

1-2014

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### Recommended Citation

Sherer, Susan A. (2014) "Patients Are Not Simply Health IT Users or Consumers: The Case for “e Healthicant” Applications," *Communications of the Association for Information Systems*: Vol. 34 , Article 17.

DOI: 10.17705/1CAIS.03417

Available at: <https://aisel.aisnet.org/cais/vol34/iss1/17>

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# Communications of the Association for Information Systems

CAIS 

## Patients Are Not Simply Health IT Users or Consumers: The Case for “e-Healthicant” Applications

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### Abstract:

Health IT applications today generally incorporate patients as passive users or consumers of information rather than active individuals who, in concert with their providers, are motivated and jointly responsible for their own good health. This article uses the healthcare value chain concept [Porter and Teisberg, 2006] as a framework to identify gaps in patient-centered e-health applications. While patient diversity poses challenges similar to consumer diversity for application design, consumer-centric design is limiting for patient-centered e-health because patients should not simply consume health care; they need to interact at multiple stages, alter their behaviors, and actively participate. This article raises critical research questions specific to this challenge. It defines a new term, “healthicant,” to motivate a research focus on technology-enabled applications that support individuals responsible for their own health and well-being, and who seek appropriate assistance as needed to prevent, diagnose, prepare, intervene, rehabilitate, monitor, and manage their health throughout their lifetime. The article contrasts the objectives of healthicants with both healthcare providers (for whom most health IT has been created) and more passive patients (for whom current “patient-centered” applications are evolving), in order to identify important gaps today. These include systems that support healthicant motivation, measurement, analysis, data mining, real-time personalized feedback, and multidirectional communication.

**Keywords:** mobile health; patient-centered e-health; healthicant; healthcare value chain

**Editor's Note:** The article was handled by the Department Editor for Special Section on Patient-centered e-Health

Volume 34, Article 17, pp. 351–364, January 2014

### I. INTRODUCTION

The United States spends more per capita on health care than any other country, and still has one of the highest growth rates in healthcare spending, rising from 9 percent of GDP in 1980 to over 17 percent today. Yet, this spending has not equated to higher quality care. Health IT has been identified as one of the critical forces that could significantly improve healthcare delivery and quality. Government initiatives such as creation of the National Coordinator for Health Information Technology and the 2009 HITECH Act that provides funds for the development of electronic health records are indicative of the U.S. government’s recognition of the role of health IT in improving care and reducing costs. Yet, most of the investment has been in applications such as electronic health records that support providers rather than patients [Wilson, 2009].

Empowering patients to engage in and manage their own health has great potential for efficient and effective care. Tele-health applications and self-management tools have been shown to have a positive impact on healthcare process outcomes [Finkelstein et al., 2012]. Improved health outcomes and reduced costs have been demonstrated when empowering chronically diseased patients [Bodenheimer, Lorig, Holman and Grumbach, 2002; Holman and Lorig, 2004; Warsi, Wang, LaValley, Avorn and Solomon, 2004]. But effective self-management of individuals with chronic disease and multiple comorbidities requires innovative strategies to optimize communication, improve access to timely and accurate information, and maximize patient support [Bodenheimer, Chen and Bennett, 2009; Holman and Lorig, 2004]. Clearly, empowering individuals to prevent disease can also significantly reduce healthcare costs. For example, obesity has been shown to raise annual medical costs by \$2,741 per person (in 2005 dollars) [Cawley and Meyerhoefer, 2012]. Empowering and motivating patients to prevent obesity can therefore have significant impacts on healthcare costs both individually and for the population as a whole. And it is expected that empowered patients who are involved as partners in the care process can also improve quality of acute care while reducing costs. For example, knowledgeable patients can recognize and prevent duplicate testing and participate in selection of best treatment options and providers for their conditions.

Traditionally, most health IT applications were developed to support the care provider’s objectives, which can differ from those of the patient. These are primarily clinical and transactional systems used within healthcare organizations [Wilson, 2009]. They generally assume high levels of knowledge and expertise as they were designed for the more homogeneous populations of the providers compared to patients. Therefore, they often limit patient access to important information. For example, patient portals only allow patient access to limited portions of the electronic health records such as medication lists. Patients are also provided information from multiple sources through the Internet. In fact, the Internet has become a major resource for health information, with 61 percent of all U.S. adults searching online for health information in 2009 [Fox and Jones, 2009]. Typically, patient applications involve one-way communication from the source to the patient; few enable active patient participation in providing, analyzing, and interpreting information.

