1.5	4.38	4.27	4.12	2.82	**0.0026**	3.66	4.18	0.1039	1.67	1.73	4.30	4.42	**<0.001**
% Use Internet for bills?	73.1 ± 44.6	81.3	88.6	72.0	31.6	**<0.001**	62.5	78.3	0.0978	25.0	41.7	82.6	79.0	**0.0039**
Use Internet for health? (0-4)§	2.42 ± 1.3	3.25	2.67	2.28	1.32	**<0.001**	2.13	2.57	0.1158	0.50	1.45	2.35	2.76	**<0.001**
Discomfort w/Internet privacy (1-4)§§	2.20 ± 0.91	1.75	2.14	2.42	2.5	0.0694	2.29	2.18	0.6170	1.00	2.63	2.00	2.26	0.1888
Discomfort w/online med list (1-4) §§	1.85 ± 0.95	1.50	1.84	1.87	2.21	0.2384	1.86	1.85	0.9407	1.00	1.88	1.70	1.92	0.6340
% Think reminders helpful	96.0 ± 19.6	93.8	93.2	100	100	0.4240	93.8	97.1	0.4268	75.0	100	100	95.2	0.1022
Preferred reminders:														
% Appt. card	34.6 ± 47.8	25.0	29.5	40.0	47.4	0.4266	40.6	33.3	0.4815	50.0	50.0	39.1	30.6	0.5356
% Personal call	18.3 ± 38.8	0	22.7	12.0	31.6	0.0694	25.0	15.9	0.2831	50.0	41.7	4.3	17.7	**0.0185**
% Automated call	31.7 ± 46.8	56.2	25.0	40.0	15.8	**0.0377**	28.1	34.8	0.5117	0	41.7	21.7	37.1	0.2483
% Email / SMS	64.4 ± 48.1	81.2	79.5	56.0	26.3	**<0.001**	53.1	72.5	0.0565	0	25.0	78.3	74.2	**<0.001**
% Website	4.8 ± 21.5	6.2	4.5	8.0	0	0.6699	12.5	1.4	0.0170	0	16.7	8.7	1.6	0.1202

Table 2 continued --

Alt. Ways to Talk to Doctors (1-5)δ														
Email	4.40 ± 1.26	4.72	4.83	4.46	3.00	**<0.001**	4.15	4.52	0.1826	1.00	2.73	4.80	4.75	**<0.001**
Website	3.99 ± 1.38	4.22	4.25	3.83	3.00	0.0634	3.80	4.08	0.3891	--	3.38	4.5	3.89	0.0932
Smartphone	3.12 ± 1.77	3.78	3.22	2.77	2.50	0.2265	3.44	2.98	0.2730	--	3.44	3.05	3.10	0.8450
Text Messaging	3.39 ± 1.69	3.91	3.63	3.00	2.44	0.0897	3.76	3.24	0.1816	3.00	3.38	3.50	3.36	0.9844
Interest in website or smartphone to track (0-3):δδ														
Medications	2.11	2.31	2.30	2.4	0.87	**<0.001**	1.81	2.25	0.0571	0	1.82	2.43	2.18	**<0.001**
BP, glucose, weight	2.02	2.31	2.16	2.2	1.0	**0.0017**	1.81	2.12	0.2097	0.5	1.83	2.04	2.15	**0.0385**

Table 2 Key:

Significant values are when P < 0.05, and are presented in bold.
* where 1 = once a month, 2 = once a week, 3 = many times per week, 4 = every day, 5 = many times a day

** where 0 = don't have email, 1 = less than once a month, 2 = once a week, 3 = multiple times per week, 4 = every day, 5 = many times a day

§ where 0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = very often

§§ where 1 = very comfortable, 2 = somewhat comfortable, 3 = somewhat uncomfortable, 4 = very uncomfortable

δ where 1 = unlikely and 5 = likely. There was a visual scale of three lines in between these values, graded 2-3. If the patient circled the entire choice, it was scored as a 3.

δδ where 0 = not at all interested, 1 = somewhat uninterested, 2 = somewhat interested, 3 = very interested

Provider Survey – A Comparison

A total of 35 responses to the online provider survey came from the four clinics. Because of the limited number of clinics participating, along with a relatively small response rate, analysis of this survey is limited to those questions that can be more directly compared to the patient survey.

Internet & Technology Use

The design of the survey assumed that all or nearly all providers would respond that they use the Internet at home and at work, so providers were asked more detail about their mobile device use as a finer-grained indicator of their adoption of newer technologies, including tablet computers. Table 3 shows that 77% of the providers reported using smartphones or PDAs (compared to about 34% of patients who reported using Internet on their phone). Nearly a third (29%) of providers are using some form of tablet computer.

Table 3 – Computer device use among providers.

	N = 35	%
Home computer	29	83%
Office computer	32	91%
Smartphone / PDA	27	77%
Tablet computer at home	10	29%
Tablet computer at work	10	29%
Other	2	6%
I don't regularly use any computer devices	0	0%

Although there is a large gap in smartphone use between providers and patients, the distribution of mobile platforms among users is similar. As Figure 3 demonstrates, the most popular platform for both patients and providers was Apple's iOS (iPod, iPad, and iPod Touch), followed at almost equal usage amounts by RIM's Blackberry and Google's Android.
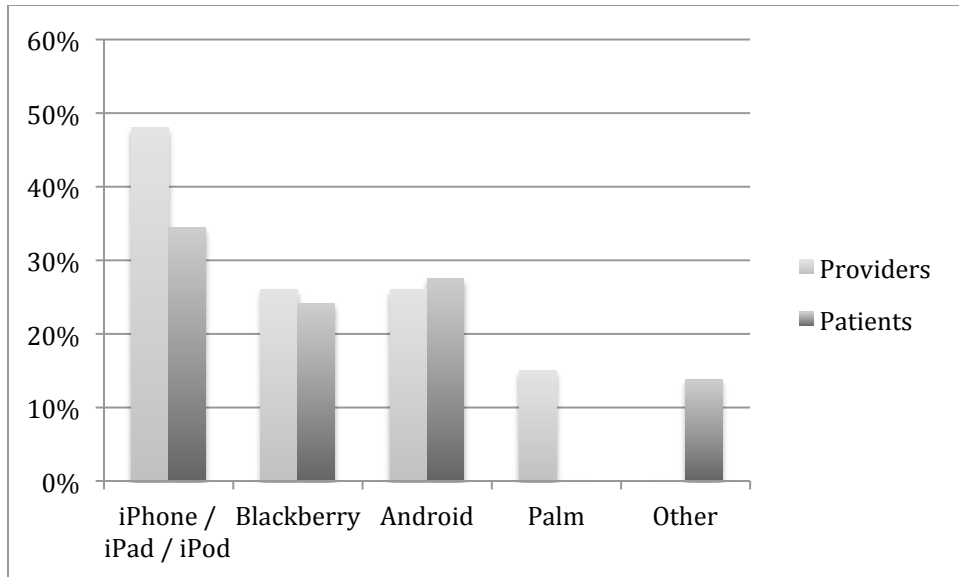

Figure 3 – Mobile platform use among patients and providers.

