

# Patient-Centered E-Health: A Status Report

Vance Wilson

*School of Business, Worcester Polytechnic Institute, Worcester, MA, United States., vancewilson@gmail.com*

Weiyi Wang

*School of Business, Worcester Polytechnic Institute, Worcester, MA, United States., wangweiyi@wpi.edu*

Steven Sheetz

*Acct & Info Sys, Virginia Tech, Blacksburg, VA, United States., sheetz@vt.edu*

James Connolly

*California State University-Chico, Chico, CA, United States., jconnolly@csuchico.edu*

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# Patient-Centered E-Health: A Status Report

**E Vance Wilson**

Worcester Polytechnic Institute  
vancewilson@gmail.com

**Weiyi Wang**

Worcester Polytechnic Institute  
wangweiyi@wpi.edu

**Steven D. Sheetz**

Virginia Tech  
sheetz@vt.edu

**James R. Connolly**

California State University-Chico  
jconnolly@csuchico.edu

## ABSTRACT

Patient-Centered E-Health (PCEH) is an increasingly important part of health information technology. Yet the literature in this area is mainly descriptive and atheoretical, which limits opportunities for research advancement. This paper addresses the theoretical proposition that the benefits of PCEH can be maximized by incorporating three essential characteristics: Patient-focus, patient-activity, and patient-empowerment. We conduct a literature review of e-health research published between 2007 and 2011 to assess the relevance of these characteristics to the underlying domain and their relationships to one another. The results indicate the PCEH characteristics are generalizable to the existing research literature, are generalizable across place and time, and exhibit substantial interrelationships. These findings are encouraging to further development of a predictive theory of PCEH.

## Keywords

Health Information Systems; Health Information Technology; Health Communication; Healthcare Interventions.

## INTRODUCTION

In the past five years, the PCEH concept has gained significant traction. While a current Google search finds only 31 references to the exact phrase “patient-centered e-health” dated prior to 2007, over 70,000 references have been entered from 2007 onward. Yet we find there is little consensus as to what people mean when they refer to PCEH and only limited theory defining what characteristics PCEH should incorporate. This situation motivated us to conduct research to clarify definitional aspects of the PCEH concept, to illuminate what types of PCEH services actually are being implemented in research settings, and to thereby move toward a theory of PCEH.

In this paper, we explore the conceptual and historical underpinnings of e-health and PCEH. We then conduct a qualitative analysis to assess the degree to which e-health services reported in the healthcare literature incorporate essential characteristics of a recent theoretical definition of PCEH. The resulting status report provides a basis for discussion of implications for future research and practical development in the PCEH area.

## BACKGROUND

The term e-health was coined in the late 1990’s “in line with other ‘e-words’ such as e-commerce, e-business, e-solutions, and so on, in an attempt to convey the promises, principles, excitement (and hype) around e-commerce (electronic commerce) to the health arena, and to give an account of the new possibilities the Internet is opening up to the area of health care” (Eysenbach, 2001, p. e20).

Many e-health websites were commercial endeavors which provided encyclopedic health information to individual consumers, and most of these sites went out of business during the dot-com bust (Itagaki et al., 2002). Nonetheless, consumer demand for e-health remained strong (Fox, 2005), and healthcare providers began to implement e-health services of their own, despite initial reluctance to enter this domain (Lazarus, 2001).

One reason for resistance by healthcare providers is constraints they faced in the types of e-health services they could offer. Potts (2006, p. e23) explains,

“Away from healthcare, the Internet has been revolutionary and transformational because it has democratized production and distribution. Traditional healthcare, given its safety critical context, utilizes an evidence base and a process of risk management that generally involves some sort of governance. These are conflicting trends: the great value of the Internet is how easy it is to make material available, but the strictures of safety and proof of efficacy run counter to that.”

Yet e-health supplied by healthcare providers does offer the opportunity for individuals to be linked to their own health records, physicians, and clinical staff. This has proved to be a significant benefit, and Kaiser-Permanente (Silvestre et al., 2009) and other healthcare providers have drawn large subscriber bases by implementing e-health that incorporates services that appeal to patients, such as viewing test results, sending email to doctors, and viewing past office visit information online.