Yet, patients must be integrally connected with providers throughout the value chain and should be actively involved in maintaining their own good health. Unlike traditional consumers who interact primarily with the final portion of the value chain, patient interactions occur at multiple points throughout the value chain. The patient does not simply consume the output of the value chain. The patient should be integrally involved in every aspect. In the traditional value chain, for example, the consumer pays for the quality of the end product or service. As long as the organization delivering the product ensures quality of the individual components, the consumer has no need to interact with the purchasing process. However, if the patient is to remain healthy, she needs to be involved in every stage of the value chain, beginning with prevention. Patients have an important joint responsibility for following and maintaining a healthy lifestyle. Patients must be motivated to participate as well as modify their behaviors to ensure healthy lifestyles. Patient-centered e-health needs to be not only patient-focused, but patient-active, and patient-empowered [Wilson, 2009]. Those interacting with these systems should not simply use or consume them; they must be motivated to be responsible for their own health and interact with all parts of the healthcare delivery value chain.

Today, technologies are evolving that can enable more active engagement of the patients. “PHRs [*personal health records*] are poised to alter patient engagement with their health care” [Agarwal, Gao, DesRoches and Jha, 2010]. Social networks, such as PatientsLikeMe, enable sharing of experiences. As more individuals provide input to such networks, rather than just digest the information in these applications, their interaction with the healthcare delivery system changes. Emerging technologies, such as mobile applications for patients coupled with new sensor

technology for remote and self-monitoring, can further increase the responsibility of patients to become more involved in their own healthcare delivery. Mobile applications that support healthy lifestyles, including appropriate diet control and exercise tracking, are emerging.

There has not been much research that attempts to categorize patient-centered applications based upon the objectives of active participants, nor an understanding of how these systems should differ from either provider-based applications or current patient-based applications, particularly in motivating new patient responsibilities. In a report for the Agency for Healthcare Research and Quality, Agarwal and Khuntia [2009] conclude that “A key gap that needs to be addressed is a comprehensive and situated understanding of what individuals actually do when they manage their personal health information and what challenges they face in doing so effectively.”

This article uses the healthcare value chain concept [Porter and Teisberg, 2006] to identify and differentiate types of applications that support various parts of the value chain. It differentiates between provider and patient objectives and activities in order to better categorize and understand types of applications that are needed by patients. While providers and patients share the overall goal of improved health for the patients, specific goals in accessing and using information at each stage of the value chain vary between them. In addition to different objectives, providers and patients have different levels of knowledge and access to information that further differentiate types of applications that would support each. Also, the patient population is much more diverse than the provider population, creating additional challenges for developing patient-centered e-health applications. In fact, it is this difference that has led some to conclude that patient systems design should be consumer focused [Eysenbach, 2000]. However, I believe that patient applications are unique from consumer applications. I suggest that today we should be developing health IT that is directed more to the responsible and interactive patient, not just a consumer of a service or information. I define a new term, the “healthicant,” that highlights the fact that current systems can only support limited objectives of patients, since these systems are narrowly focused and unidirectional, even if they are developed to account for the specific needs of the current patient population. I identify system gaps that exist as I expand the role of the traditional patient/user/consumer to the “healthicant,” a motivated and responsible individual who participates in his or her own care. This article addresses an identified gap in the literature: the need to classify users, use activities, and use contexts [Agarwal and Khuntia, 2009] by focusing on user objectives to help us identify further gaps in the research.

## II. BACKGROUND

There is a growing body of literature on personal health information management and patient-centered e-health applications [Agarwal and Khuntia, 2009; Wilson, 2009]. However, there have been few studies classifying the types of applications. The few classifications that exist are based upon the types of information, activities or use of information, types of systems, or types of technology. Moen and Brennan classified types of information used by individuals within households into three categories: logistic information, personal information relevant to a household member, and reference material. In addition, they identified three different types of activities: observing and assessing a household member’s health conditions; organizing and differentiating information types according to perceived relevance; and obtaining, retrieving, and keeping track of health information [Moen and Brennan, 2005]. Agarwal and Khuntia [2009] classified the literature based upon four categories of devices: tools and artifacts that support (1) information storage, archiving, and retrieval; (2) health monitoring; (3) health information seeking and searching; and (4) infrastructural tools. They also classified personal health information management by sources of information and types of information, as well as its value from a temporal perspective (prospective, ephemeral, working, and retrospective). Others have classified types of systems such as patient registration or reminder systems [Blaya, Fraser and Holt, 2010]. And others have classified patient applications by the type of technology: Internet-based applications, mobile IT devices, or home tele-health applications [Demiris et al., 2008].