As with the usage patterns of smartphone platform use between patients and providers, patients and providers were very similar in their use of online social media services (Figure 4). One exception was the Yahoo! Answers service, which had a much higher response rate among patients than among providers, which may have been the result of patients simply selecting that choice because of a familiarity with Yahoo! and the company's search engine or other offerings. Further survey questions about providers' searching and information-gathering strategies on the web would be interesting.
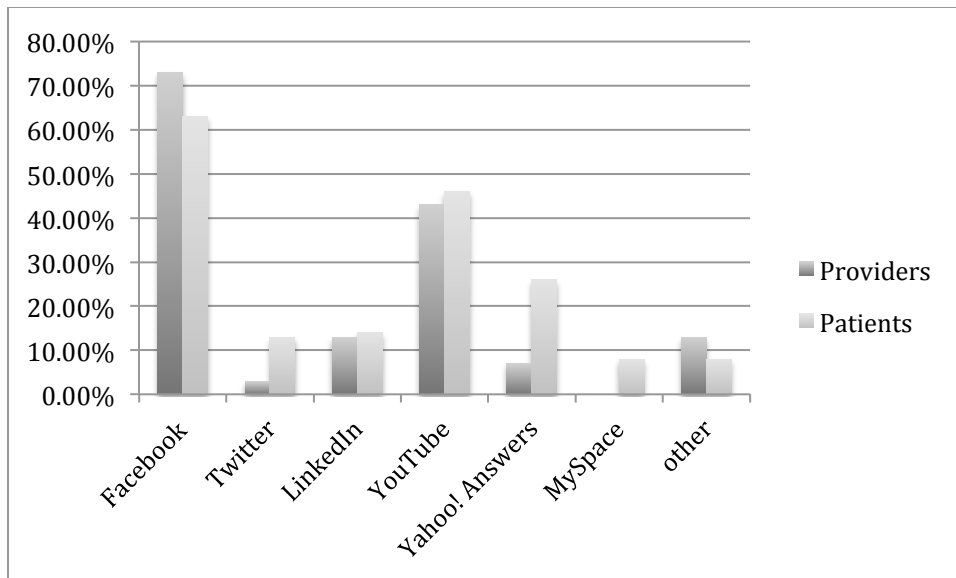
Figure 4 – Social media service use among patients and providers.

In addition to similar high levels of reported use among social networking sites, patients and providers also demonstrated that they use these services often. The social networking service that had the most users among providers (n=22) also had providers using the site on average between "once a week" and "2-3 times per week." This was calculated by taking the mean of the frequency options that ranged from "less than once a month" to "multiple times per day" as they were coded 1-7. As described earlier, coding the patient response in a similar fashion showed that their average social media use frequency was between "many times per week" and "every day." For email, 57% (n=20) reported checking their email "several times a day," 23% (n=8) checked it "at least daily" and 20% (n=7) reported checking it "when notified." If one assumes that providers who are notified by their email receive at least one email per day, then it could be said that 100% reported checking their email at least once per day. This means that the true average provider email use frequency should be somewhat higher than at least once per day, which would make it very comparable to the average patient email usage reported in Table 2 of "every day."

Several questions in both the patient and provider surveys were designed to gauge participants' interest in using new technologies that could be made possible by utilizing principles of Web 2.0 and social media. The questions asked about topics such as using a shared, unified medication list, communicating using mobile devices, and tracking patient data using such devices. Although some of the patient responses are already described above, they are repeated here for direct comparison to the provider responses.

Although the questions were phrased slightly different to accommodate both patients and providers, when asked about a hypothetical online system for unified medication management, both providers and patients responded very favorably. Figure 5 shows their responses.
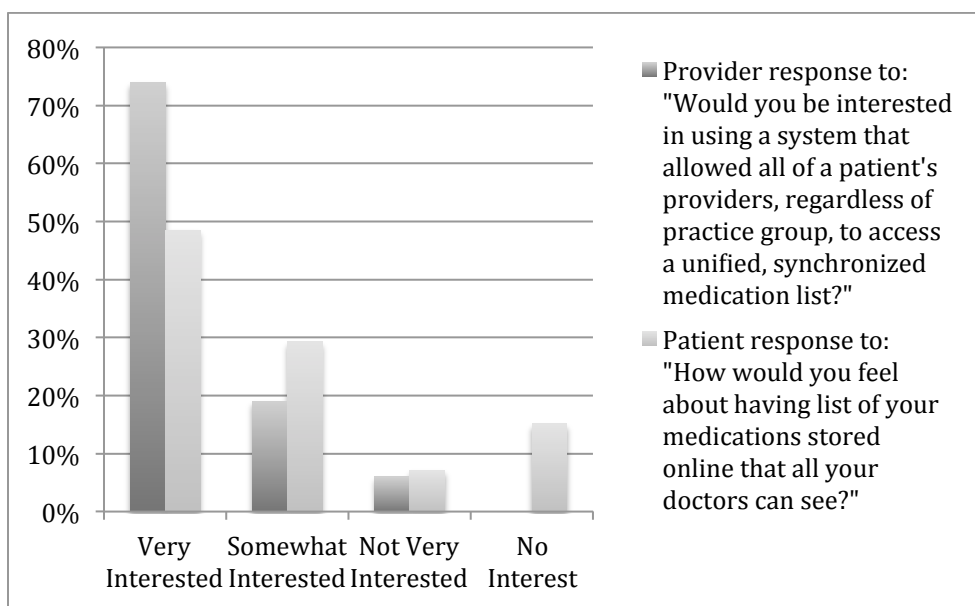

Figure 5 – Provider and Patient Interest in Online Medication Management

The majority of providers (74%, n=23) responded that they would be very interested in such a system, while patients responded slightly more cautiously with 48% (n=48) expressing

that they were very interested, and 29% (n=29) somewhat interested. Although providers were

very interested in this system, they were able to temper their interest and more accurately predict

patients' response the patient response to the corresponding question. These questions are
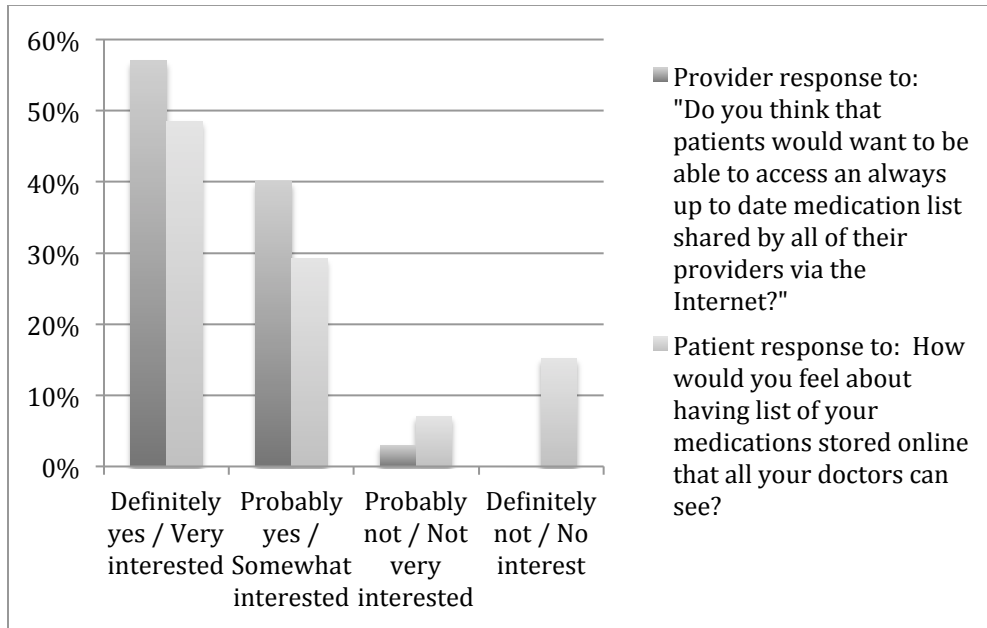
compared below in Figure 6.