The need for e-health to appeal to patients should not be underestimated. Unlike health information technologies that are internal to healthcare provider organizations, e-health adoption cannot be easily mandated. Numerous e-health services have been implemented that patients failed to adopt, leading to underutilization or abandonment of the service. Examples include diabetes decision support (Payton & Brennan, 1999), asthma self-management (Sassene & Hertzum, 2009), and personal health records (Greenhalgh et al., 2010).

### Defining Patient-Centered E-Health

In practice, “e-health” has come to be used as an umbrella term, covering wide-ranging services including electronic patient records, telemedicine, and biomedical informatics (Pagliari et al., 2005). At the same time, some sources, e.g., Health.gov (2012), continue to use “e-health” to refer to services accessed by the public rather than services supporting health professionals, insurers, or third-party payers. However, neither usage of the term adequately describes the form of e-health supplied by healthcare providers, which is targeted toward that subset of the public comprising the provider’s patients and their caregivers. This situation motivated researchers to become more specific in describing the type of e-health they studied, using such terms as provider-delivered e-health (Wilson & Lankton, 2004), consumer health informatics (Lewis et al., 2005), and personal health informatics (Wilson, 2006).

The first scholarly reference we find to “patient-centered e-health” appears in the doctoral dissertation of Christopher Lau (2003). He describes several e-health services that healthcare providers frequently offered at the time, including content delivery, appointment scheduling, and patient-provider email. He goes on to propose that PCEH could be extended by adding such transformative capabilities as personal health knowledge management (which we have come to know as personal health records), referral support, and home monitoring applications. Lau used the term “patient-centered” as a *description* of e-health that comprises features that are oriented toward use by patients, and similarly atheoretical use of the phrase “patient-centered e-health” continues in recent studies (Binczewski et al., 2011; Resnicow et al., 2010).

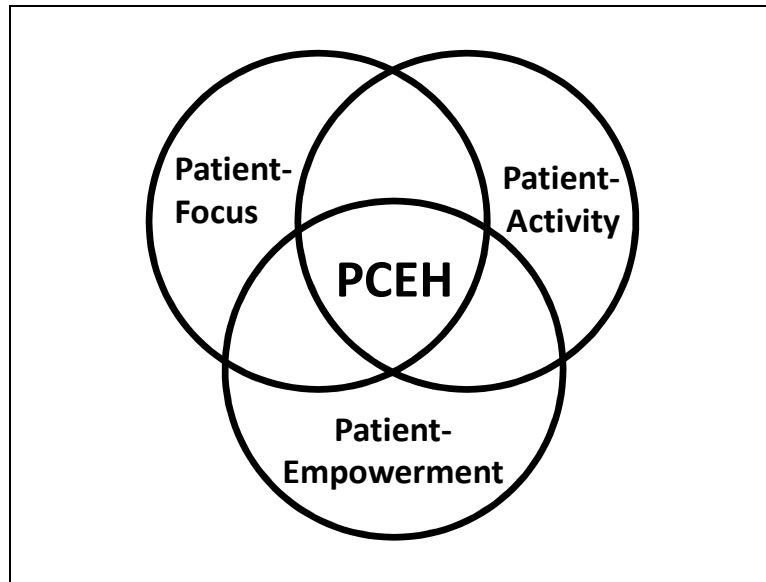
Healthcare is frequently criticized for reluctance to build and follow theory-based research frameworks (Eccles et al., 2005; Grimshaw et al., 2004), even though there is recognized need “to establish the theoretical basis of interventions and undertake exploratory studies to choose and refine interventions” (Grimshaw et al., 2004, p. 107). The U.S. National Cancer Institute advises,

“Using theory as a foundation for program planning and development is consistent with the current emphasis on using evidence-based interventions in public health, behavioral medicine, and medicine. Theory provides a road map for studying problems, developing appropriate interventions, and evaluating their successes. It can inform the planner’s thinking during all of these stages, offering insights that translate into stronger programs. Theory can also help to explain the dynamics of health behaviors, including processes for changing them, and the influences of the many forces that affect health behaviors, including social and physical environments.” (NCI, 2005, p. 5)