These classifications do not incorporate any information about the use of the technology relative to patient objectives in various parts of the healthcare delivery value chain. Moreover, they often assume one-way retrieval of information, which has been the typical involvement of the patient. I believe that there is a need to expand research to consider ways to use information technology to incorporate more involved and responsible users who contribute to the healthcare delivery process.

## III. THE HEALTHCARE DELIVERY VALUE CHAIN

The healthcare delivery value chain provides a framework for classifying how health IT supports the provider’s objectives in delivering care. It can be used to classify the types of systems that have evolved to support providers, the mainstream of health IT. I suggest that this framework can also be used to determine what types of applications are used or needed by patients, through understanding how patient objectives differ from providers in each stage of the healthcare delivery value chain.

Porter and Teisberg introduced the value chain concept to delineate the process of care delivery at the medical condition level [Porter and Teisberg, 2006]. The care delivery value chain begins with monitoring and preventing; progresses through diagnosing, preparing (pretesting and treatments), intervening, and rehabilitating; and ends with monitoring and managing. Cutting across the care cycle are four additional types of care delivery activities: knowledge management, accessing, measuring, and informing. Table 1 describes these activities.

**Table 1: The Healthcare Delivery Value Chain [Porter and Teisberg, 2006]**

Value chain stage	Key provider activities
Monitoring and preventing	Tracking a patient's circumstances, assessing risk, and taking steps to prevent or reduce the seriousness of illness or injury
Diagnosing	Analyzing the situation and creating a treatment plan
Preparing	Planning
Intervening	Performing procedures
Rehabilitating	Supporting recovery and fine tuning plan
Monitoring and managing	Managing a medical condition over time to sustain good results and minimize reoccurrences
Activities that cut across the value chain	
Knowledge management	Measuring results, tracking, training, and improving processes
Accessing	Gaining access to patient (patient visits, movement through care settings, remote consultation)
Measuring	Measuring patient's medical circumstances
Informing	Educating and counseling patient

The healthcare value chain activities are traditionally assumed to be the responsibility of the provider. However, unlike traditional value chains, where the consumer interacts primarily with the final stage of the value chain and simply uses the output, in healthcare the patient is intimately involved in each stage of the value chain. Thus, the patient also has responsibility for activities in each stage of the value chain. For example, a patient should be controlling weight gain to prevent diabetes, following rehabilitation guidelines, or adhering to best practices for managing heart disease.

### Patients Are Not Simply Specialized Users or Consumers of Provider Health IT

Most health IT applications today help healthcare providers carry out activities in each stage of the value chain. For example, monitoring equipment and health records support a provider's ability to prevent problems, as well as monitor and manage their patients. Medical databases support providers' efforts in prevention, as well as diagnosis. All types of computerized medical equipment such as MRIs or CAT scans support intervention. These systems were developed for highly trained professionals. In the last decade, a number of patient-centered applications have been developed to also support patient interaction with activities within each of these stages. However, these are generally informational, providing one-way information from the professional to the patient, as opposed to interactive applications that enable patients to share information and participate in the care process. Table 2 summarizes the different objectives of providers in each stage of the value chain, with examples of provider health IT supporting provider activities, along with examples of evolving patient health IT.

Provider applications have been expanded to provide information to users (e.g., patient provider portals, appointment scheduling, PHR) or electronic resources provide patient information (Internet websites, social networks). Patients are considered to be either specialized users of provider systems or consumers of information. We have not developed many opportunities for patients to interact and participate in their own care processes. One exception is active patients who provide information to social support networks such as PatientsLikeMe.com.

Few PHRs provide any functionality for interpreting content, helping patients understand information, rendering clinical advice, or helping patients take action [Krist and Woolf, 2011]. Few PHRs provide access to physician notes, even though an experiment in which patients were invited to read their provider's notes led to patients feeling more in control of their care with increased medication adherence [Delbanco et al., 2012]. Internet sites provide information that can be used by patients to search for information that could help prevent problems, maintain good health, and understand diagnoses and treatments. Physician-patient email communication is minimal; a survey found that less than 3 percent of physicians reported frequently using email with patients; even when email was used, they did not often adhere to best practices [Menachemi, Prickett and Brooks, 2011]. But many patients today want to participate more fully in their care processes. However, their needs differ from providers in terms of systems

