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Editors' Introduction to the Special Section on Patient-centered e-Health: Research Opportunities and Challenges

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Editors' Introduction to the Special Section on Patient-centered e-Health: Research Opportunities and Challenges

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Abstract:

We initiated the CAIS Special Section on Patient-Centered e-Health (PCEH) to provide support for the PCEH discipline, which has recently emerged to meet the practical need of supporting patients in managing their health. Because there are significant challenges in designing, developing, and using PCEH applications, there are many opportunities for IS researchers to study familiar topics, but in the very different healthcare delivery context. As an emerging discipline, PCEH is struggling with reconciling ambiguous definitions across studies, defining the discipline boundaries (how they overlap and are distinct from related research areas), and developing the exemplary research studies that can guide future research. Thus, the goal of this Special Section, as far as possible, is to gather a set of research articles that will move the PCEH discipline forward by providing resources and examples to support future PCEH research that is theory-based, is focused, and can build a cumulative literature and research tradition.

In this Introduction to the CAIS Special Section, we argue that IS researchers are especially well-equipped to undertake PCEH research and thereby overcome the many challenges unique to PCEH study. We discuss the challenges in the emerging PCEH discipline and present approaches that IS researchers might take to meet these challenges and produce the exemplary studies needed to further the discipline. Our arguments and observations are supported by the fourteen articles that make up the Special Section. These fourteen articles represent four areas of emerging PCEH research, namely PCEH and the Healthcare Delivery Context; Models of Acceptance, Use, and/or Outcomes; Patient-centered Design Research; and Assessment of PCEH websites.

Keywords: Health Information Systems; Health Information Technology; patient-centered

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I. INTRODUCTION

Patient-Centered e-Health (PCEH) is an emerging research discipline that holds many opportunities for information systems (IS) researchers, as well as a number of challenges. Thus, we have created this special section of *Communications of the Association for Information Systems* to explore, clarify, and expand the emerging PCEH discipline. To introduce the special section, we not only provide an overview of the fourteen articles that were accepted for publication, but also present our sense of where the opportunities and challenges lie in conducting PCEH research (from an IS perspective) and in advancing the PCEH discipline.

Motivations for PCEH

Wilson [2009, p. xiv] wrote that development of PCEH is motivated by “three transformative trends that cross health-care industries and society at large.” These trends are:

- *Ongoing diversification of e-health research* promotes the need for a specialized discipline that focuses on e-health services that are used by patients and caregivers.
- *Diffusion of Web applications into everyday life* leads to greater expectations that healthcare providers will make available high-quality online services in the same manner as other organizations, such as banks, online retailers, and government agencies.
- *Consensus that information technology (IT) should be used more effectively to improve healthcare* has emerged internationally.

To these motivators it is now appropriate to add a fourth trend relating to comprehensive health legislation and regulation, exemplified by the U.S. Affordable Care Act (ACA) of 2010. The ACA implements a significant number of requirements that healthcare providers can address, at least in part, through online interaction with patients. According to Healthcare.gov [2013], requirements that have already come into effect (and their deadline years) include:

- Putting information for consumers online (2010)
- Establishing consumer assistance programs (2010)
- Preventing disease and illness, e.g., through smoking cessation and obesity reduction programs (2010)
- Introducing new innovations to bring down costs (2011)
- Understanding and fighting health disparities (2012)

Laws and regulations outside the U.S. have similarly motivated expansion of e-health services to patients and caregivers. For example, European Union Directive 2011/24/EU directs development of an e-health network that is capable of “enhancing continuity of care and ensuring access to safe and high-quality healthcare” across member states [Directives, 2011] and is funded as part of a proposed €446 million program for the period 2014–2020 [EU Health, 2013].

What Is PCEH?

Over the past decade, the concept of PCEH has become increasingly prevalent¹ as a description of online health services that are accessed by patients; however, no concise definition of PCEH has emerged that is shared across the research disciplines that focus on health and IT. Indeed, the need to develop such a shared definition was a key motivation for proposing this special section on the topic.

We have chosen to apply a working definition of PCEH based on the argument Wilson [2009] makes that PCEH should integrate three themes:

- *Patient-focus*: PCEH applications are developed primarily based on needs and perspectives of patients.

¹ A Google search conducted in March 2013 for the various permutations of the phrases *patient-centered* and *e-health* finds over 140,000 results.

- *Patient-activity*: PCEH application designs assume that patients will participate meaningfully in providing and consuming information about them and of interest to them.
- *Patient-empowerment*: PCEH applications assume that patients want to, and are able to, control far-ranging aspects of their healthcare via PCEH.

We note that Wilson and his colleagues have expanded these arguments in their article in this special section in an effort to initiate development of a guiding theory of patient-centered e-health [Wilson, Wang and Sheetz, 2014].

II. THE CHALLENGE OF BECOMING PATIENT-CENTERED

The well-known 2001 Institute of Medicine report [IOM, 2001] urges healthcare delivery to become more patient-centered, which it defines as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” The reasoning in the report is that a patient-centered approach would lead to “care that is safer, more reliable, more responsive to their needs, more integrated, and more available” [IOM, 2001, p. 3].