The underlying idea that healthcare should be patient-centered has a strong theoretical component. The Institute of Medicine defines patient-centered 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” and theorizes that a patient-centered approach will contribute to “care that is safer, more reliable, more responsive to their needs, more integrated, and more available” (IOM, 2001, p. 3). From this perspective, e-health can be patient-centered only if it derives from patients themselves rather than from the preferences, needs, and values of healthcare providers or software developers. As Winkelman et al. (2005, p. 312) argue,

“The patient-user’s perspective on what constitutes technology usefulness is both distinct from and complementary to that of physicians and developers. To build useful ICT tools for patients, direct patient participation must be made part of all steps in the design and development process and, most importantly, in the earliest conceptual stages.”

The need for a prescriptive, theoretical definition of PCEH motivated Wilson (2009) to propose that three essential characteristics must be present in order to maximize benefits of PCEH through increased patient adoption and utilization. These characteristics are illustrated in Figure 1 and are briefly described as follows (readers are referred to the original source for full arguments supporting each characteristic).



**Figure 1. Essential Characteristics of Patient-Centered E-Health (Wilson, 2009)**

- *Patient-focus*: PCEH is developed based primarily on the needs and perspectives of patients.
- *Patient-activity*: PCEH supports meaningful participation by patients in providing information about themselves and consuming information of interest to them.
- *Patient-empowerment*: PCEH provides the ability of patients to control far-ranging aspects of their healthcare.

### **Moving Toward a Theory of PCEH**

Wacker (2008, p. 7) defines theory as an “explained set of conceptual relationships” comprising four essential properties, each of which must exhibit several further subproperties to qualify as “good” theory:

- *Definitions* describe who and what the essential components are. In “good” theory, definitions are characterized by conservatism (distinct from similar terms already in existence), uniqueness (to the specific concept), and parsimony.
- *Domain* describes when and where the theory applies. In “good” theory, the domain outlines the degree to which the theory will be generalizable to existing populations and to which it may be abstracted (i.e., generalized) across place and time.
- *Relationships* describe how and why empirical findings occur. In “good” theory, relationships exhibit fecundity (suggesting new areas of research), internal consistency, statistical parsimony (not requiring complex statistical explanations), and substantive significance.
- *Predictions* describe effects that should, could, and would occur. In “good” theory, predictions must be falsifiable, i.e. capable of being disproven.

Wilson’s (2009) definitions of PCEH characteristics meet Wacker’s logical criteria for conservatism, uniqueness, and parsimony, in that terms are distinct from similar terms and from one another, unique to the concept of PCEH, and parsimonious in number. In this paper, we conduct research to ascertain the generalizability and abstraction properties of the theoretical domain and to explore relationships among the characteristics as a means of moving toward a theory of PCEH. These aspects are key to ensuring that the concepts comprising PCEH are relevant to the underlying domain as well as to one another. In the following sections, we apply the Wilson (2009) definition of PCEH to create a qualitative measure for assessing levels of patient-focus, patient-activity, and patient-empowerment. We then apply this assessment measure to recent research conducted in the domain of e-health services supplied by healthcare providers.

## RESEARCH METHOD

Our method in this research was to assess a representative selection of relevant recent studies. The research was conducted as a keyword-based literature search and review of peer-reviewed journal articles published during the five-year period of 2007-2011. We conducted our search using the PubMed database, which currently indexes more than 21 million citations for biomedical literature (PubMed, 2012).

We entered the exact phrase “(e-health OR ehealth) AND (patient OR patients)” as a keyword search on all fields in PubMed and set the date range between January 1, 2007 and December 31, 2011. This query resulted in 2920 initial results.