**Table 2: Comparing Provider and Patient Health IT**

Value chain stage	Provider objectives	Provider activities	Provider health IT	Patient health IT
Preventing	Search and access information; monitor and analyze data; motivate behaviors	Medical history, screening, identifying risk factors, communicating prevention programs	Medical databases, office/hospital-based monitoring equipment, health records	Internet sites, support networks, mobile health applications
Diagnosing	Collect and analyze information to make proper diagnosis	Medical history, specifying tests, interpreting data, consulting with experts, determining treatment plans	Diagnostic systems, communication systems, medical databases	Internet websites
Preparing	Communicate with provider partners	Choosing the team, pretesting, pretreatment	Communication	Social support networks, Internet websites
Intervening	Provide successful treatment program	Ordering and administering drugs, performing procedures, counseling	Delivery equipment, electronic prescription refills	Patient provider portals, electronic prescription refills
Rehabilitating	Monitor and analyze	Inpatient and outpatient rehabilitation, therapy fine-tuning, developing discharge plans	Health records	Social support networks
Monitoring and managing	Search and access information, monitor and analyze	Monitoring and managing patient's condition, monitoring compliance with therapy, monitoring lifestyle modifications	Medical databases, health records	Internet sites, social support networks
<b>Activities That Support All Value Chain Stages</b>				
Informing	Communicate and interpret	Patient education, counseling, compliance counseling	Patient communication portals, email	Internet websites
Measuring	Store and retrieve	Tests, imaging, patient record management	Picture archiving and communication (PAC), lab reports, health records	Personal health records (PHR)
Accessing	Retrieve information, communicate	Office visits, lab visits, care sites, remote consultation	Health records	Appointment scheduling, online communications with providers, patient portals

to support their objectives. Patients need systems to help them navigate, interpret, and respond to activities at each stage of the value chain. They need to interact with the healthcare delivery process. For example, to manage chronic conditions, they might wish not only to access critical monitored information, but also to self-manage their conditions through appropriate behavioral modifications. This would involve not only providing technology to patients to self-monitor, but also communication tools to provide critical information to providers, and interpretative and analytic tools for patients and providers to mine this wealth of data, supported by timely two-way communication tools. Patients may also wish to communicate with similar patients and support groups to share guidelines on effective behavioral modifications and motivate change through community.

There are several major differences between patients and providers in terms of their usage of information systems within each stage of healthcare delivery. Provider applications can assume high levels of medical expertise and interpretive capabilities for their users who generally represent a more homogeneous population. Simply expanding

these applications to patients will have limited applicability, due to these differences. In this regard, patients are more similar to consumers, who are generally more heterogeneous than producers.

Medicine is a highly specialized profession, with significant training requirements. Thus, there will always be significant differences between information access, knowledge, and ability of patients compared to providers to analyze and process medical information. Untrained patients will be unable to analyze and interpret the same type of information as providers. This information asymmetry suggests that expansion of existing applications to the patients will be limited. This is one of the reasons that most personal health records today are designed to provide only a limited amount of information, such as vaccinations and medications, but not details of medical evaluations.

While there are different levels of training for different providers (e.g., nurses vs. physicians), we expect that similar types of providers have similar training; as a result, traditional health IT has been developed assuming consistent training. For example, we expect that cardiologists have sufficient training to interpret echocardiograms. However, when it comes to patient populations, there is tremendous diversity in objectives, attitudes, literacy, access to technology, cultural expectations, emotions, and privacy concerns, all of which influence system use. Diversity presents additional challenges in extending traditional health IT to the patients. Diversity in age, culture, language, and economic status exacerbate health disparities. Design of patient-centered applications needs to consider population cultural characteristics. For example, Children's Hospital's use of mobile health text messaging to send health alert tips to populations has been translated into Spanish [Fishbach 2012]. However, wearable sensors may not be culturally appropriate in certain sub-populations. Cultural differences must be considered in developing patient-based systems for each stage of the healthcare delivery system. And we need to determine how these differences influence outcomes for each stage of the healthcare delivery process.

Tens of millions of Americans have limited health literacy, the capacity to understand basic health information and make appropriate health decisions, so the U.S. government has taken several initiatives to improve health literacy. These initiatives include the 2010 Affordable Care Act, HHS's National Action Plan to Improve Health Literacy, and the Plain Writing Act of 2010. This last initiative requires information from the federal government to be written in a clear, concise, and well-organized manner. However, a population level study of health literacy reported that only 12 percent of U.S. adults are proficient enough in health literacy to understand and use health information effectively and more than a third of adults are in the basic or below basic groups [Koh et al., 2012]. Thus, patient-centered applications must address and support improvement of health literacy. In cases where a population may have low health literacy, and there is information asymmetry between the providers and the patients, I expect that we will see an increased role for health advisors who can navigate the complexity of care. Systems will need to support these patient advocates in working with the patients.