A number of challenges are involved in transitioning healthcare delivery to a more patient-centered system. First, as well-described by Sherer [2014], there is a major information asymmetry between physicians and patients. Physicians, with their many years of training, have much more medical knowledge than their patients. As a result, a paternalistic system has evolved where physicians expect, and patients expect them, to make the decisions about, or at least recommend, an appropriate course of treatment. Moving to shared decision making is not only a cultural change, but is also very difficult when patients lack the necessary information to make decisions and physicians are too rushed to spend the time to help their patients make those decisions. Furthermore, in situations where a caregiver, rather than the patient, must take on decision-making responsibilities, healthcare providers, in following HIPAA rules [HHS.gov, 2013], might not share patient status information that is needed for decision making because they are unsure who is allowed to know, as illustrated in Pardue, Campbell, Campbell and Wisniewski [2014].

Second, as illustrated by Pardue et al.’s teaching case [2014], in some healthcare delivery situations it is hard to believe that the system can be more patient-centered. The case describes the journey of a patient, accompanied by a family member, arriving at an emergency room, being admitted to the hospital, and then being discharged to hospice care. Anyone who has accompanied a loved one to the emergency room for a serious problem has probably experienced difficulties similar to those described in this article of trying to determine what is happening and why, and of making informed decisions with little information in an environment that is focused on moving the patient to discharge as quickly as possible. In the acute care context of hospitals and their emergency rooms, the care delivery system can seem hostile to patients and their caregivers, rather than patient-centered.

Despite these and other challenges, moving toward patient-centeredness is important. *Health Affairs*, in its February 13, 2013, Policy Brief [James, 2013] noted that “a growing body of evidence demonstrates that patients who are more actively involved in their healthcare experience better health outcomes and lower costs.” This policy brief describes two constructs: *patient activation* and *patient engagement*. *Patient activation* refers to the extent to which patients have the abilities, skills, and willingness to be involved in making decisions about their care. Studies employing a measure of *patient activation* [Hibbard, Mahoney, Stock and Tusler, 2004, 2007] have demonstrated that more activated patients are lower-cost patients [James, 2013]. *Patient engagement* means that patients are not only activated but also involved in activities that promote positive patient health behaviors; that is, they are taking some responsibility for their own health. The article cites barriers to achieving *patient activation* and *patient engagement*. On the patient side, factors include the lack of health literacy, lack of cognitive abilities related to decision making, the diverse cultural and religious backgrounds of patients, and patients’ beliefs that more expensive care is generally better care. On the physician side, factors include lack of time, the belief in traditional physician-directed decision making, and insufficient training in shared decision making.

The same Institute of Medicine report mentioned above [IOM, 2001] also calls for more use of IT in the healthcare delivery domain. Based on this call and the significant governmental initiatives and support for health IT, health IT applications have become common. However, most of these applications focus on the needs of healthcare providers and organizations, rather than the e-health services that patients actually desire. This is not surprising because most health IT and health and medical informatics research has necessarily started with the development and integration of electronic records and related systems, rather than delivering e-health to patients.

The PCEH discipline focuses on the research and practice of assuring that the electronic health systems that patients use are patient-centered; it is not attempting to move the entire healthcare delivery system toward patient-centeredness. These, however, are not independent—the patient-centeredness of e-health systems and of the entire healthcare delivery system are related. Specifically, while some e-health applications can operate

independently of the healthcare delivery system, many must operate within a healthcare delivery system that is still not particularly patient-centric.

Although the PCEH discipline is tackling a narrower problem than that of the lack of patient-centeredness in the healthcare delivery system, PCEH in its definition has higher expectations than those discussed in the *Health Affairs* special issue on patient engagement. The three characteristics we are using to define whether an e-health application is patient-centered, namely that it is *patient focused*, allows for meaningful *patient activity*, and promotes *patient empowerment*, are much stronger criteria than the two criteria mentioned in *Health Affairs*, namely *patient activation* and *patient engagement*. Specifically, *patient empowerment* places control with the patient, whereas *patient engagement* requires only that the patient be somehow engaged, in order to ensure compliance with the objectives of the healthcare provider.