Figure 6 -- Provider Thoughts on Patient Interest Compared to Actual Patient Interest

Another hypothetical system that was presented to patients and providers was that of

using a smartphone to track and monitor individualized patient data, such as weight, blood

glucose, or blood pressure. Such systems have already been studied as tools in chronic disease

management or health care prevention strategies.[10,16,17] Figure 7 shows that both patients and

providers demonstrated interest in such tools, with 46% (n=46) of patients and 32% (n=10) of

providers responding "very interested" and 29% (n=29) of patients and 42% (n=13) of providers

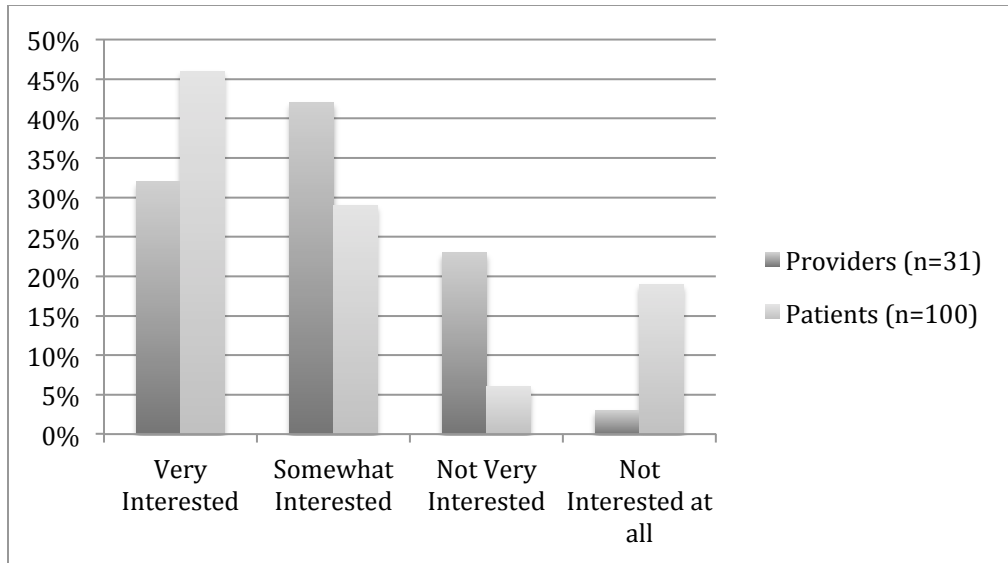responding "somewhat interested."

Figure 7 -- Patient and Provider Interest in Smartphones for Tracking Health Data

Although providers and patients both generally indicated their interest in using smartphones to track patient data, providers, despite their own interest, had little faith that patients would be able to use such devices effectively. When asked if patients would be able to use smartphones to track their own data, the majority of providers (71%, n=22) replied, "probably not." Figure 8 presents these data in contrast to providers' responses about their own interests in such tools.
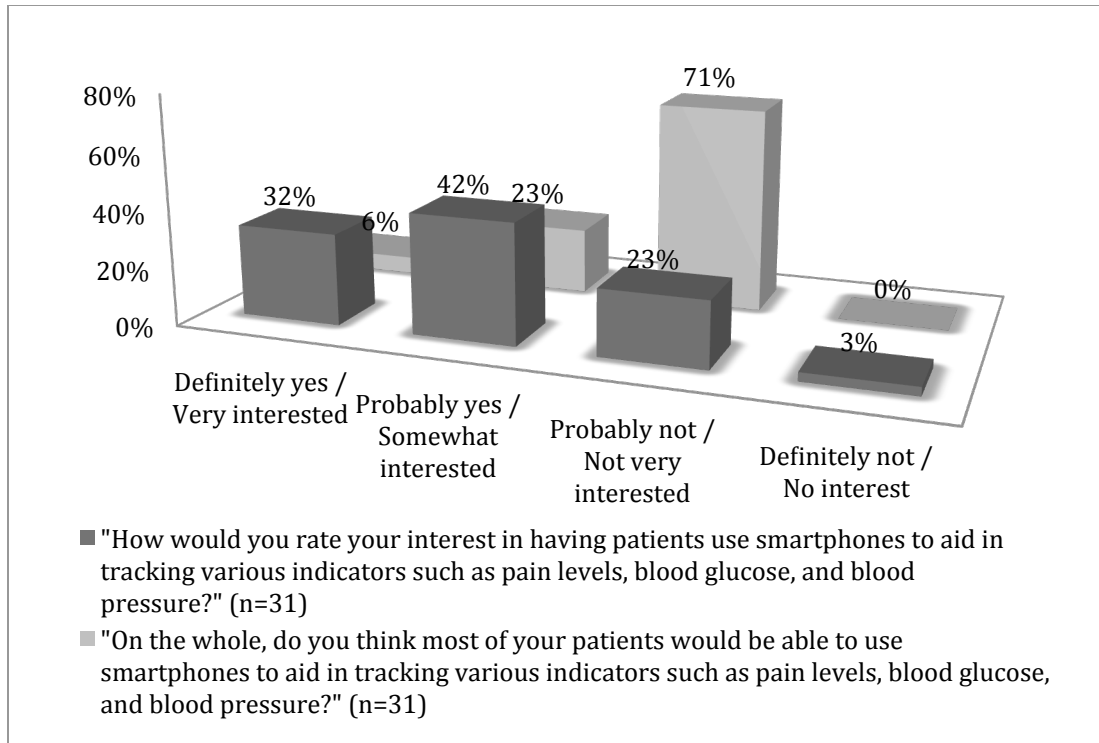
Figure 8 -- Providers' Interest in Smartphone Use Compared to Their Beliefs on Patient Use

In addition to describing hypothetical systems that could Web 2.0 and social media principles, providers were asked directly about their interests in using current social media to communicate with patients, as well as their beliefs as to how patients may respond to such alternative communication methods. The majority of providers were not interested in using social media outlets to communicate with patients, as shown in Figure 9, although they thought that most patients would, indeed, be interested in using these methods.
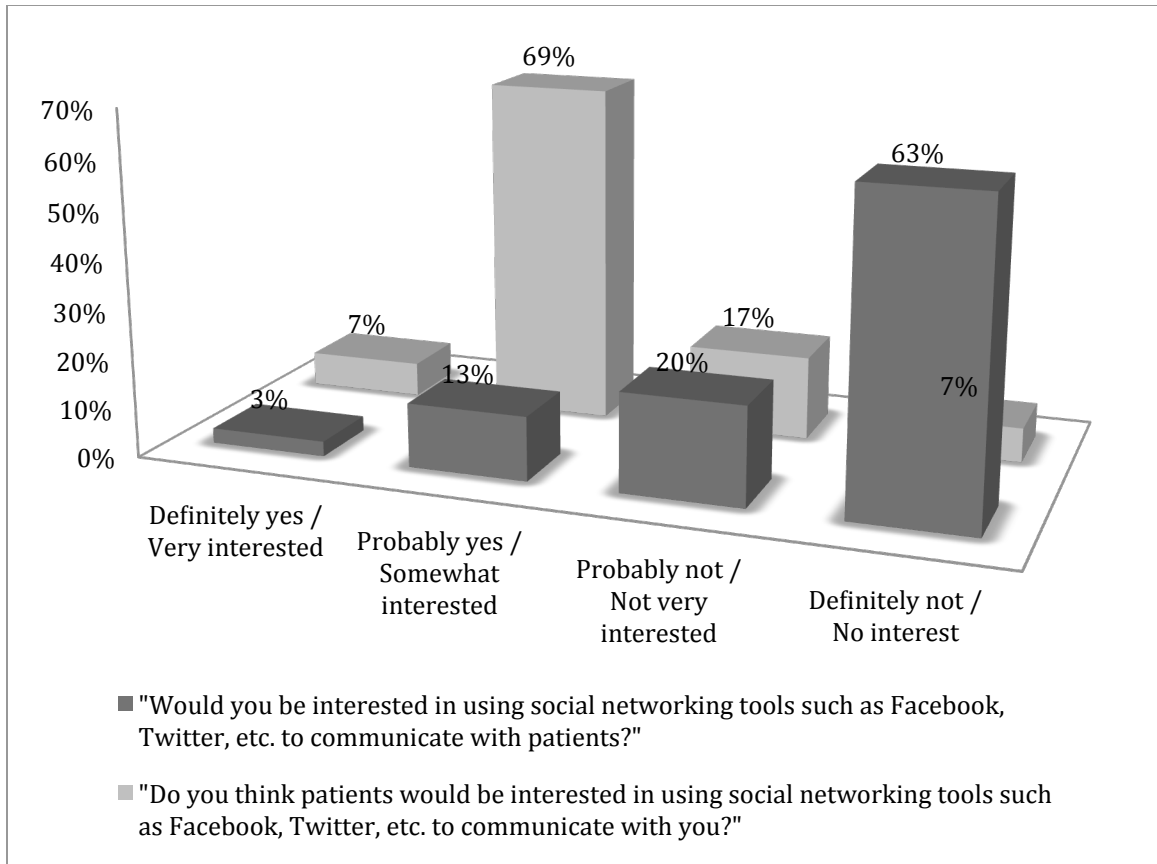
Figure 9 -- Comparison of Providers' Thoughts on Social Networking Tools For Communicating With Patients

Discussion of Findings

This study captured a snapshot of usage patterns and feelings towards existing and emerging technologies for patient-provider communications among selected family practice clinics in North Carolina. In an effort to improve understanding of how newer "Web 2.0" methodologies and trends in social media could be applied to health care, participants of both surveys were asked about hypothetical applications of such principles for tasks such as: talking with each other, managing medications, and tracking long-term health data. Although many publications have recently touted the possibilities of combining social media and health care,[18-27] few have gathered empirical data about how such shifts in communication would be accepted by patients and their providers. The results of this study show that within a population where both patients and providers are using the Internet and email at relatively high rates, attitudes towards using newer methods of handling health care information are generally positive, but may be tempered by particular characteristics of the study group or proposed intervention.