Finally, access to different technologies can also lead to disparities. Today, mobile Internet has overtaken fixed Internet, which means that more individuals today can access location-based services, time-based information, and push notifications. However, sensor technology is still in its infancy. As the technology evolves, access to both wearable and home sensors may become an access issue leading to disparities. Designers of applications will need to consider who they wish to target, their level of health literacy, and their access to the technologies. It is hoped that these applications can be developed to engage the underserved in minority and rural populations where health disparities currently exist. This will require specific design and testing with these populations as well as consideration of the role of health advisors and their interaction with the healthcare delivery process.

Another consideration of patients is privacy concern. Research has shown that contextual factors relating to the requesters and the purpose of the request play an important role in moderating the relationship of the privacy calculus. Also, emotion plays an important role in influencing privacy decisions [Anderson and Agarwal, 2011]. Attitudes can be altered with appropriate message framing [Angst and Agarwal, 2009]. Thus, patient-centered designs need to consider the privacy concerns of the populations and the context in which the systems will be used.

### Patients or Healthicans?

I suggest that the traditional definitions for healthcare participants, including patients, users, or consumers, are limiting in their scope because they focus on limited components of the healthcare value chain. Table 3 summarizes the limitations of these definitions. The term "patient" focuses primarily on individuals who have been diagnosed and are currently under treatment. It derives from our existing healthcare delivery system, which was designed primarily so that medical professionals could prevent, diagnose, and treat illness in "patients." The derivation of the word "patient" is the Latin verb "*patior*" meaning "to suffer," both in the sense of feeling pain and in the sense of forbearance. Our medical delivery system has long reflected this focus on patients. Patients suffer from ailments, and medical care has been structured around medical specialties and discrete services to address suffering from these ailments. Fragmented services mean that patients have also had to forbear inefficient delivery. A patient has to navigate a complex path through specialty providers not only for diagnosis and treatment, but also for prevention

and chronic disease management. Today it is recognized that maintenance of good health can reduce the need for healthcare; as a result, much more attention has been placed on maintaining healthy lifestyles. Thus, health information management tools should be defined more broadly for users that are not just patients who are ill or forbear poor delivery. They should focus on individuals who are interested in maintaining good health, whether prior to, or after, diagnosis.

<b>Table 3: Limitations of Current Terminology</b>		
Current term	Definition*	Limitation
Patient	An individual awaiting or under medical care and treatment	Focuses on the sufferer, not the healthy individual; focuses on diagnosis through rehabilitation, not on prevention and monitoring/management
Consumer	One that consumes or uses economic goods	Focuses on the end output of the value chain; assumes someone else provides the product/service, not on the need to partner with delivery mechanisms throughout the value chain
User	One that uses	Focuses on use/involvement with technology but not on responsibility for lifestyle change to accompany this use
*Webster's dictionary		

The consumer-driven approach has moved the language of discussion to market-driven approaches that deliver more value to individuals. But individuals should not just use or consume health care; they should be responsible for managing their own health in conjunction with the healthcare delivery system. The rising costs of managing chronic diseases cannot be reduced simply by consuming more health care. Individuals need to participate in managing their own health. They need to participate at each stage of the value chain. Moreover, consumers who do not pay directly for health care often have little incentive to drive changes that increase value. We need to change the focus to a shared responsibility for improving health care, with more efficient delivery mechanisms to support individuals in achieving their health goals.

I suggest a new term for the user of healthcare applications, a “healthicant,” an individual responsible for his or her own health and well-being, who seeks appropriate assistance as needed to prevent, diagnose, treat, and manage her health throughout her lifetime. The word is derived from “health” and the two suffixes “ic” and “ant,” which mean “characteristic of” and “a person who,” respectively. These individuals actively accept responsibility for their own decisions regarding maintenance of good health, and will seek to use efficient healthcare services to assist them in doing so. These individuals will use “e-healthicant” applications that involve (1) a shared responsibility for the service recipient and the provider; (2) a focus on long-term health, including prevention and long-term care and risk management, not just diagnosis or treatment of ailments; and (3) a drive for more efficient and effective individualized but integrative care delivery mechanisms.

I believe that use of the new term, “healthicant,” clarifies and broadens the concept of who is the user of these applications; in particular, this term focuses on the important role of prevention and monitoring and management of health (i.e., maintenance of healthy lifestyle practices). Second, the new term suggests that design of these systems must account for the healthicant’s role and responsibility for maintaining good health. Table 4 summarizes key differences between the user/consumer/patient view and the active responsible healthicant.