III. WHY INFORMATION SYSTEMS RESEARCHERS SHOULD STUDY PCEH

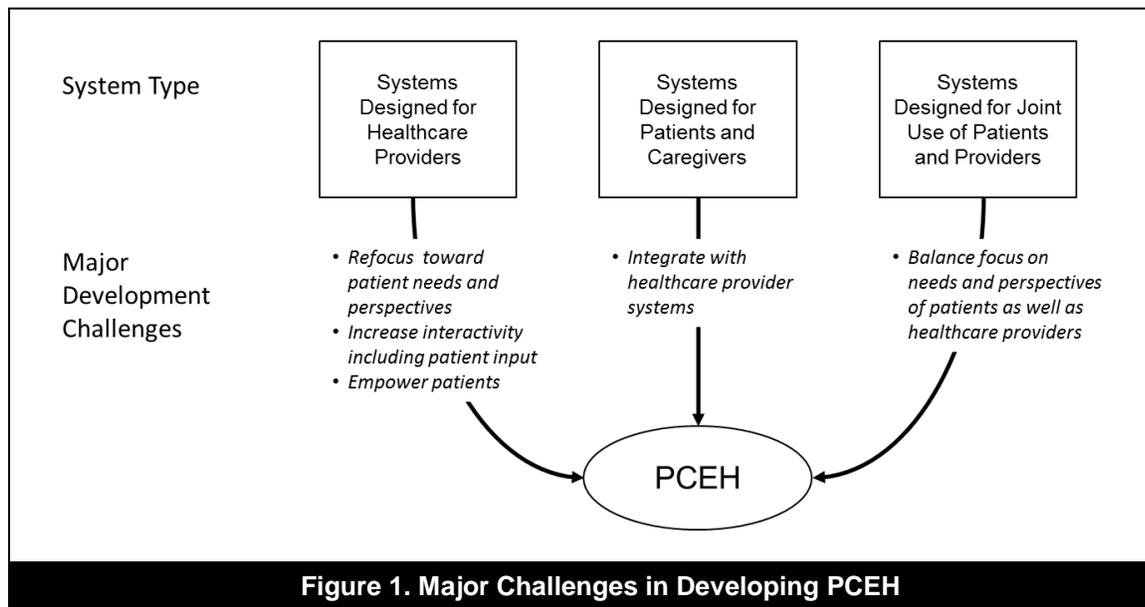
Since the emergence of the IS discipline, IS researchers have faced a continually changing environment that calls for “a mutable and adaptive identify for IS [that] might permit the flexibility needed to change” [Robey, 2003, p. 353]. As a result, IS researchers are experienced in the study of diverse core areas, including IT and organizations, IS development, IT and individuals, IT and markets, and IT and groups [Sidorova, Evangelopoulos, Valacich and Ramakrishnan, 2008]. We argue that research expertise in each of these areas is relevant to the PCEH context.

- *IT and Organizations.* Expertise in IS planning and management, systems integration, and enterprise systems implementation is a necessity in healthcare, which the Institute of Medicine recently described as an industry that “falls short on such fundamentals as quality, outcomes, cost and equity,” adding that “[e]ach action that could improve quality—developing knowledge, translating new information into medical evidence, applying the new evidence to patient care—is marred by significant shortcomings and inefficiencies that result in missed opportunities, waste, and harm to patients” [IOM, 2012].
- *IS Development.* IS researchers pioneered development of systems for decision support, database management, and collaboration, each of which is applicable and relevant to PCEH software.
- *IT and Individuals.* Although end-user computing was a novelty in the 1980s, IS researchers over the past two decades have become experts in the study of technology adoption and use, service quality, trust, personalization, and human-computer interaction, including research in user-centered design that underlies the patient-focus component of PCEH.
- *IT and Markets.* Deep experience in e-business and e-service domains allows IS researchers to integrate best practices from online auctions, e-marketplaces, and Internet privacy/security into the e-health context.
- *IT and Groups.* Research expertise in the study of technology-supported groups can help to improve performance of telehealth applications, online peer support, and other collaborative group health services.

Healthcare has not always been attractive to IS researchers. Few health-related articles were published in IS journals prior to 2003 [Chiasson and Davidson, 2004], and medical informatics was considered to be a fundamentally foreign discipline to the IS community. More recently, however, Wilson and Tulu [2010, p. 138] note that the healthcare landscape is changing to become more attractive to IS practitioners and researchers because “recent healthcare IT investment has been directed in large toward generalized business IT, including data warehouses, enterprise systems, and web-based applications, such as e-health websites for use by patients.” Correspondingly, mainstream IS publication venues are increasingly available for health-related IS research, as exemplified by the Information Systems and Healthcare Department of *Communications of the Association for Information Systems*, which has published over fifty articles since its inception in 2004.

IV. THE CHALLENGES OF DEVELOPING PCEH SYSTEMS

While IS researchers are experienced in studying IS development and how the resulting systems are used by individuals, groups, and organizations, there are special challenges in designing, developing, and using PCEH systems, which provide many opportunities for researchers in the PCEH discipline. In this section, we characterize these challenges in terms of the starting points and goals in developing PCEH systems. The articles in this special issue, illustrate three starting points for developing PCEH applications (see Figure 1). The first is to start with systems developed primarily for physicians and their healthcare organizations, e.g., EHRs, and then add patient-centered functionality to them, e.g., PHRs. The second is to develop applications solely for patients, e.g., the PatientsLikeMe.com website. The third is to develop systems designed to meet the goals of both physicians and patients using PCEH principles. We discuss each of these in turn.