For the patient portion of the study, significant differences in usage and attitudes toward technology were apparent between age groups and levels of education. These stratifications were minimal among age groups when asked about older and more general-use technologies such as email and overall Internet use. However, usage of newer technologies, such as mobile Internet, text messaging, social media, and the frequency of usage these demonstrated a much sharper bias towards the younger populations. These patterns have already been recognized among those in the Health IT sector, as Dr. Robert Berger, Professor of Medicine and Chief Information Officer of the UNC Health System said: "….as we go to another generation, as your generation ages, they are going to expect that kind of thing." Therefore it seems reasonable to conclude that although the most effective current application of new communication methods

would be among younger generations, and that over time these methods will continue to penetrate older cohorts, as have Internet and email.

The same conclusions regarding education groups cannot be made as easily. Previous research by Chou et al. has shown that "among Internet users, social media are found to penetrate the population regardless of education, race/ethnicity, or health care access."[14(p7)] Although there were similar stratifications for technology use among education groups (with less educated patients generally reporting less use), not every category with significant differences among age groups had significance among education groups. This non-significance among certain categories may correspond to Chou et al's findings that newer technologies such as social media are penetrating the population regardless of education.

In this study, although overall general Internet and email use was significantly lower among those with less education, the differences in the categories for social media and mobile phone Internet were not significant. If one were to use education level as an overall proxy for socioeconomic status, one may suppose that this may be related to the recently dropping cost and increasing of availability of mobile phones that connect to the Internet. Continuing advances in technology combined with increased competition and mobile phone service contracts are contributing to the increased prevalence of these devices among wider populations.[15,28] Indeed, often individuals who may not be able to afford or access landline Internet, may have a mobile phone with data capabilities. As social media outlets typically provide use of mobile interfaces in conjunction with traditional services, they may be expanding their audience to groups that lack traditional home Internet access. These findings, while far from conclusive, may provide a spark for new research to examine opportunities for mobile health care communications in those of lower education and socioeconomic groups.

Both patients and providers responded favorably to interventions that would use the principles of "Web 2.0" and social media described above in the systematic review of the literature. These principles were embodied in the questions that asked about using websites and smartphones to track medications among a patients' circle of physicians, using texting and email to keep track of appointments and communication, as well as new ways to use mobile phones to track patient lab data crucial to monitoring chronic illness. However when individualized social media services were mentioned, the response was less than enthusiastic. Perhaps the most illustrative example of this among the surveys was when providers were asked directly about using websites such as Facebook and Twitter to communicate with patients, and also whether they thought patients would want to use these. Providers overwhelmingly did not want to use such services to communicate with patients, despite their belief that patients would want to use these services to communicate with them. Why might this be? The answer most likely lies in the privacy and control of such sensitive health data. UNC's Dr. Berger explained that in his view these systems are 'too open,' and 'too insecure' and is instead choosing to implement a commercially available patient portal at UNC to handle patient-provider communications. He believed that the worst thing that could possibly happen would be for a patient to have access to their labs and results before proper interpretation and explanation by their physician, and that the patient portal gave him control over such information flow.

This leads to the conclusion that while providers and health information technology administrators are wary of current social media because of privacy and control concerns, when asked about using similar principles in the context of health care communications, they are more enthusiastic. This is not likely the result of a misunderstanding of current social media outlets, or the lack of desire to better communicate health information. It is most likely because there has

yet to emerge a system that has successfully incorporated such principles in an EHR or PHR that allows for the same types of integrated, universal, and portable transfer of detailed personal information for health data the way systems such as Facebook have done for interpersonal communication data. At one point in our interview, Dr. Berger also recognized a lack of parsed, transferable data, by describing the lack of hypothetical medication management system similar to the one that was used as an example of social networking principles in the provider surveys:

> Well, the standards are already developed, and we can send the records, there's just no place to accept from or send to at the moment in North Carolina. [….] So both AllScripts and WebCIS are capable of sending and receiving these standard documents, and it's basically your problem list, your med list, your procedure list over a given period of time that you are able to send and receive, but its a document, its not parsed out yet. There is nobody doing that, that I'm aware of. Meaning that to combine the meds from one system with one system, at the time of the visit, and notate where they're coming from….
>
> **--Dr. Robert Berger, UNC**

Although it was beyond the scope and resources of this paper to analyze individual and commercial PHRs of various health systems, it is quite clear that even with the health information exchange (HIE) standards currently under development, there is no universal system that allows for the kind of seamless, notated, tagged, and portable information transfer that is currently exemplified by online social networking services.

Analyzing the recent collapse of Google Health, a PHR project by one of the largest and most successful Internet companies, will likely provide better insight into how to approach future attempts at PHRs and patient-provider communications. Recently, Adam Bosworth, the former Google employee who helped create Google Health said that the service failed because "It's not social" and that "Google didn't push to see what they could do that people would want."[29] Others have surmised that there will be an inevitable failure of any such PHR that is not interoperable with EMRs or does not automatically capture real-time health data (Google Health

required patients to enter their own data).[30] The results of the pilot surveys in this paper show

significant patient and provider interest in new technologies for health communication, which in

light of Google Health's recent failure, raise important questions about what the future of EHRs

and PHRs should look like. Will systems that are more social, connected, and mobile help

increase engagement with patients and efficiency for providers, or are there deeper issues that are

preventing the ease in which medical information is handled and shared?

Although this study takes a small step, further research must be done to more accurately

quantify not only patient and provider attitudes towards such methods of handling patient data,

but to see if these methods may eventually improve the efficiency of health care communication

and overall health of the people who use them.

Conclusion: A Conceptual Model of the Social EHR and the Medical Home

"A medical home can be understood as a clinical setting that serves as a central resource for a patient's ongoing medical care."[31(p819)] Medical homes have shown the potential not only to improve patient outcomes, but to also decrease the rate of continually increasing medical spending. This combination of improved outcomes and decreased spending may seem unrealistic, but it has already been demonstrated in medical homes around the country[31(p823)] This setting would be the excellent avenue in which to begin researching and implementing social networking and Web 2.0 principles in ambulatory care.

The National Committee for Quality Assurance assigns medical home practices to tiers based on the number of features shared with the committee's overview of what a medical home should be. It has defined nine categories, including access and communication, patient tracking and registry, care management, patient self-management support, electronic prescribing test tracking, referral tracking, performance reporting and improvement, and advanced electronic communication.[32] The purpose of listing all of the categories is to illustrate that almost all of them can be accomplished either in part or full by instituting a comprehensive, standardized electronic medical information system that incorporates or borrows principles from the Web 2.0 and social networking services. Creating such a system in the context of the medical home is perfect, because the structural changes to the health care delivery system created by the medical home mirror the patient-centric framework for utilizing social media tools described earlier in this paper.