<b>Table 4: Key Differences Between the User/Consumer View of Patients and the Active Healthicant View</b>
1. Healthicants interact at multiple points in the value chain. They are not just consumers of final output.
2. Healthicants are actively involved throughout the value chain. They provide input as well as consume output.
3. Healthicants have joint responsibility with the providers for achieving goals. They do not simply evaluate the quality of the product/service; they can alter it through their own actions.
4. Healthicants require bi- and multidirectional communication with all points in the value chain, not just unidirectional communication.
5. Healthicants are involved throughout the entire value chain, including prevention and monitoring/management. They are not simply patients who are suffering and require treatment.
6. Healthicants have a continuing relationship with their providers.

Table 5 contrasts the types of patient objectives that current patient/user/consumer-centric health IT applications support in each stage of the value chain with the objectives of healthicants. This enables us to identify gaps in the research and tools that are needed to address these gaps.



**Table 5: Comparing Patient E-Health and E-Healthicant Applications**

Value chain stage	Patient e-health apps	Patient objectives	Healthicant objectives	Healthicant activities	Healthicant gaps
Preventing	Internet sites, support networks, mobile health information	Search for answers about good health	Maintain healthy lifestyle	Identify individual risk factors; participate in prevention programs	Motivational tools
Diagnosing	Internet websites	Understand the problem	Select the best care option	Review and analyze treatment plans	Measurement tools
Preparing	PHR, social support networks	Learn about and prepare for intervention	Find the right providers	Select the best pretreatment providers and plans	Measurement tools
Intervening	Patient provider portals, electronic prescription refills	Receive interventions	Achieve personal health objectives	Improve responses to outcomes through patient-centered activities	Analysis and communication
Rehabilitating	Social support networks	Adhere to rehabilitation plans	Maintain a healthy lifestyle	Self-monitor, analysis and interaction with healthcare professionals	Analysis and communication
Monitoring and managing	Internet sites, social support networks	Answer questions about health	Self-manage chronic conditions, maintain a healthy lifestyle	Self-manage condition, comply with best therapy, modify lifestyle	Data mining and response
Activities That Cut Across the Value Chain					
Informing	Internet websites	Receive information	Maintain and improve	Interpret information	Analysis and communication
Measuring	PHR	Personal health record access/retrieval	Make appropriate healthcare decisions	Personal health record input	Analysis and communication
Accessing	Appointment scheduling, on-line communication with providers, patient portals	Communicating with providers (office, hospital, e-communication)	Influence care decisions	Personal health record input	Analysis and communication

**IV. THE GAPS: WHAT RESEARCH AND APPLICATIONS ARE NEEDED TO SUPPORT HEALTHICANTS**

When I compare the healthicant's objectives to the objectives that are currently met by emerging applications, I find that there are significant gaps. First, I identify a number of research questions that should be addressed before we extend provider health IT to patients through a better understanding of how patient objectives differ from those of providers throughout the healthcare delivery value chain. Second, I identify several research questions that arise from understanding how patient objectives differ from provider objectives throughout the healthcare delivery value chain. Finally, I provide some examples of gaps in emerging patient-centered e-health applications. These include the need for more personalized and motivational push technologies during prevention and monitoring/management, standard measures to assist patients in evaluating diagnoses and preparing treatment plans, feedback mechanisms and personalized tracking for patient involvement during intervention and rehabilitation, data mining and communication tools for monitoring and management, and bi- and multidirectional communication throughout the value chain.

## Research Questions: Consideration of Patient Diversity and Unique Objectives Throughout the Healthcare Delivery Value Chain

Since patients are more diverse than providers, and do not have specialized training, more research is needed before we simply expand provider applications for patients. Some critical research questions follow. First, is the information made available to patients in their PHRs sufficient to support patient interaction throughout the value chain? Are there other types of information that could be shared with a patient to support good health? And if so, can we develop systems that can be evaluated by patients without training? In some cases, we have begun to establish health advisors, who assist in interpreting information for the patient. For example, Cigna's Health Care program provides both telephonic and Web-based access to a personal health coach [Cigna, 2004]. This raises additional research questions; for example, what are the guidelines for understanding when and how health advisors will be needed and what types of technology can best support their interactions with both patients and providers?

Development of patient-centered systems to support various stages of the healthcare delivery value chain suggests a variety of research questions that arise from the difference between provider and patient objectives. For example, what are the patient challenges with monitoring and analyzing data associated with preventing illness? What data could influence patients during these stages? How does this differ when rehabilitating? How do these challenges differ from those associated with motivating and incentivizing new patient behavior? When is a health advisor required and how can information technology assist? How do these challenges differ among the underserved populations? How will applications need to differ when they support these different segments of the value chain? We need research that will study patient needs during each part of the value chain, understand differences in the patient populations, and develop systems that could support these needs, providing information in a format that is understandable by either the patient or a health advisor who could assist the patient in interpreting information. One of the key issues that require study is the differences in objectives between patients and providers in different parts of the value chain. Since patients do not just consume a final product (good health), but need to be involved in the process throughout the healthcare delivery value chain, applications must support this unique interaction.