Start with Systems Designed for Healthcare Providers

Although e-health applications have become common, most applications focus on the needs of healthcare providers and organizations, rather than on the e-health services that patients actually desire. Implementation of Electronic Health Record (EHR) systems, usually as packaged software purchased from vendors, has been the focus of health IT in the U.S. for the past few years, fueled by funding from the HITECH Act in 2009 [HealthIT.gov, 2013a] and the requirements for Meaningful Use of these EHR systems [CMS.gov, 2013]. In the U.S., the result is that over 50 percent of physicians used EHRs in 2012 [Decker, Jamoom and Sick, 2012, as cited in Archer and Cocosila, 2014]. According to the U.S. Office of the National Coordinator for Health IT, EHR adoption doubled in three years—in physician offices, adoption increased from 17 percent in 2008 to 34 percent in 2011, and in hospitals, from 13 percent in 2008 to 35 percent in 2011 [HealthIT.gov, 2013b]. One of the Meaningful Use requirements is that patients have some form of electronic access to their medical records. As a result, vendors are supplying Personal Health Record (PHR) functionality in the EHR packages, and healthcare organizations are providing this functionality to patients [Archer and Cocosila, 2014; Tulu et al., 2012].

The typical PHR system, as tethered to an associated EHR system, provides some useful information to patients. Patients can typically view their test results, their appointments, and their medication list, but they are viewing only the information that physicians have decided to allow them to see. For example, rarely are patients allowed to view physicians notes, although patients have expressed an interest in seeing them [Tulu et al., 2012]. They may also be able to make or cancel appointments and send email to their medical team, but they often cannot change information about themselves even when it is incorrect.

Thus, from a PCEH viewpoint, typical PHR systems are not sufficiently patient-centered. First, such systems are not patient-focused because they were developed as a side feature to EHRs, providing only the information and activities that the healthcare organization owning the EHR decided to give to patients, rather than starting with patient needs. Second, they support only a few of the activities patients would ordinarily be able to do when interacting with their healthcare organization. Third, patients are only somewhat empowered via the use of the system. For example, by viewing their test results before an appointment, they may be better prepared to ask questions of their physician. As several articles in this special issue note, PHR systems, although providing useful information and functionality to patients, are likely to never reach true patient-centeredness. A primary reason, as noted by Wilson et al. [2014], is that the EHR's patient information is the legal medical record. As a result, patients are unlikely to be able to do more than suggest corrections to that record. They are unlikely to ever have the same control over those data that their physicians do.

In summary, while extending systems developed for physicians and healthcare organizations (or for payers) to include functionality for use by patients is likely to provide some useful functionality for patients, using these systems as a starting point is unlikely to address the full healthcare information and activity needs of patients.

Develop Systems Solely for Patients

Typical of systems designed solely for patients are various websites. Kamis, Yao and Kim [2014] uses Wilson's [2009] PCEH model to classify patient-focused health websites, resulting in five types of patient-centered websites, as follows:

1. *Consultation* websites provide virtual visits of patients with physicians using real-time communications. These are the least common type and represent applications that fall in our third category of applications that must meet both patient and physicians goals because both must willingly participate. An example site is American Well (www.americanwell.com).
2. *Records* websites store patient records. These sites are essentially PHRs, some of which are independent of providers and payers and under full control of each patient. Others, as mentioned above, are closely tied to a corresponding EHR. An example site that is independent of providers and payers is Microsoft's HealthVault (www.healthvault.com).
3. *Monitoring* websites are designed for frequent capture of a patient's health indicators. Such sites often require special devices to collect the measures.
4. *Information* websites provide general information about diseases, conditions, treatments. As noted by Huang, Chengalur-Smith and Ran [2014, citing Fox and Jones 2009], 61 percent of Americans have accessed such a site in 2009 as compared to 20 percent in 2000. Well-known and respected sites include WebMD (www.webmd.com), the Mayo Clinic (www.mayoclinic.com), and the Cleveland Clinic (my.clevelandclinic.org/health).
5. *Community* websites provide online gathering places for people with similar health problems or interests. Probably the most well-known of such sites is Patients Like Me (www.patientslikeme.com), but there are many others.

The fifth type, community sites, are of particular interest for PCEH researchers because they are typically developed outside of the traditional healthcare industry, are designed solely for patients, and meet the needs of patients not addressed by the traditional system of healthcare delivery. As such, they provide a mechanism for studying what patients really want and need. In addition, such sites provide a different context for studying online behaviors enabling researchers to compare results across contexts. This interest is evident in four articles in this special issue that study aspects of online health communities [Kordzadeh, Liu, Au and Clark, 2014; Choi et al., 2014; Fan, Lederman, Smith and Chang, 2014; and Huang et al., 2014].

Another type of PCEH application that is being developed solely for patients are health- and wellness-focused apps for smartphones. Because there are no articles in the special issue illustrating this source of PCEH applications, we briefly illustrate this source of PCEH applications with some smartphone app development activities at Worcester Polytechnic Institute (WPI). With NSF-funding, we are developing a smartphone app for patients with advanced type 2 diabetes to help them self-manage their chronic disease [Strong, Agu, Pedersen and Tulu, 2012]. The app has modules for recording glucose and weight from blue-tooth enabled devices, for recording physical activity, and for tracking diet. Because patients with advanced diabetes often have diabetic foot ulcers, the app provides functionality for taking pictures of those wounds with the smartphone's camera and analyzing them. The research challenges are to develop algorithms for the analysis of wound images that can be run solely on the smartphone and to develop feedback to users based on the health indicators collected that will motivate them to continue using the app and to move toward healthier behaviors that will bring their diabetes under better control. While this app is currently designed for standalone use by patients, eventually patients will be able to share their health indicators with their physicians if they choose to do so. Another example of a patient-centered health and wellness app being developed at WPI, called the Mom-O-Meter, supports women during pregnancy so that they maintain their health and achieve healthy weight gains [Tulu et al., 2011].