Current EMR/EHR systems are derivative from the large hospitals and companies that have spent millions of dollars developing systems that are disparate and inoperable. The result

has often been to separate further the lines of communication and teamwork between physicians -- creating a terrible convolution of medical data that is neither available nor useful when it is truly needed. This has created the interoperability nightmare that the Office of The National Coordinator for Health Information Technology is working hard to solve by developing new standards for a nationwide Health Information Exchange.[33] However, this system, while embracing the free flow of patient data between providers, is being designed to allow the exchange of static documents that are the electronic equivalent of a sheet of paper containing patients' information. These standards being developed do not have the dynamic, parsed, and tagged data containers that are currently being implemented throughout the Web 2.0 to create seamless interactions among millions of users. If the government sponsored a framework that focused more on handling data according to these principles, then a privatized system of interchanging health data that operates alongside existing EMR/EHR strategies could be realized.

Then, on top of this system, private companies and EHR vendors could deploy application programming interfaces (APIs) to build new extensions on top of the government's standards to create an interchange of data that is extensible, flexible, and interoperable. Such collaboration between federal and private organizations could lead to a health information system that mirrors the system of web developers whom must follow standards to ensure secure reliable transmission across the standards-based Internet.

Once a system such as the above allows for a platform to exchange parsed patient data, medical homes and other providers could authenticate themselves for access to such a platform and begin using it to handle patient data. In such a system, I envision that patients would have a medical home, with a physician that is assigned to represent them in the system. This will allow all other physicians and specialists to see this connection and coordinate their care with the

patient's home doctor. All patients and health care providers would have accounts, including pharmacists, while the patients would be able to manage their own privacy in which providers may communicate with each other. A patient's medical home physician would have automatic access to all of the records pertaining to that patient from other physicians unless the patient specifically denied access to certain providers. When a patient visits a new provider that does not have access, the patient can simply type or present their personal secure key into that doctor's computer or mobile device, and she will automatically be granted the info needed from other providers.

Although much of this is wishful thinking for the future, if private entities were to agree on a certain set of standards, even deeper integrations could be made between a patient's various health care providers and that patients personal data. These integrations would allow for such things as

- A problem list, medication list, and allergy list visible to all doctors and pharmacists, along with wiki-like collaboration complete with which doctors and pharmacists are managing which conditions and medications, regardless of health system, along with notations and time-stamped changes.

- Charts that intelligently integrate a patient's past information, and organize themselves by provider, or by acute problem or chronic condition, via tagging, smart data detection, and indicators that help automatically push the most important data to the forefront.

- A universal format for storing and accessing imaging across different providers.

- A calendar and location-aware function that integrates providers and patients to provide details of medication management, locations for appointments, and home

assignments like self-glucose or blood pressure monitoring. These details could

then synchronize with patient's smartphone and home medical devices.

These ideas, although they remain remote from implementation as of yet, represent some

of the possibilities inherent in a future "social EHR." This paper has sought to demonstrate that

both patients and providers are interested in new and different ways to communicate with each

other. They are already adept at using social networking tools such as Facebook, and younger

generations will inevitably seek such integrated, mobile, and well-designed interfaces to manage

their health care. It is difficult to imagine a scenario that could lead to the exchange of health

information that is as simple and seamless as tweeting, yet incredibly more secure and private.

However, government and private organizations should continue to work together to research,

rebuild, and revise our current EHR systems from ones that see the patient as a passive entity that

should simply be described, and give patients the system they deserve – one that puts them at the

center of a collaborative, integrated, and contributory medical home – in essence, we should

strive for EHR 2.0.

Limitations

There were many limitations in undertaking the broad, vague, and sometimes overwhelming task of attempting to understand how social media and the rapid changes inherent in online communications may in-turn change the way we communicate about health. Besides the limitations involved in any form of survey research, this effort was particularly challenged by the time and resource constraints imposed on a master's student completing his final task.

The most limiting factors of this study are ones common to many survey projects. With constraints of time and resources, as well as incentives, this study was primarily limited in its ability to recruit participants for both surveys. The limited number of patients and providers surveyed, distributed among four family practice clinics in North Carolina, significantly restricted the ability of the research to find significant data, as well as the generalizability of that data to other populations. Additionally, the accuracy of self-reports of specific Internet and online service use may be affected by recall bias and the respondents' comprehension of the survey questions.

Another limiting factor of this study became evident when collecting the paper survey boxes from the clinics. Although the patient and provider data were aggregated and analyzed as a whole, it was evident when collecting the surveys that the UNC family practice clinic was much busier and had collected many more surveys in its boxes than had the other three clinics. Since the UNC clinic is also located in a predominately higher educated and more affluent area than are the other participating clinics, it is likely that this may have contributed selection bias towards individuals who have better access and ability to use the types of online services that the surveys asked about.

Finally, the original design of the paper involved using a method of qualitative analysis for analyzing a number of elite-stakeholder interviews on the broader policy-based subject of EHRs and the possibilities of incorporating such social networking principles and ideas into them, but because of a very low response rate (two of ten) from the stakeholders contacted, this part of the study was relegated to providing further illustrative background in analyzing the results of the two surveys.

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Appendix 1: Patient & Provider Survey Materials

Since they originated as separate documents, the following materials are added to this appendix as separate pages in the following order:

1. Letter to clinics for recruitment to survey portion of study

2. Survey administration guide for the clinics

3. Patient survey

4. Print version of online provider survey

5. Clinic flyer for provider survey

6. Sign attached to box for patient survey

Julian Willoughby

101 Rock Haven Rd
Apt A103
Carrboro, NC 27510

T 336 749 8845
Julian0714@gmail.com

[Date]

Subject Line: UNC med student needs your clinic's help in a study regarding health care and technology.

[NAME OF CLINIC CONTACT]
Title
Company Name
4321 First Street
Anytown, State ZIP

Dear [NAME],

My name is Julian Willoughby, and I am a UNC medical student pursuing a master's in public health, also at UNC. As a health care provider who has hosted many UNC medical students such as myself, you have already been extremely important not only in our personal education, but the education of many future doctors, and the health of future patients. I want to first thank you for the valuable time, knowledge, and teaching that you have already so generously given to the education of future health care providers.

I am writing you today to ask if you would be willing to have your clinical staff and patients participate in a IRB approved study (IRB#11-0972) that consists of two short surveys. These surveys will generate useful information for my master's paper, the final requirement for the UNC master's in public health. My faculty advisor for this paper is Dr. Sue Tolleson-Rinehart, the co-Associate Director of the Health Care and Prevention concentration in the UNC School of Public Health. This paper will explore the possibility of using Web 2.0 and social networking technologies to improve patient communication with both their providers and other patients. Your clinic's participation would make a vital contribution towards my paper, and the understanding of how patients and providers view emerging technologies in health care.

If you are willing to participate, I will conduct the survey at your clinic in two parts. First, I will personally deliver or mail your office paper surveys, along with a sign, and a secure collection box to be set up in a prominent area of your waiting room. I will include a written set of instructions for your staff in how to handle the surveys, as well as make myself available for any questions or concerns. Second, I will provide your office with a URL for an online survey to be taken by the licensed health care providers in the clinic (RN, PA, MD, DO, NP etc.). Both surveys simply ask questions relating to personal use of technology, and personal feelings regarding technology and health care. Individual participation in both of these surveys is completely VOLUNTARY and ANONYMOUS. I will not be collecting any identifying information, or personal health information. The survey will collect information from on or about June 3rd until June 17th, at which point I will provide your office packaging and postage to return to me the paper patient surveys. If you have any questions or concerns, please feel free to contact me using any of the methods provided above, I would love to hear from you!

