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INFORMATION SYSTEMS AND HEALTH CARE X: A USER-DRIVEN APPROACH TO PERSONAL HEALTH RECORDS

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ABSTRACT

User acceptance issues and user-centered design have long been an important theme in information systems research. In the field of health care information systems, much attention has been devoted to user issues in the health care provider domain, e.g. physicians, nurses, medical records. Recent developments toward promoting more consumer-oriented healthcare information systems have opened new questions about how individuals can and should relate to their personal health information in the form of Personal Health Records (PHR) systems. This paper adopts a user-driven perspective toward these new and challenging questions. Drawing upon ideas and discussions from a cross-section of information systems researchers, health care providers, private industry, and government, we examine several of the major issues that will need to be addressed in order to meet a national challenge to adopt PHR for all Americans by 2014.

Keywords: Personal Health Records, User-Driven Systems Approach

I. INTRODUCTION

PERSONAL HEALTH RECORDS

While the field of information systems has grappled with user acceptance issues for some time, the idea of a personal health record (PHR) controlled by the individual is a relatively new idea in the health care arena. Among the earlier conceptualizations was the Markle Foundation's of 2004, which stressed PHR's purpose as a *comprehensive personal health information repository* together with *control by the individual* as defining characteristics [Markle, 2004]. On-going conceptual work continues to refine the idea of PHR, including as key criteria that the record be *longitudinal*, ideally covering the entire lifespan; that the *consumer has control* over access to the information in the record; and that PHR must be *distinct from the legal* medical records that

institutions are required to maintain [AHIMA e-HIM, 2005]. The concept of individual ownership and control of health information is what makes the concept of PHR new and distinguishes it from the broader Electronic Health Record (EHR). A truly person-centric system for PHR must be one in which the individual is not only the focus of the data, but also the owner of the data. This is consistent with the Institute of Medicine (IOM) recommendation that the patient should be the *source of control* in making health care decisions [Institute of Medicine, 2001]. This vision of PHR reflects one of the main goals in the federal government's vision for health care in 2014: to provide consumers with "ready access to...complete and...patient-friendly information upon which to make informed decisions about their...care" [Frist, 2004]

The conceptual framework of PHR also includes the idea that the content of the PHR comes from many sources: personal information, clinical data, insurance data, tele-health data, and more. It is important to fully understand how various consumers will contribute to and utilize this content within the current health care system. Achieving this will require a common language and a framework within which issues related to PHR can be discussed as the concept of PHR is further refined and fleshed out. An important touch-point in this dialogue is that "a research agenda should be developed and funded to guide the evolution of PHR technology, including the development of a taxonomy for classifying PHRs." [Tang and Lansky, 2005]. When fully assembled, a complete conceptual framework for PHR will include a significant systems-related component, since any type of PHR must be represented by some kind of system.

A PHR SYMPOSIUM

The authors sought to advance such a conceptual framework by engaging experts from both the medical informatics and information systems domains. This symposium, entitled "The Many Faces of Person-Centric Electronic Health Systems" drew together nationally recognized experts to address PHR, a topic that has assumed increasing importance in the national discussion on information technology in healthcare. As part of an academic-industry collaboration between Claremont Graduate University (CGU) and QTC Management, the two-day event provided an interactive forum in which some 75 participants examined research and developments related to consumer-user perspectives toward PHR. The discussions ranged around three broadly identified user groups: the healthy, the chronically ill, and the disabled. The unique needs of each of these major PHR user groups must be addressed as a national PHR infrastructure is established. A major premise of the symposium was that an information systems (IS) approach will contribute to achieving a fuller understanding of consumer-user needs, to design PHR systems to meet those needs, and to integrate such systems within the overall national healthcare information infrastructure. As David Brailer, National Coordinator for Health Information Technology at the U.S. Department of Health and Human Services, expressed at the October 2005 meeting of the American Medical Informatics Association, if his office could accomplish only one thing, it would be to make unified, consumer-oriented PHR available to all Americans in a meaningful way, with guaranteed privacy and security [Brailer, 2005]. The chief goal of this symposium and related follow-on activities was to contribute to the development of a robust understanding of PHR in order to foster user-oriented research and deployment throughout the healthcare industry and society at large.

PHR SYMPOSIUM OBJECTIVES

This symposium differs from other efforts to research and discuss PHR by taking a user-centric approach to the issue and doing so within the academic domain of information systems. To this end, the symposium was co-sponsored by the AIS Special Interest Group on IT in Healthcare (SIGHealth), and it served as a platform where information systems and medical informatics researchers got together and identified immediate research needs that will benefit from the collaboration of these two communities.

The specific objectives of the symposium were to: 1) understand how person-centric health systems can address the diverse health needs of the different user communities (well, unwell, disabled), and 2) identify key research findings and needs for achieving person-centric health

systems that serve the many faces of the user communities. To encourage broad participation, a call for presentations was widely distributed to both the medical information and information systems communities. In addition, a background paper¹ prepared by the symposium organizers provided conceptual and practical underpinnings to the proceedings. The material that follows summarizes the presentations and discussions relative to the achievement of these objectives.

II. SYMPOSIUM KEY POINTS AND HIGHLIGHTS

The PHR symposium took place over a two-day period and featured a range of invited presentations, technical papers, and roundtable discussions. The following are some key points and ideas from the symposium. They are summarized here in the hope that they may spark additional interest in the information systems community, as many issues are well suited to an IS research approach. Speaker presentations, a background paper, and video highlights of the symposium are available through the symposium web site (<http://ehrsymposium.cgu.edu/>).