The major challenge of systems designed for patients and caregivers is to obtain a sufficient level of integration with internal systems of healthcare providers, beginning with EHR systems. Until this issue is overcome, patient activity and patient empowerment of these e-health systems will be structurally constrained.

Use PCEH Principles to Design Systems to Meet Both Physician and Patient Goals

For the first source of possible PCEH systems described above, i.e., start with systems designed for physicians and healthcare organizations and add patient-centered features, we concluded that this process is desirable and useful, but will probably not produce systems that are truly patient-centered. The second source of PCEH systems, i.e., designing patient-centered websites and mobile apps for patient use only, is clearly a feasible and useful way to generate applications that are truly patient-centered.

While patient-only applications are useful, the needs of patients cannot be isolated from the healthcare delivery system. As noted by Sherer [2014], patients are not simply consumers of information produced by a healthcare organization or users of an information system, but are actively involved in co-creating that information and participating in the care process. Baird [2014] similarly argues that PCEH users are actively involved stakeholders and decision makers, not passive users or consumers. This means that some applications designed solely for patients, especially the smartphone apps, may be of more value to patients if the information they generate can be made available to their physicians, who could then provide feedback. Thus, we turn to the difficult case of determining what a patient-centered system designed for use by, and with value to, both physicians and patients would look like and what development process is appropriate for creating such a system. Three articles in this special issue examine aspects of this problem.

Dohan and Tan [2014] discuss electronic symptom reporting (ESR) systems, which are designed so that patients can collect symptom information and send it to their physician. Their article uses the examples of diabetes and inflammatory bowel diseases, both of which are chronic diseases that require patient self-monitoring, but could also benefit from physician feedback at various points. As the authors note, ESR tools are effective only if they provide value to both patients and physicians. If either party stops doing their ESR-related activities, the other party is also likely to stop. For example, a patient is likely to stop collecting data if the physician does not provide encouraging feedback. A physician is likely to stop providing feedback if the data received from the patient is perceived to be inaccurate or faked in any way. Both parties also have independent reasons to stop participating, including lack of time and perceived lack of value. The article develops, but does not test, a model that combines a physician-level model and a patient-level model to predict the success of an ESR intervention.

Aspria, de Mul, Adams and Bal [2014] discuss what is essentially a failed attempt to provide educational webinars on cystic fibrosis (CF) to children between twelve and eighteen who have CF. The problem they address is common to many chronic diseases, that of educating patients about their new diagnosis and how they should self-manage that disease on a daily basis. Physicians do not have sufficient time to spend on educational activities with individual patients, and patients, at the time of diagnosis, are unable to absorb all the new information. This problem is even worse when the patient is a child, as is common with CF. The idea of the project described in the article is to deliver a series of interactive webinars that provide information about CF and answer questions from the audience. Unfortunately, teenagers with CF (the target audience) were not interested and did not participate unless required by their parents. Even then, they did not see any value. The webinars did have an unexpected audience, namely, parents of young children recently diagnosed with CF, but the webinars were not tailored to them.

While a number of factors contributed to this failure, a general issue is that the problem as perceived by healthcare professionals, namely, the lack of knowledge by patients about how to self-manage their disease, is not a problem as perceived by the teenagers with that disease. More generally, this situation is an example of the issue mentioned by both Sherer [2014] and Baird [2014]. Specifically, the people who are the potential users of the PCEH systems or interventions being developed cannot be designed for in the same way we design for business users who have tasks to accomplish with the system or as we design for consumers as final purchasers of our information product or service. Furthermore, for chronic diseases or conditions, patients may prefer not to actively engage with and self-manage their condition. The educational project reported in this article demonstrates the need to better understand the requirements of such patients as potential PCEH users.

San Nicolas-Rocca, Schooley and Joo [2014] report on a somewhat similar project of developing videos to support the provision of discharge instructions. Similar to the previous article, discharge instructions can be complex and physicians (or their assistants) do not have adequate time to educate patients as they are discharged from the hospital. The common practice is to also give the patient these instructions in writing, but patients and their caregivers may not understand the written instructions sufficiently well to follow them, resulting in possible harm to the patient and readmission to the hospital. The project, as reported in the article, follows user-centered design principles in developing the videos. The videos are designed to be viewable in the hospital and also in the patient's home via a laptop or smartphone. The prototypes received positive evaluations, but implementation and full testing have not been conducted.

These three articles illustrate the difficulties of designing systems that meet physician criteria but are also useful to patients. None of these projects seemed to start from patient needs as perceived by the patient, but rather from patient needs as perceived by physicians and their organizations. As Sherer [2014] notes, this approach is unlikely to work. What is necessary is an approach which balances the development focus on needs and perspectives of patients as well as healthcare providers. As discussed in the next section, we need more research directed toward understanding the needs of patients (or "healthicans," as Sherer [2014] prefers to call these potential users), as well as more research directed toward developing PCEH design principles.