Thank you so much for your consideration,

Julian

Julian Willoughby

Social Networking in Health Care

A Study by Julian Willoughby, at the University of North Carolina at Chapel Hill

IRB Study # 11-0972

Principal Investigator:	Julian Willoughby
UNC-Chapel Hill Department:	Public Health Leadership Program
Faculty Advisor:	Sue Tolleson-Rinehart PhD
UNC-Chapel Hill Department:	UNC Center for Education and Research on Therapeutics and Departments of Public Health Leadership, Pediatrics, and Political Science
Advisor Phone #:	(919) 843-9477
Advisor e-mail:	suetr@unc.edu

Study Contact telephone number: (336) 749 8845

Study Contact email: Julian_Willoughby@med.unc.edu

Instructions for Administering the Patient and Provider Surveys

Thank you so much for helping me with my master's paper by agreeing to host this survey! You will be or have already received a package containing the following materials needed to collect the patient and provider surveys:

1. 200 paper patient survey forms
2. 10 flyers for provider surveys
3. Collection box for patient survey forms
4. Sign for patient surveys
5. FAQ for front desk staff re: surveys
6. Packing tape and FedEx shipping label (if outside the Chapel Hill area) to return patient surveys

Patient Survey Administration:

For the patient survey, starting **June 3, 2011,** you may distribute the forms in two possible ways:

1. *Preferred:* A secretary or administrator may hand the paper survey to the patient at check in, and ask them if they would be "willing to submit a VOLUNTARY and ANONYMOUS survey to help a UNC medical student study how patients talk with their doctors." If you use this method, please place the collection box and its

accompanying sign near the area of check-in and indicate that they should place the form in the box when they are done.

2. If you do not wish to hand out surveys, please place the paper surveys in a stack, along with the collection box and sign on a table in a visible area of the waiting room. If you can, please still inform the front desk staff to tell patients about the survey.

3. Post the attached FAQ sheet in a prominent location at the front desk for the staff to see at all times, and inform them to tell patients about the survey.

4. At the end of the day on **June 17, 2011**, please take the collection box and seal the opening with the provided tape, then apply the provided FedEx shipping label and you may either drop it off at any FedEx location, or you can schedule a pickup at your office.

Provider Survey Administration:

For the provider survey, please do the following:

1. Post the included provider survey flyers in prominent areas of staff workspaces, bathrooms, break-rooms, and offices.

2. **Email** the following URL to the entire office:

http://tinyurl.com/4providers

Along with the following message:

"Please take 5 minutes to help a UNC medical student with his master's paper by filling out this short survey!

It is VOLUNTARY and ANONYMOUS, and will only ask about thoughts and feelings regarding new technologies and how it they influence patient-provider communication.

Your input will make a vital contribution towards a student's education, and further our understanding in how we can implement new communication technologies in health care.

Thank you!
(clinic administrator's name)"

65

UNC
GILLINGS SCHOOL OF
GLOBAL PUBLIC HEALTH

PATIENT SURVEY FAQ

This sheet will help anyone at the front desk handle patient questions regarding the survey.

Q: **"What's this survey for?"**

A: This survey is a part of a UNC medical student's master's paper. He is trying to understand how patients use the Internet and social networking sites like Facebook, and if they would be comfortable using similar tools to communicate with their doctor.

Q: **"Do I have to fill this out?"**

A: No, it is VOLUNTARY and ANONYMOUS, but it will go a long way towards helping a UNC medical student finish his master's paper needed for graduation.

Q: **"Do I have to put my name on it?"**

A: No, please don't. This survey is ANONYMOUS.

Q: **"Where do I put it when I'm done?"**

A: You can put it in the slot of the box located here. (then show them where the box is)

Q: **"Will you, my doctor, or the clinic see the results? Who WILL see the results?"**

A: The survey is ANONYMOUS, only Julian, a medical student, and his school advisor will see the individual surveys. The results of all of the surveys will be put together and analyzed for his master's paper.

Q: **"Do I get anything for filling it out?"**

A: By filling it out you should know that you have done a great deal towards helping out a UNC medical student finish his education!

I am Julian Willoughby, a medical student at UNC, I am doing a survey of how patients might like to use new technologies to work with their doctors. The survey is voluntary, you don't have to answer it, and you cannot be identified in any way. This is an IRB exempt study. If you have questions you may contact me directly at 336-749-8845 or or my advisor, Sue Tolleson-Rinehart at 919-963-9477. Thank you for your help!

1. How do you use the Internet? Choose all that apply.

- ○ home computer
- ○ work computer
- ○ library
- ○ phone
- ○ I don't use the internet

2. Do you get on the Internet with a phone or mobile device?

- ○ Yes, and I use:
  - ○ iPhone / iPod touch / iPad
  - ○ Blackberry
  - ○ Android
  - ○ Palm
  - ○ Nokia
  - ○ Other_____
- ○ No

3. Do you use any of these services? Choose all that apply.

- ○ Facebook
- ○ Twitter
- ○ MySpace
- ○ LinkedIn
- ○ YouTube
- ○ Yahoo! Answers
- ○ Other_____

4. How often do you use them?

- ○ once a month
- ○ once a week
- ○ many times a week
- ○ every day
- ○ many times a day

5. How often do you check email?

- ○ less than once a month
- ○ once a week
- ○ multiple times a week
- ○ every day
- ○ multiple times a day
- ○ don't have email

6. Do you pay bills online or use the Internet for banking?

- ○ yes
- ○ no
- ○ no, but I would like to

7. Have you used the internet to look up things about your health or your family's health?

- ○ very often
- ○ often
- ○ sometimes
- ○ rarely
- ○ never

8. How do you feel about your privacy on the Internet?

- ○ very comfortable
- ○ somewhat comfortable
- ○ somewhat uncomfortable
- ○ very uncomfortable

9. How would you feel about having list of your medications stored online that all your doctors can see?

- ○ very comfortable
- ○ somewhat comfortable
- ○ somewhat uncomfortable
- ○ very uncomfortable

10. How often do you need to talk with a doctor, nurse, or pharmacist?

- ○ almost never
- ○ a few times a year
- ○ a few times a month
- ○ weekly or more

11. How do you usually talk with them?**

- ○ in-person
- ○ phone
- ○ email
- ○ fax
- ○ other_____

12. Are appointment reminders helpful?

- ○ yes
- ○ no

13. What kinds of reminders would you like?**

- ○ appointment card
- ○ personal phone call
- ○ automated phone call
- ○ email or text message
- ○ website like Facebook, Twitter, etc.

14. Have you ever forgotten your doctor's instructions?

- ○ never
- ○ rarely
- ○ sometimes
- ○ most of the time
- ○ always

15. What if a website or smartphone could help you and your doctors keep track of your medicines? Would you be interested in that?

- ○ Very Interested
- ○ Somewhat Interested
- ○ Somewhat Uninterested
- ○ Not at all interested

16. Here are some different ways to get in touch with your doctor. If your doctor offered these, would you use them? (circle a spot spot on the lines below)

a. email

Unlikely |—|—|—| Likely
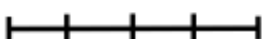
b. website

Unlikely |—|—|—| Likely

c. smartphone

Unlikely |—|—|—| Likely

d. texting

Unlikely |—|—|—| Likely

17. How interested would you be in tracking things like your weight, blood pressure, or blood sugar on a smartphone, if cost was not a factor?

- ○ Very Interested
- ○ Somewhat Interested
- ○ Somewhat Uninterested
- ○ Not at all interested

18. What is your age? _____

19. Are you . . .   Male   or   Female

20. How may years of school have you completed?

- ○ Less than 10
- ○ 10 - 12
- ○ 12 - 14
- ○ More than 14

Thank you! Please put in box labeled "surveys."

Default Question Block

Health Care Providers & Technology Survey

Hello, I am Julian Willoughby, an MPH candidate between my third and fourth years of medical school at UNC.

I am studying how health care providers at primary care clinics currently use technology, and their attitudes towards new technologies in communicating with patients. The aggregated responses from this survey will provide important data for my master's paper.

Thank you for your willingness to take this survey. It should only take about 5-10 minutes of your time.

This is an IRB exempt study. Completing this survey provides no more than minimal risk to you. By clicking on the button below, you are agreeing to participate, but you are free to leave the survey at any time simply by closing your browser.

If you have any questions or concerns about this survey or my master's paper, please feel free to contact:

Julian Willoughby, student investigator
julian_willoughby@med.unc.edu
336-749-8845

Dr. Sue Tolleson-Rinehart, faculty advisor
suetr@unc.edu
919-843-9477.

Thank you! If you are willing to start the survey, please click the button below to go to the first screen of the survey.

Section 1: Personal use of technology

Which of the following computer devices do you regularly use? Check all that apply.