## Research Gaps: Tools to Support E-Healthicants

### Motivational Tools

The healthicant's active role is particularly critical during prevention and monitoring/management. Today, motivated individuals can access Internet sites to consume information about prevention and management of chronic illness. They can download and use healthy living applications that can help them track their health status, including dietary and fitness goals. But what healthicants particularly need are motivational tools to not only search for, consume, and use information, but also to change lifestyles. Still in its infancy, sensor technology is emerging to measure the human's exposomes, beginning with the measurement of air pollution, physical activity, and diet, using environment sensors, GPS, acceleration sensors, and cameras [Borrell, 2011]. These tools are currently limited to those who are motivated to search and access them and to self-monitor. Moreover, even for this population, individuals still need to be motivated to modify behaviors in conjunction with this monitoring. While research centers such as the University of Florida's Center for Digital Health and Wellness are focusing on research in this area, a gap today exists for personalized push technology that can motivate individuals within certain populations who may be at risk for certain problems. This requires research to understand motivational factors and how to incorporate these into new systems. One of the current issues with this type of research is privacy laws, which limit access to information on patient populations. Educational outreach will be necessary to alter privacy concerns and tools will need to be unobtrusive and integrated within daily living. Bi- and multidirectional communication with providers will be needed, since healthicants will need to create and send self-monitored data to their providers. They will also need to interpret their analysis and response, using this information to motivate new behavior.

### Measurement Tools

Currently, diagnosed patients often use and consume information to further understand their problems. Today they can search Internet sites and participate in social networks that discuss diagnoses and treatment plans. However, healthicants want to participate in selecting the best treatment plans and providers for themselves. Their ability to truly evaluate their options is limited by the fact that we lack standard results measurements as well as systems to support understanding the measurements that are available. Mandatory measurement and reporting of results has been noted as the single most important step in reforming the healthcare system to create competition [Porter and Teisberg, 2006]. While there have been some efforts to create outcome metrics, these are still limited and difficult for the healthicant to use effectively. Healthicants interested in selecting the best care options require tools that will help them evaluate their choices to make the best care decisions for themselves. E-healthicant applications are needed to help them compare and contrast the options; for example, the impact of various plans on overall cost and quality of life throughout treatment, rehabilitation, and management. This information must be presented to healthicants with various levels of health literacy.

### Real Time Feedback Mechanisms for Personalized Tracking

During intervention and rehabilitation, patients today are generally limited to interactions with their providers at specific intervals, typically during office visits. While patient portals can support communication, they are often limited in their use. Today, healthicans can self-monitor key variables using, for example, wireless heart rate monitors and blood pressure machines that collect information in real time. Mobile phones that include GPS, accelerometers, and cameras can provide additional behavioral information. While sensor technology is still in its infancy, it is evolving to automate recording of health status using both home and wearable sensors. Centers such as the Center for Embedded Network Sensing at the University of California are working on further development of these types of technologies. While there has been a growth of consumer health monitoring devices, in most cases today the physiological data is used for offline processing, analyzed at a later time [Raad and Yang, 2009]. Applications that enable patient input to be available in real time to providers for analysis and response could improve intervention and rehabilitation. One of the key issues today is that this information needs not only to be measured and input, but also received and analyzed. Today, providers typically do not have incentives to analyze data reported from patients, except during office visits. Since the potential exists for monitoring huge amounts of data, we need systems that can analyze what real-time patient input means. We need mechanisms for flagging events that need immediate provider attention and we need systems that support two-way communication. If providers have neither the time nor the incentives, then new health advisors may be needed to analyze and communicate responses.

### Data Mining and Response

It has been suggested that the biggest opportunity for mobile health is to help people better self-manage their chronic conditions. Chronic diseases make up about 75% of the healthcare system's \$2.3 trillion in costs [Dolan, 2010]. Sensor technology is evolving that can enable real time monitoring of key variables. However, with all of the information that can be captured, we will need applications and individuals who can mine this data to determine appropriate actions if we wish to support healthicans in their efforts to monitor and manage their own health. Personalized tracking mechanisms are needed to support healthican interactions with the healthcare delivery system at multiple points, ensuring patients interact with and receive all the care that they need. We not only need to track and receive information from the healthicans, but also to mine the information so that we do not overwhelm the delivery systems' capabilities, but still use this additional information effectively. As sensor technology develops and we begin to gather large amounts of data from the healthicans, there may be limitations to the amount of analysis that can be automated. Healthicans may need to be supported not only by systems, but by individuals who have the capabilities to mine the data and interpret the results. Given the time and financial constraints on today's providers, we may find that this will be a new role in the healthcare delivery system. Clearly, healthicans who are involved in self-monitoring and management will not simply consume information; they will also provide information, and lots of it. This can strain the system, unless we develop efficient ways of mining and interpreting the data.