### Screening

Our objective in screening was to identify papers which described specific e-health services supplied by a healthcare provider. These included papers that address use of e-health by patients as well as papers that describe e-health services that are designed for such use, such as prototype software. Screening proceeded in three stages. In the first stage, one of the researchers reviewed titles to remove papers that clearly did not meet our criteria, including conceptual articles, frameworks, reviews, and meta-analyses. In the second stage, one of the researchers applied the same criteria to review abstracts of the remaining papers. In the third stage, copies of the 62 papers left after prior reviews were obtained and their research designs were reviewed by both researchers using the previously-described criteria plus the criteria that the papers were published in peer-reviewed journals and that no two papers described the same e-health services. Following screening, 17 papers were identified as meeting our criteria for final assessment.

### Assessment Protocol

To assess the extent to which the e-health services described in each paper met the theoretical definitions of patient-focus, patient-activity, and patient-empowerment described by Wilson (2009), we applied the following protocol.

#### *Patient-Focus*

Central criterion: Attention of e-health designers and administrators is primarily directed toward the patient-users; evidenced by prior study of patients’ needs or desires, e.g., through observation, interviews, surveys, or focus groups; contradicted by evidence the e-health design is primarily dictated by organizational or commercial interests or use of a top-down development approach. Evaluate as:

- High = overwhelmingly patient-focused (coded as 2)
- Moderate = comprised of a mix of patient-focused and non-patient-focused parts (coded as 1)
- Low = minimally patient-focused (coded as 0)

#### *Patient-Activity*

Central criterion: Patients are given meaningful abilities to provide information as well as consume it within the context of the e-health service; evidenced by capability for patients to use system to communicate with healthcare providers and/or to update or augment personal health information in a form that is viewable by healthcare providers as well as the patient; contradicted by storage not viewable by healthcare providers, by firewalls between patient data and provider staff, or by other obstructions to patient input or feedback. Evaluate as:

- High = overwhelmingly patient-active (coded as 2)
- Moderate = comprised of a mix of patient-active and non-patient-active parts (coded as 1)
- Low = minimally patient-active (coded as 0)

#### *Patient-Empowerment*

Central criteria: Meaningful control and a high level of usability; evidenced by including features that provide a similar level of control over the target processes that would be available to the patient in alternative contexts, e.g., via the phone or office visit, and by evidence of usability testing; contradicted by failure to include control options that are commonly available in that use context, by lack of usability testing, and/or by evidence that in-depth patient training is needed in order to achieve adequate usability. Evaluate as:

- High = Evidence of usability testing AND no obvious missing control functionality (coded as 2)
- Moderate = Evidence of usability testing OR no obvious missing control functionality (coded as 1)
- Low = Obvious missing control functionality AND no evidence of usability testing (coded as 0)

## ANALYSIS PROCEDURE AND RESULTS

Two of the researchers reviewed each of the 17 selected papers and independently applied the assessment protocol to create an evaluation. The researchers then met to compare their evaluations. Where evaluations did not match, each researcher explained his rationale for assessing the paper, and all differences were resolved by consensus. The final evaluations are shown in Table 1. Keys to numeric coding are explained in the Assessment Protocol section that immediately precedes this section.

Every e-health example we assessed exhibited moderate or high levels of at least one PCEH characteristic, and five examples (29%) fully implemented all PCEH characteristics. The mean assessments for patient focus, patient activity, and patient empowerment were all  $> 1$ , indicating that the e-health services we studied exhibited moderate to high levels of these characteristics on average. Of the 51 total assessments we made (three assessments each of 17 e-health examples), 25 were high level, 17 moderate level, and only 9 low level; 82% were moderate or high level (see Figure 2). The results indicate PCEH characteristics are broadly represented across the studies we assessed. Presence levels were highest for patient-activity and lowest on patient-empowerment.

## DISCUSSION

Our research objectives were to ascertain the generalizability and abstraction properties of patient-focus, patient-activity, and patient-empowerment to the theoretical domain and to explore relationships among the PCEH characteristics. These objectives are part of an overarching goal to move toward a theory of PCEH which may at some future time become useful for explaining relationships in this area as well as predicting empirical effects of those relationships. We explain in the following sections how these research objectives were supported by our research design and findings.