- ☐ home computer
- ☐ office computer
- ☐ smartphone / PDA
- ☐ tablet computer at home
- ☐ tablet computer at work
- ☐ other
    [   ]
- ☐ I don't regularly use any computer devices

Please estimate the percentage of your total internet / email use on each of the following devices (put zero if do not use them at all):

» home computer   [0]

» office computer   [0]

» smartphone / PDA	0
» tablet computer at home	0
» tablet computer at work	0
» other [ ]	0
» I don't regularly use any computer devices	0
Total	**0**

Which smartphone / PDA platforms do you use? Check all that apply.

- ☐ Blackberry
- ☐ iPhone / iPad / iPad
- ☐ Android
- ☐ Nokia
- ☐ Palm
- ☐ Other
  [   ]

Which, if any, of the following social networking services do you use? Check all that apply.

- ☐ Facebook
- ☐ Twitter
- ☐ LinkedIn
- ☐ YouTube
- ☐ Yahoo! Answers
- ☐ MySpace
- ☐ Flikr
- ☐ other
  [   ]

How often do you these social networking sites?

	None	Less than Once a Month	Once a Month	2-3 Times a Month	Once a Week	2-3 Times a Week	Daily	Multiple times per day
» Facebook	○	○	○	○	○	○	○	○
» Twitter	○	○	○	○	○	○	○	○
» LinkedIn	○	○	○	○	○	○	○	○
» YouTube	○	○	○	○	○	○	○	○
» Yahoo! Answers	○	○	○	○	○	○	○	○
» MySpace	○	○	○	○	○	○	○	○
» Flikr	○	○	○	○	○	○	○	○
» other [ ]	○	○	○	○	○	○	○	○

How often do you check an email account?
- ○ when notified

70

○ several times a day

○ at least daily

○ 2-3 Times a Week

○ once a Week

○ 2-3 Times a Month

○ once a Month

○ less than Once a Month

○ don't use email

Section 2: Office use of technology

How do you communicate with specialists and other providers who share the care for your patients? Check all that apply.

☐ in-person

☐ phone

☐ fax

☐ email

☐ EMR-based messaging

☐ via other staff

☐ social media (Facebook, Twitter, LinkedIn, etc.)

☐ other

    [   ]

Please estimate the time you spend using each method in percentages. Please make sure your percentages total to 100.

» in-person   [0]

» phone   [0]

» fax   [0]

» email   [0]

» EMR-based messaging   [0]

» via other staff   [0]

» social media (Facebook, Twitter, LinkedIn, etc.)   [0]

» other [   ]   [0]

Total   [0]

Does your clinic use an electronic medical record system (EMR)?

○ Yes

○ No

How would you rate the following features of your clinic's EMR?

	don't have and don't need	doesn't work well at all	works, but not very well	works pretty well, but could be better	works well for me	don't have but would like

Ease of use	○	○	○	○	○	○
Reliability	○	○	○	○	○	○
Electronic prescribing	○	○	○	○	○	○
Communication with patients	○	○	○	○	○	○
Using system remotely	○	○	○	○	○	○
Viewing test results	○	○	○	○	○	○
Communication with providers in same practice group	○	○	○	○	○	○
Viewing / editing problem list	○	○	○	○	○	○
Viewing / editing drug list	○	○	○	○	○	○
Communication with providers outside practice group	○	○	○	○	○	○
Integrated access to medical references	○	○	○	○	○	○
Ability to view medical images	○	○	○	○	○	○
Usefulness of search functions	○	○	○	○	○	○

How would you rate your overall satisfaction with your clinic's EMR?

○ Very Dissatisfied

○ Dissatisfied

○ Somewhat Dissatisfied

○ Somewhat Satisfied

○ Satisfied

○ Very Satisfied

What would most like to see changed about your clinic's EMR?

Does your clinic plan on implementing an EMR within the next 5 years?

○ Yes

○ No

○ Don't know

Please think not just of your practice, but of the whole health system: what are the largest barriers to implementing EMRs? Please rank the following.

Cost

Changing current workflows

Lack of data exchange with other systems

Training staff / learning a new system

Lack of financial incentives

Effort of converting paper records

Do you think current EMR systems save money?

○ Definitely yes

○ Probably yes

○ Maybe

○ Probably not

○ Definitely not

Section 3: Communication with patients

How do you communicate with your patients? Check all that apply.

☐ in-person

☐ phone

☐ fax

☐ email

☐ EMR-based messaging

☐ via other staff

☐ social media (Facebook, Twitter, LinkedIn, etc.)

☐ other

[   ]

Please estimate how much time you spend communicating with your patients, using the following methods, in percentages. Please make your percentages add to 100.

» in-person	0
» phone	0
» fax	0
» email	0
» EMR-based messaging	0
» via other staff	0
» social media (Facebook, Twitter, LinkedIn, etc.)	0
» other [ ]	0
Total	0

How does your clinic send patients appointment reminders? Check all that apply.

☐ Letter

☐ Card from previous appointment

☐ Staff calls

☐ Automated phone call

☐ Staff sends email

☐ Automated email

☐ Automated text message

☐ Social networking tool (Facebook, Twitter, etc.)

☐ We don't send reminders

How do you find out when a specialist has changed or added something to your patients' medication regimen? Please drag and drop items into the appropriate groups.

Items

Ask the patient if there have been any changes in medications

Get a fax / call / email / note from specialist

Automatically updates in EMR when specialist prescribes

Patient brings in bag of all medications

Patient keeps list of updated medications

Check with patient's pharmacy

other

[   ]

Always

Sometimes

Never

Would you be interested in using a system that allowed all of a patient's providers, regardless of practice group, to access a unified, synchronized medication list?

○ Very Interested

○ Somewhat Interested

○ Not Very Interested

○ No Interest

Do you think that patients would want to be able to access an always up to date medication list shared by all of their providers via the Internet?

○ Definitely yes

○ Probably yes

○ Probably not

○ Definitely not

Would you be interested in using social networking tools such as Facebook, Twitter, etc. to communicate with patients?

○ Very Interested

○ Somewhat Interested

○ Not Very Interested

○ No Interest

Do you think patients would be interested in using social networking tools such as Facebook, Twitter, etc. to communicate with you?

○ Definitely yes

○ Probably yes

○ Probably not

○ Definitely not

How would you rate your interest in having patients use smartphones to aid in tracking various indicators such as pain levels, blood glucose, and blood pressure?

○ Very Interested

○ Somewhat Interested

○ Not Very Interested

○ Not Interested at all

On the whole, do you think **most** of your **patients** would be able to use smartphones to aid in tracking various indicators such as pain levels, blood glucose, and blood pressure?

○ Definitely yes

○ Probably yes

○ Probably not

○ Definitely not

facebook & health care?

a research study to better understand how health care providers use social networking and technology.

Just visit:

www.tinyurl.com/ 4providers

Health Care Providers & Technology Survey
Julian, a UNC med student is conducting a research study on how patients and providers use technology to communicate, and would be most grateful if you would take 5-10 minutes to fill out the survey at the link above. Any health care provider is eligible to participate, and your incentive is knowing you've helped a student finish his education.

Who: ANY health care provider in this clinic

When: June 3rd - June 17th, 2011

How: Just enter **www.tinyurl.com/ 4providers** in your web browser. Your responses are voluntary and anonymous!

Contact: **Julian** at **336-749-8845** with any questions.

UNC Tech Survey www.tinyurl.com/ 4providers

UNC Tech Survey www.tinyurl.com/ 4providers

UNC Tech Survey www.tinyurl.com/ 4providers

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UNC Tech Survey www.tinyurl.com/ 4providers

UNC SURVEY

a research study to understand how patients may use social networking and technology in their health care.

Questions?

Ask someone at the front desk

or

Call Julian directly at: 336-749-8845

Julian Willoughby, a UNC med student is conducting a research study on how patients may use technology to communicate with their doctors.

If you would like to help, please take 5-10 minutes to fill out this paper survey. Your response is VOLUNTARY and ANONYMOUS. Any adult patient is eligible to participate, and you will know that you have helped a student finish his education!