V. PCEH RESEARCH APPROACHES AND OPPORTUNITIES

As can be seen from the discussion above, developing and studying PCEH applications involve many challenges. Because PCEH systems are relatively new, we lack sufficient knowledge about:

- Patients as e-health users, especially those with chronic diseases or conditions
- What e-health applications that are of value to both physicians and patients would look like
- What the design and development processes should be for e-health that is truly patient-centered

Thus, there are many opportunities for research. The articles in this *CAIS* special section illustrate some of the research approaches that could be productive. Below we discuss several possible PCEH research approaches.

Empirically Testable Models

Of the fourteen accepted articles, eight (57 percent) proposed models or hypotheses for empirical testing. Most of these also tested the model, at least to some extent. The dependent variables for some of the models were adoption and use [Wilson et al., 2014; Archer and Cocosilia, 2014], while others had health-related outcomes, e.g., active coping with one's disease [Dohan and Tan, 2014], and taking actions to effect life-changing interventions [Ghosh, Khuntia, Chawla and Deng, 2014]. For the studies of online health communities, dependent variables included support or help provided to others [Kordzadeh et al., 2014], senior's quality of life [Choi et al., 2014], engaging in trust behaviors [Fan et al., 2014], and number of message threads initiated [Huang et al., 2014]. In addition to these eight articles, Kamis et al. [2014] used Wilson's [2009] framework to empirically classify health-related websites.

From these articles, we see two general opportunities for PCEH research that develops and empirically tests PCEH models. First, these articles demonstrate models that combine traditional IT variables with health-related variables in a variety of ways. We believe these articles are only a small sample of the possibilities for exploring and testing how health and IT variables jointly influence health outcomes, e.g., quality of life, and IT outcomes, e.g., intention to use PCEH technologies. Such models can be used to study PCEH systems derived from healthcare provider systems, PCEH systems designed primarily for patients, and PCEH systems designed for joint use by providers and patients.

Second, the PCEH context requires changes to our traditional technology acceptance models such as TAM, which also provides many opportunities for researchers. Specifically, TAM-related models assume usefulness as a key driver of intention to use. But usefulness for accomplishing a task at work or at school, as TAM is usually applied, does not translate well to the PCEH environment. Patients often do not use systems or fail to continue to use them even when such systems are useful for helping them control their diseases. For example, Dohan and Tan [2014] argue that the IS Continuance model is more appropriate than TAM for studying tools to support chronic diseases. Thus, we need research that will investigate what the drivers are for PCEH-system use across a variety of disease types. Another example is that PHRs are used more by the elderly and much less by younger patients, contrary to the typical results for age effects on the adoption and use of other systems [Tulu et al., 2012].

As Baird [2014] notes, e-health access often occurs sporadically rather than as a frequent or regular need. This reduces the importance of TAM's behavioral intention component in predicting actual use [Wilson et al., 2010; Wilson and Lankton, 2014]. In addition, there is likely to be a lifecycle of use for PCEH websites as patients are initially diagnosed with a new disease and thus seek information about that disease, but then have the information or support they need so that usage declines. All of these situations are opportunities for developing and testing new models.

Design Science

Two articles in this special issue address the process of designing PCEH applications. Both applications are educational offerings, one for patients with cystic fibrosis (CF) and one for patients being discharged from a hospital. One study conducts a formative evaluation of the project to understand how and why the user-focus changed from teenagers with CF to parents of young children with CF and how that change in focus changed the educational offering [Aspria et al., 2014]. The other study employs a design science research methodology to iteratively design and develop a system for discharge instructions [San Nicolas-Rocca et al., 2014].

Our smartphone diabetes application under development at WPI also illustrates the value of developing design principles for PCEH applications. We have articulated three general design principles to guide our various app development projects, specifically that it must be medically sound, technically sound, and patient-centered [Strong et al., 2012], but sometimes it is difficult to maintain consistency among these principles. To ensure medical soundness, we collaborate with physicians, and to ensure patient centeredness, we involve patients in the design of the app. Yet patients want to receive only positive feedback from the app, whereas positive feedback may not be the

appropriate response from the perspective of medical practitioners. As we continue to develop our app, we are discovering new PCEH design principles.

These studies illustrate the design science opportunities associated with PCEH systems. Specifically, as we build PCEH systems, we simultaneously need to develop principles for designing, developing, and testing them. Those principles are likely to differ from those used for business systems, because, as described above, the drivers of adoption and use are likely to differ. Studying what and how design and development processes and principles for PCEH systems differ from those for business systems is likely to be a good opportunity for research.

Theory Development and Refinement

There are also opportunities to develop PCEH theories and refine existing theory to include PCEH aspects. In this special issue, Wilson et al. [2014] work toward developing the theoretical underpinnings for the PCEH discipline based on definitions of the three aspects of patient-centeredness.