### Generalizability and Abstraction

The findings show that a substantial portion of the e-health literature in this area has incorporated the PCEH characteristics proposed by Wilson (2009). Nearly a third of the e-health examples we reviewed fully implemented all three characteristics. The ubiquitous presence of patient-focus, patient-activity, and patient-empowerment characteristics across the literature we reviewed argues that the characteristics meet the theoretical criteria of generalizability and abstraction.

Our selection of the literature was drawn by entering search terms related to patients and e-health into the PubMed database, resulting in over 2900 results. We recognize that numerous other search terms could have been entered, e.g., “online”, “Internet”, “portal”, “consumer”, and “e-patient”, and other research databases could have been searched in order to find additional papers which described specific e-health services supplied by a healthcare provider. Given our goal of assessing a representative selection of studies rather than identifying the maximum number of studies, we argue that the findings obtained in this manner are adequately generalizable across the research literature domain which we intended to sample.

E-health services are supported and transported via Internet technologies, which are dynamic and fast-changing. Our approach to ensure adequate time abstraction in our research design was to search across the most recent five years of published studies rather than extending the search back to an era of limited bandwidth and reduced computational capabilities. Abstraction across space was ensured by the wide reach of publications indexed in the PubMed database. We argue that this approach ensures adequate abstraction in assessment of the PCEH domain.

### Relationships Among PCEH Characteristics

To explore relationships, follow-up correlational analysis was conducted using the ordinal coded data from the patient-focus, patient-activity, and patient-empowerment columns in Table 1. We find the PCEH characteristics to be substantially intercorrelated (Spearman's  $\rho = .69 - .77$  between columns). This indicates that, although conceptually distinct, these characteristics are strongly related in the manner in which they are implemented in e-health services. The significant shared variance exhibited by these characteristics further suggests that it may be appropriate to model a distinct PCEH construct as a second-order latent factor in future theory development. Further research will be necessary to confirm this interpretation, however, the initial finding is encouraging.

Papers Under Assessment	Patient-Focus	Patient-Activity	Patient-Empowerment
Adams, A, et al. (2007). Barriers to the use of e-health technology in nurse practitioner-patient consultations. <i>Informatics in Primary Care</i> , 15, 103-9	0	1	0
Andreassen, H. K. (2011). What does an e-mail address add? Doing health and technology at home. <i>Social Science &amp; Medicine</i> , 72, 521-8	1	2	1
Arsand, E., & Demiris, G. (2008). User-centered methods for designing patient-centric self-help tools. <i>Informatics for Health &amp; Social Care</i> , 33, 158-69	2	2	2
Atkinson, N. L., et al. (2011). Assessing the impact of user-centered research on a clinical trial eHealth tool via counterbalanced research design. <i>Journal of the American Medical Informatics Association</i> , 18, 24-31	2	2	2
Chang, H. H., & Chang, C. S. (2008). An assessment of technology-based service encounters & network security on the e-health care systems of medical centers in Taiwan. <i>BMC Health Services Research</i> , 8, 87	1	1	0
France, F. R. (2011). ehealth in Belgium, a new "secure" federal network: role of patients, health professions and social security services. <i>International Journal of Medical Informatics</i> , 80, E12-6	0	1	0
Gustafson, D. H., et al. (2008). Internet-based interactive support for cancer patients: Are integrated systems better? <i>Journal of Communication</i> , 58, 238-257	1	2	1
Han, J. Y., et al. (2010). Factors associated with use of interactive cancer communication system: An application of the comprehensive model of information seeking. <i>Journal of Computer Mediated Communications</i> , 15, 367-388	1	2	1
Hansen, D. P., et al. (2011). The Australian e-Health Research Centre: Enabling the health care information and communication technology revolution. <i>Medical Journal of Australia</i> , 194, S5-7	0	1	0
Hogan, T. P., et al. (2011). Promoting access through complementary ehealth technologies: Recommendations for VA's home telehealth and personal health record programs. <i>Journal of General Internal Medicine</i> , 26, 628-35	1	2	2
Kollmann, A., et al. (2007). Feasibility of a mobile phone-based data service for functional insulin treatment of type 1 diabetes mellitus patients. <i>Journal of Medical Internet Research</i> , 9, E36	1	2	0
Lee, Y., & Lee, M. (2008). SMS application using EMG signal of clenching teeth for e-health communication. <i>Telemedicine Journal and E-health</i> , 14, 593-7	1	2	2
Madhavan, S., et al. (2011). Pediatric palliative care and ehealth opportunities for patient-centered care. <i>American Journal of Preventative Medicine</i> , 40, S208-16	2	2	2
Marziali, E. (2009). E-health program for patients with chronic disease. <i>Telemedicine Journal and E-health</i> , 15, 176-81	2	2	2
Nijland, N., et al. (2008). Evaluation of internet-based technology for supporting self-care: problems encountered by patients and caregivers when using self-care applications. <i>Journal of Medical Internet Research</i> , 10, E13	2	2	1
Sheaves, B., et al. (2011). Phase 1 pilot study of e-mail support for people with long term conditions using the Internet. <i>BMC Medical Informatics and Decision Making</i> , 11, 20	1	1	0
Tripathi, M., et al. (2008). Engaging patients for health information exchange. <i>Health Affairs</i> , 28, 435-43	2	2	2
Mean Assessment	1.18	1.71	1.06