PLEASE PLACE SURVEY IN BOX
THANK YOU!

Appendix 2: Elite-Stakeholder Interview Materials

Since they originated as separate documents, the following materials are added to this appendix

as separate pages in the following order:

1. Recruitment email for requesting interviews with elite-stakeholders

2. Interview protocol used to administer and guide interviews.

<div align="center">

Julian Willoughby
101 Rock Haven Rd
Apt A103
Carrboro, NC 27510
T 336 749 8845
Julian0714@gmail.com

</div>

[Date]

Subject Line: Request to be interviewed by medical student for research study on health care and technology

[NAME OF ELITE STAKEHOLDER]
Title
Company Name
4321 First Street
Anytown, State ZIP

Dear [NAME],

My name is Julian Willoughby, and I am a UNC medical student pursuing a master's in public health, also at UNC. I am writing you today because of your eminent position in the fields of health care informatics and electronic health records. I am writing a master's paper that involves the policies, politics, and future of electronic health records and health data exchange. I am hoping that you may be willing to assist me in writing my paper by providing a brief telephone interview where you would provide me with your thoughts and opinions on such topics.

My master's paper is the final requirement for the UNC master's in public health. My faculty advisor for this paper is Dr. Sue Tolleson-Rinehart, the co-Associate Director of the Health Care and Prevention concentration in the UNC School of Public Health. In order to collect data to support my paper, I will conduct an IRB approved study (IRB#11-0972) that consists of a patient survey, a health care provider survey, and interviews with elite stakeholders, such as yourself, specifically regarding emerging technologies in health informatics. More specifically, I hope to explore the possibility of using Web 2.0 and social networking technologies to improve patient communication with both their providers and other patients, while also analyzing the current policies and politics involved in shaping the future of electronic health records. Your participation would make a vital contribution towards my paper, and help me further understand how trends in technology and policy will shape the future of health care.

If you are willing to participate, our interview will be a one-to-one and private phone conversation consisting of several questions, all in open-ended format. It should last anywhere from 20 to 40 minutes, depending on the availability of your time and what you want to tell me. I would like to record this interview on a digital voice recorder to make absolutely sure that I have the most accurate record of your comments, but I will not record this interview without your permission. If you do grant permission for this conversation to be recorded on a digital audio recorder, you have the right to revoke recording permission and/or end the interview at any time. I will transcribe the interview as soon as possible, and any audio data made of the interview will be kept in a locked cabinet and destroyed after the transcript is made. Transcripts will be encrypted on my computer and the computer of my faculty advisor, Dr. Tolleson-Rinehart, and they will be controlled by a password. Finally, I will provide you with a copy of the transcript of your interview.

I am available at any time to conduct this interview at your convenience, and I will gladly work to set up a time that is best for you. If you have any questions whatsoever, please feel free to contact me at the information provided above.

Thank you so much for your consideration,

Julian

Julian Willoughby

Social Networking in Health Care
A Study by Julian Willoughby, at the University of North Carolina at Chapel Hill

Information Sheet

IRB Study # 11-0972   **Consent Form Version Date:** May 2011

Principal Investigator: Julian Willoughby
UNC-Chapel Hill Department: Public Health Leadership Program

Faculty Advisor: Sue Tolleson-Rinehart PhD
UNC-Chapel Hill Department: UNC Center for Education and Research on
                                           Therapeutics and Departments of Public Health
                                           Leadership, Pediatrics, and Political Science

Advisor Phone #:   (919) 843-9477
Advisor e-mail: suetr@unc.edu

Study Contact telephone number: **(336) 749 8845**

Study Contact email: Julian_Willoughby@med.unc.edu

[Introductory script, embedding fact sheet and consent information]:

Hello, I am Julian Willoughby. Thank you so much for talking with me today. I am an MD/MPH candidate at The University of North Carolina at Chapel Hill. I am conducting research to fulfill the requirements of the Master's of Public Health degree in the Health Care & Prevention program.

I have asked to interview you because of your knowledge of electronic health records and health information technology. I am talking to people like you who are involved with health information technology in the context of research, business, and public policy. I am interested in your views about the current state of electronic health records, as well as the future for digital communications in health care.

My faculty adviser is Dr. Sue Tolleson-Rinehart, who is a faculty member of the UNC Schools of Public Health and Medicine. We hope this analysis will help people better understand the implications of the social media revolution and the emergence of "Web 2.0" technology on health information technology. My advisor and I do hope that the results of this study will be published in a scholarly journal.

The interview has several questions, all in open-ended format. The interview should last anywhere from 20 minutes to one hour, depending on the availability of your time and what you want to tell me. I would like to record this interview on a digital voice recorder to make absolutely sure that I have the most accurate record of your comments. You may request the taping to stop at anytime. I will not record this interview without your permission. If you do not wish to be audio recorded, I will simply take handwritten notes. I will transcribe the interview, and I will email you a copy of the transcript as soon as it is completed.

The audio data made of the interview will be kept in a locked cabinet and destroyed after the transcript is made. Transcripts will be encoded on my computer and the computer of my faculty advisor, Dr. Tolleson-Rinehart, and they will be controlled by a password. No one else has this password. I will provide you with a copy of the transcript of your interview.

Your participation in this study is completely voluntary. Your choice of whether or not to participate will not influence your future relations with the University of North Carolina at Chapel Hill. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty. At any particular point in the interview, you may refuse to answer any particular question or stop participation altogether.

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact me by phone at **(336) 749 8845** or by e-mail at **Julian_willoughby@med.unc.edu.**

Dr. Tolleson-Rinehart and I hope to publish the results of this project, and will be glad to make findings available to you. For any questions about the study, please send a message to **suetr@unc.edu** or call **(919) 843 9477.**

Risks and Benefits: I know of no risk to you from completing this survey. While you may not benefit personally from completing this survey, I believe that you will be helping the larger health care community by enabling us to understand the public health implications that new information technologies and standards may have on the future of electronic health records.

Before we continue, would you please agree to any or all of the statements I'm about to read?

☐   I AGREE to having this interview tape recorded with a digital voice recorder.

☐   I GIVE PERMISSION for the following information to be included in publications resulting from this study:

☐ **my name**   ☐ **my title**   ☐ **direct quotes from this interview**

_____   _____

Name of Participant (please print)   Date

Thank you for your help with my project! Now we are ready to begin.

Electronic Health Record questions:

Stakeholder surveys will focus on current methods for EHR, ideas about social networking and social media, problems in current EMRs (including interoperability, and patient communication), politics and policy of EHRs

What, in your opinion, are the biggest problems facing EHR technology today?

→ room for follow up questions, appropriate to interviewee response here.

How do you think we will overcome these problems?

The Health Information Technology for Economic and Clinical Health Act was enacted as part of the American Recovery and Reinvestment act of 2009, and is designed to promote the widespread adoption and standardization of health information technology. How has this act changed your approach to EHRs?

How far is your organization towards reaching "meaningful use" criteria?

The Office of the National Coordinator for Health IT (ONC) has created "Direct Project" pilots to help further the development of EHRs. Do you think that the federal government is doing enough to help the development of EHRs?

The past decade has seen the rise of social networking to become a daily part of many people's lives. Do you or your organization utilize social media networks such as Facebook or YouTube to communicate with patients or customers?

→ If you don't, why not? Have you considered it?

Do you see EMR technology expanding towards the use of mobile devices like smartphones and tablets?

if so, how are you planning on implementing such use by doctors and patients?

Have you heard of Google Health? If so, what are your thoughts?

What are your thoughts on utilizing social networking with EHRs?

What steps are you taking to improve interoperability in EHRs?

What features are physicians most asking for in EHRs?

Are patients interested in using technology to access their EHRs? Communicate with their doctors?

Would you support a government sponsored or developed standard for exchanging health information data? Why or Why not?

How would you imagine a standard for exchanging health information data should work?

What are your thoughts on where the industry is moving in terms of changing the way health information data is being created, stored, and exchanged?

Final Question:

Thank you again for your time! Is there anything else you'd like to say, anything I haven't asked that I should have?