As we develop PCEH models and design principles, we are at the same time refining and extending IS theories to cover a new and different domain, that of healthcare delivery. In some areas, we may need completely new theories, while in others, we may be able to modify and extend existing IS theories. Each of the articles in this special issue is developing new knowledge that might contribute to new theories or refinements to existing IS theories. We encourage PCEH researchers to consider developing and refining theory.

Educational and Motivational Applications

Any of these methods can focus on particular types of systems or applications, e.g., as mentioned above, studies can focus on systems designed solely for patients or systems designed for joint use by patients and providers. Two types of applications are particularly important for study in the PCEH discipline: educational and motivational applications.

As mentioned earlier, two articles in this special issue examine the development of health education applications, one for a particular disease (CF) and one for discharge instructions. Such educational systems are of particular importance in the PCEH discipline. Most of us are not physicians, but when we are diagnosed with particular diseases or conditions, are referred for particular treatments, or are newly released from the hospital, we suddenly have a need for knowledge sufficient to make health-related decisions or take appropriate actions for a condition about which we know little. Currently, there are various websites that provide some of that information in a way that patients can understand. Yet those websites can be ineffective because they often provide too much information initially but not enough later when one has learned the basics. What we need is information that is tailored to particular patients' needs and that can evolve as patients learn and as their needs evolve. As educators and IS researchers, we may be able to contribute to developing the theories and design principles needed to develop such systems.

A major healthcare problem is that patients, especially those with chronic diseases, often fail to maintain the healthy habits needed to maintain maximal health. While various IT applications can be designed to provide the knowledge needed for self-care, a major issue is to motivate and empower patients to engage in those behaviors [Sherer, 2014]. Thus, PCEH educational systems designed for long-term use also need to be motivational systems so that patients continue to use them. Much research is needed on how to use IT to motivate users to engage in healthy behaviors. In this issue, Ghosh et al. [2014] is an excellent start on a model of the role that IT-based communication can play in helping to motivate patients to better manage their chronic diseases. For our diabetes app at WPI, we are working with behavioral medicine specialists to understand how we might capture their motivational techniques in our smartphone apps. Another avenue some are exploring is to use gaming techniques, but turning a chronic disease into something fun may just not be possible.

There is clearly a need for more understanding of how to include educational and motivational aspects into PCEH applications. Furthermore, as the PCEH discipline develops, we are likely to discover other special types of systems to study.

VI. OVERVIEW OF ARTICLES IN THIS SPECIAL SECTION

A call for the PCEH Special Section was issued in January 2012 requesting articles that report PCEH conceptual development and empirical research as well as articles directed toward support of PCEH and researchers, a key part of the *Communications of the Association for Information Systems* mission [Wilson, 2004]. Prospective authors were invited to submit abstracts for initial direction by the guest editors during the spring and summer of 2012, and twenty-three articles were submitted by the October 1, 2012, Special Section deadline. Two rounds of peer reviews

were conducted, and fourteen revised articles were invited for publication. Editorial production of the accepted articles began in March 2013.

Below we present a brief overview of each of the fourteen articles in this special section. While each article is cited in our discussion of the many opportunities for PCEH research, the descriptions below provide a better sense of the articles, which should assist readers with finding those articles that match their interests.

PCEH and the Healthcare Delivery Context

Four articles provide material that is useful for understanding PCEH research and the context of healthcare delivery. The first defines what we mean by PCEH from a theoretical viewpoint, the next two explain important differences between the healthcare delivery context and the usually business context of most IS research, and the final one presents a teaching case to illustrate health IT use in hospitals.

Wilson, Wang and Sheetz [2014], "Underpinning a Guiding Theory of Patient-centered e-Health," applies the Wilson [2009] definition of PCEH to create qualitative measures for assessing levels of patient-focus, patient-activity, and patient-empowerment in e-health, and apply these measures to analyze recent studies of e-health services supplied by healthcare providers. The theoretical model proposes that these three factors are antecedents to patient-centering in e-health, which in turn is expected to predict e-health adoption and use by patients.

Sherer [2014], "Patients are Not Simply Health IT Users or Consumers: The Case for 'e Healthicant' Applications," argues for a new term, *healthicants*, rather than patients, users, or consumers, because individuals engage throughout the healthcare delivery value chain, not just as *patients* being treated, not just as end *consumers* of healthcare services, and not just as health IT *users*. Using this understanding, the article analyzes the value chain to determine gaps and propose applications needed by healthicants that go beyond extending health IT designed for providers.

Baird [2014], "Making the Case for Leveraging the Patient-centered e-Health (PCEH) Context to Expand Information Systems Theory," argues for treating PCEH users as stakeholders and decision makers rather than passive users or consumers. As such, the PCEH context provides a very different context for IS theory development than the business firm context of most IS theories. The article describes a variety of opportunities for IS theory development in the PCEH context.

Pardue, Campbell, Campbell and Wisniewski [2014], "Mission Impossible? Putting the Patient Back in Patient Care," is a teaching case that illustrates the emergency room and hospital experience of patients and their families by describing the journey of one such patient from the arrival at the emergency room to discharge from the hospital the next day. The use of IT and the interactions of care providers with the patient and her family are described as they occur during the process. The case ends by wondering whether the patient experience could have been better.