Table 1. Results of Qualitative Analysis

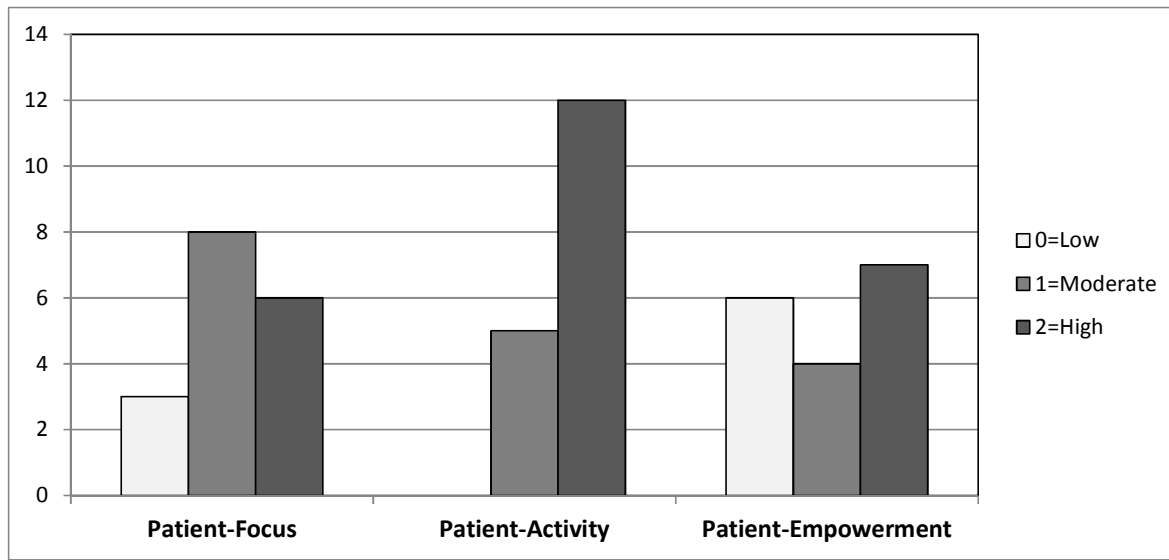


Figure 2: Histogram of patient centered e-health characteristics.

### Additional Implications

There are two further implications from observations we made during screening and analysis in this study.

First, despite retrieving nearly 3000 initial papers, we found only 17 peer-reviewed journal articles published between 2007 and 2011 which describe e-health services supplied by a healthcare provider. As discussed previously, this could be due to our choice of search keywords and use of only the PubMed database. However, related research suggests the small representation is more likely due to a bias in the healthcare informatics research community toward topics that do not involve patients' use of e-health. Samoocha et al. (2010) report a review and meta-analysis of randomized controlled trials that studied effects of web-based interventions on patient empowerment. Their study searched the Medline, Embase, and PsychInfo databases from January 1985 to January 2009 and netted only 14 studies.