It is expected that healthicans will be motivated to share more information electronically during all stages of the value chain; therefore, they will support further growth in social networks that might support not just patients with chronic illnesses, but also patients who receive similar diagnoses, interventions, and rehabilitation plans. As more information is shared, there will be a need to mine this additional trove of information, perhaps finding unanticipated patterns. Discussions among healthicans who have received particular treatments or medical devices may indicate problems or issues that may not be readily recognized by a single provider who lacks such broad input. Mining this data can provide information that may not have been readily available previously.

### Analysis and Communication Capabilities

As healthicans take on greater responsibility for their own health, they will need to share more information with their healthcare providers more often. Today, most patient applications support one-way communication of information from the providers to the patients. We need to incorporate tools for patients to provide information to their providers and interact with them using new technologies. Both bi- and multidirectional communication tools will be necessary. Some of the tools may need to filter or interpret the information to account for the knowledge differentials between patient and provider populations. In some cases, we may find that tools alone cannot accommodate these differentials and we may need to augment these tools with healthcare advisors/advocates. In this case, we will also need tools to support these advisors in communicating with the healthicans.

## V. CONCLUSIONS AND FUTURE RESEARCH

This article has used the value chain framework to identify how existing health IT supports either the provider or the passive user/consumer. I have then used this framework to suggest why e-health-enabled applications for patients should not simply expand traditional health IT applications to new specialized users or assume that patients will simply consume information. I want to change the goal to consider supporting individuals who will be motivated to create and sometimes change behaviors that enable them to prevent poor health, monitor good health, and be

actively involved in their treatment and response programs. Health IT today for patients is simply not geared toward these types of individuals. We need additional research to better understand the needs of these individuals and ways to support them. I define a new term for these individuals, "healthicants," to bring attention to the fact that our applications today are limited by our definitions that focus on only a portion of the value chain, and view the users of these applications simply as users or consumers. By expanding our notions of who these systems support, I have identified important gaps in the literature and call for development of systems that support bi- and multidirectional interaction with the healthcare delivery process, rather than one-way consumption of a service.

I have shown that a motivated and active healthicant has different objectives from either providers or passive consumers of information. This has enabled me to identify several major gaps in the systems, including lack of motivational tools to support prevention and management; measurement tools for diagnosis and planning; real time personalized feedback mechanisms between the patient and the provider; data mining and response, particularly during monitoring and management of health; and analysis with two-way communication tools.

I have argued that simply expanding provider health IT is insufficient as these tools were not developed to address the heterogeneous population in terms of cultural diversity, privacy concerns, and health literacy. I have outlined some research questions that will need to be addressed in order to develop the needed applications, which must consider these differences. Additionally, I suggest that future research must also consider the role and support of health advisors. I have suggested that as e-healthicant applications continue to evolve, we may well need new types of providers, who can support the applications and the users by mining, analyzing, and interpreting the vast amounts of data that can be provided from the healthicant as well as navigating through and interpreting complex information for users with lower healthcare literacy. Since health care is so complex and specialized, and involves high degrees of training, healthicants will always have information asymmetry with professionals. Once we can identify the limits of systems for information simplification, we can also better define where and how health advisors can support healthcare delivery and develop systems to support them.

My goal was to classify not only current patient health IT, but also provide a framework for understanding the future needs for applications that will empower the new healthicant to take a more responsible role throughout the healthcare delivery value chain. I believe that some technologies are evolving to support this role, but that the successful applications will not simply extend existing tools. They will need to be designed recognizing the diversity of users, their motivations and concerns, and their objectives. In this respect we can draw from consumer-centric design principles that meet the needs of broad populations of users with a wide variety of preferences and motivations [Albert, Goes and Gupta, 2004]. However, we cannot simply rely on consumer-centric design since we need to develop applications that can change behaviors through interactions at multiple points of the value chain, supporting patients who will not just consume, but who also will provide information that can change the dynamics within the healthcare delivery system.

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*Editor's Note:* The following reference list contains hyperlinks to World Wide Web pages. Readers who have the ability to access the Web directly from their word processor or are reading the article on the Web can gain direct access to these linked references. Readers are warned, however, that:

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ISSN: 1529-3181

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