Models of Acceptance, Use, and/or Outcomes

Three articles use the context of chronic disease self-management to develop empirically testable models that draw on constructs and relationships from various IS models. The first two articles draw primarily from technology adoption models to explain patients' use of IT to support disease management. The third article draws on models of empowerment and media richness to explain whether patients switch to healthier behaviors.

Archer and Cocosila [2014], "Canadian Patient Perceptions of Electronic Personal Health Records: An Empirical Investigation," develop a model to explain consumers' adoption of PHR systems. In doing so, they draw on constructs and relationships in various individual-level models of IT adoption, augmented by some constructs of importance for healthcare or access to healthcare data. The model was tested using a PLS analysis of data from 389 patients with chronic diseases.

Dohan and Tan [2014], "Enhancing Patient Physician Communication with Electronic Symptom Reporting (ESR): A Multilevel Model," develop, but do not empirically test, a multilevel model to explain adoption of ESR tools. In the model, the quality of information patients provide about their chronic disease affects the satisfaction of physicians with that information, which in turn affects patients' use of ESR tools. To develop the model, the authors draw on constructs and relationships in chronic disease coping models and various IS adoption and satisfaction models.

Ghosh, Khuntia, Chawla and Deng [2014], "Media Reinforcement for Psychological Empowerment in Chronic Disease Management," develop a model to explore how to empower patients with chronic diseases to take better care of their health. The model explains whether patients change health behaviors to actively manage their diabetes based on their psychological empowerment, as moderated by the richness of the media that physicians use to

reinforce patients' motivation. The model is tested using PLS on an archival dataset from seventy-eight patients with diabetes.

Patient-centered Design Research

Two articles discuss how to involve users in designing healthcare delivery interventions. Both articles describe the design of interventions for educating patients.

Aspria, de Mul, Adams and Bal [2014], "Integrating Users in an Interactive Video Education Project: Reframing the Patient-centered Strategy of a Cystic Fibrosis Centre," report on the formative evaluation of a project for educating patients with cystic fibrosis (CF). When the educational offerings failed to attract the intended audience (teenagers with CF), the project was reframed to focus on the audience it did attract, namely parents of young patients with CF. This study illustrates the need to study users—who they are and how and why they interact with the PCEH system.

San Nicolas-Rocca, Schooley and Joo [2014], "Design and Development of a Patient-centered e-Health System to Improve Patient Understanding at Discharge," report on a project to develop videos to support the provision of hospital discharge instructions. The article demonstrates the use of design science research methods and user-centered design principles to iteratively develop a system that meets both patient and physician goals. As development cycles progressed, the system evolved from a picture book to a full multi-media system.

Assessment of PCEH Websites

Five articles focus on health-related websites. The first provides a useful classification of such websites, while the other four are empirical studies of user activities on particular health-related websites.

Kamis, Yao and Kim [2014], "An Empirical Validation of the Patient-centered e-Health Framework in Patient-focused Websites," empirically tests Wilson's [2009] PCEH model by using it to classify patient-focused websites. The PCEH model successfully differentiated among sites. In addition, the differences among sites produced a useful classification of patient-focused websites into the five categories. The fifth category, community websites, is the focus of the other four articles on PCEH website articles.

Kordzadeh, Liu, Au and Clark [2014], "A Multilevel Investigation of Participation Within Virtual Health Communities," measured participation at the individual and thread level of a sample of users in the depression group within a large health-support website. The results regarding gender, age, and highly active users differ from those typically found for social websites, demonstrating the importance of understanding the role of the healthcare context for understanding users' website behavior.

Choi et al. [2014], "Seek or Provide: Comparative Effects of Online Information-sharing on Seniors' Quality of Life," conducted a survey of seniors (over age sixty-five) who were actively involved in online social activities to understand how these activities affected their quality of life. Sites designed to support information sharing rather than social relationship formation were more successful in improving quality of life because it was through information sharing that seniors developed trust in their online interactions.

Fan, Lederman, Smith and Chang [2014], "How Trust Is Formed in Online Health Communities: A Process Perspective," used interviews and data from online postings to build a three-stage process model of how trust is formed in online health communities. The healthcare context provides a unique environment in which to study how trust develops online among those with similar health conditions who are all searching for support and information about their conditions.

Huang, Chengular-Smith and Ran [2014], "Not Just for Support: Companionship Activities in Healthcare Virtual Support Communities," studied the postings on breast cancer and prostate cancer discussion boards of a large online cancer support website. The study distinguished between social support activities and companionship activities because the latter have been largely ignored in studying online support communities. The study established the importance of companionship activities, especially in the breast cancer group, thus documenting gender differences.

Together, these fourteen articles, by presenting a broad range of PCEH topics and research methods, illustrate the challenges and opportunities available to PCEH researchers. We encourage you to read them and to conduct additional research that contributes to the PCEH research discipline and develops the knowledge needed for producing truly patient-centered health IT applications.



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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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