Our interpretation is further supported by Table 2, which shows the proportion of papers we reviewed that were published in healthcare informatics journals, non-informatics healthcare journals, and journals outside healthcare. Nearly half the papers (47%) come from journals outside the healthcare informatics category.

The implications of this analysis reprise the situation health information systems (IS) researchers once faced in publishing their work in IS journals. Prior to 2003, only 1.2% of all papers published by mainstream IS journals addressed any aspect of healthcare (Chiasson & Davidson, 2004), although the healthcare sector accounted for up to 14% of the U.S. GDP during that time. In recent years the percentage of health IS papers has increased dramatically in IS journals, suggesting that perseverance by authors, reviewers, and editors can raise visibility of under-reported topics (Wilson & Tulu, 2010).

Second, while mean assessments of patient-focus, patient-activity and patient empowerment exceeded the midpoint value of the measurement scale (1.00), these assessments varied significantly among the characteristics. Patient-activity (mean = 1.71) was implemented at higher levels than either patient-focus (mean = 1.18) or patient-empowerment (mean = 1.06). Results from the nonparametric Wilcoxon Signed Ranks test of mean differences shows  $Z \geq 3.0$  and probability  $\leq .01$  in both contrasts. Our interpretation is that some e-health designers resist giving patients control, by failing to focus on patients' desires or to empower patients with capabilities beyond the minimal actions required to use basic features of the e-health service. Winkelman makes a similar observation in reviewing a study of a patient-accessible electronic patient record system:

[The system] shares a common identity paradox with these other systems in that it portends to be patient-centered while employing physician-centered design and evaluation frameworks. It is therefore not surprising that, in their study, patient access has little measureable impact on patient-specific health outcomes. (Winkelman, 2004, p. 1)



Category	Journal	Journal Total	Category Total
Healthcare Informatics Journals	<i>BMC Medical Informatics and Decision Making</i>	1	9
	<i>Informatics in Primary Care</i>	1	
	<i>Informatics for Health &amp; Social Care</i>	1	
	<i>International Journal of Medical Informatics</i>	1	
	<i>Journal of the American Medical Informatics Association</i>	1	
	<i>Journal of Medical Internet Research</i>	2	
	<i>Telemedicine Journal and E-health</i>	2	
Non-Informatics Healthcare Journals	<i>American Journal of Preventative Medicine</i>	1	6
	<i>BMC Health Services Research</i>	1	
	<i>Health Affairs</i>	1	
	<i>Journal of General Internal Medicine</i>	1	
	<i>Medical Journal of Australia</i>	1	
	<i>Social Science &amp; Medicine</i>	1	
Journals Outside Healthcare	<i>Journal of Communication</i>	1	2
	<i>Journal of Computer Mediated Communications</i>	1	

**Table 2. Proportion of Papers in Three Journal Categories**

Our interpretation implies that at least some e-health designers and managers need to reflect on the technological context their products are going to be viewed within. Earlier in the paper we noted that e-health must appeal to patients or they will not adopt it. We further cited several examples where adoption efforts failed (Greenhalgh et al., 2010; Payton & Brennan, 1999; Sassene & Hertzum, 2009). The web is no longer new and users are not naïve in evaluating e-health. Web users have come to expect applications that satisfy their needs and give them extensive capabilities. E-health that is designed without meeting these basic expectations of web users is designed to fail.

## CONCLUSION

Our study represents a new stage in PCEH research that moves beyond the initial definitions presented by Wilson (2009). By supporting that patient-focus, patient-activity, and patient-empowerment are adequately generalizable and abstract within the theoretical domain, and by exploring relationships among these characteristics, we move toward the “explained set of conceptual relationships” that constitutes theory (Wacker, 2008, p. 7). Our findings encourage future research that can develop and test relationships and predictions based on the current PCEH model.

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