Symposium Chair Tom Horan² led off the symposium by introducing a vision of PHR that emerged from the discussions surrounding the first CGU-QTC EHR Symposium [CITI, 2005]. In working with the symposium advisory group, one of the main issues brought out was that EHR should adopt a user perspective. Adopting a user perspective requires defining the users, which brings the following distinction into sharp relief: the needs of health care providers as EHR users are very different from the needs of patients (consumers) as users. The 2005 Symposium's focus reflects a conscious decision to concentrate on the individual patient or consumer as the end user. The domain of electronic health records (EHR) is broad and far from monolithic. The provider face of EHR has been, and continues to be, the subject of intense interest among policymakers, practitioners, and researchers, while the patient/consumer face has only recently begun to be considered more fully. A main goal of the 2005 CGU-QTC Symposium is to open new pathways to understanding the transformative opportunity in health care that PHR represents.

Another goal of this symposium, as stated by Horan, was to highlight research needs and opportunities in this evolving area. The importance of this goal was echoed in opening keynotes from Helga Rippen and Mary Jo Deering: Rippen challenging the existing approaches to PHR and Deering emphasizing the importance of the unbounded research perspective of academic researchers to PHR. On day two, keynote speaker Blackford Middleton presented his outline of pressing research questions,³ followed by a roundtable discussion, generating a comprehensive list of future research directions. These suggested research directions are available in a collaborative environment at www.phrwiki.org.

A wide variety of speakers covered many different viewpoints of PHR during the two-day symposium. While diverse, these views tended to cluster around several key areas. In summarizing the symposium highlights, we place them into the context of these key focus areas: user perspectives (use cases of the well, unwell, and disabled), research findings, and research recommendations. It is important to note that the following is but a sampling of the many interesting points that were raised.

¹ Available at http://www.cgu.edu/include/2004_EMRSymposium_Summary.pdf.

² Presenter information is available in [Section VII](#).

³ Presentations of these and additional research presented at the symposiums are available for viewing at the symposiums web site <http://ehrsymposium.cgu.edu>.

III. THE PHR USE CASES: WELL, UNWELL, DISABLED

Just who is the “person” in personal health records? Even within the more narrowly defined scope of electronic health records that PHR represents, there are still many faces. Just as providers differ in their needs depending on whether they are physicians, nurses, therapists, or administrators, PHR users differ in their needs depending on a variety of circumstances. Several presenters addressed user perspectives and their relationships to health status. Horan noted that one way to examine PHR user needs is through the lens of individual health status and how that status affects PHR needs⁴. As a starting framework for discussion, he and the CGU research group in their background paper defined three fundamental health states: well, unwell, and disabled⁵.

THE WELL

The related themes of privacy and consumer control over personal health information emerged as major ones for the symposium participants. While several presentations touched on the information needs of the “well” user, perhaps the most innovative presentation in this area was Jose Lacal's. He described a handheld unit working with remotely hosted software that provides a wellness-oriented, family-centered personal health information solution. This PHR product is analogous in some ways to today's personal financial information services, yet is designed to attract consumers as “the iPod® of personal health records.” Within this system, records are maintained longitudinally and service is available universally. Lacal proposes that this type of solution will usher in a new way of thinking about wellness as “evidence-based health.” Just as modern clinicians use knowledge bases to inform their practice (evidence-based medicine), consumers can use a health knowledge base to manage their personal health decisions. He describes evidence-based health as having three key focus areas: health improvement, the individual as the point of care, and the family as the locus of PHR. By focusing on health improvement and preventive care, the burden of chronic disease would be reduced; having the individual as the point of care would implement the Institute of Medicine goal of patient-centered care [Institute of Medicine, 2001] and move the locus to the home and away from the institution or office; emphasizing the family as the primary unit of health care will empower the family, especially parents. Finding a viable economic model for such technologies can be challenging. Lacal sees a lack of existing support systems for wellness as the consumer driver for this technology. He outlined a deployment model much similar to that presently used by financial institutions in deploying online banking in which a PHR application controlled by the user would interact with data provided by institutions with whom the user has relationships. To address security issues a model similar to iTunes® digital rights management is proposed. The main user needs reflected in the conceptual design of the solution are:

- Comprehensiveness. The ability to access all records for all family members through one interface over the entire life cycle.

⁴ Other ways to frame user needs include the user's life stage, changes in user needs over time, the role of technology change over time, and the user's social, financial, and insurance status.

⁵ **Well:** Those who are not currently interacting with the provider community except for routine care such as checkups and immunizations, but who have an interest in personal health information.

Unwell: Those who have some reason to be actively interacting with the provider community, including those who are acutely ill, injured, or chronically ill. This group also includes proxies for the unwell, such as family members and legal proxies.

Disabled: Those who have some condition, which may or may not currently require on-going care, and who have a continuing need for access to personal health information [Lafky, Tulu, et al. 2005].

- Wellness support. Health care targeted at maintaining good health, instead of only treating health problems.
- Consumer control. Personal health information is owned by the person, not the institution.
- Security and privacy. Consumer-controlled data protected by encryption and other technologies is less likely to be misused.

THE UNWELL

Two main cases represent the unwell, acute (illness or injury) and chronic disease. Acute care is characterized by a short-term accumulation of incident-specific data of varying degrees of value to a long-term longitudinal PHR. On the other hand, chronic disease presents an on-going need to collect and maintain current health data, as well as a need to access it routinely. Warren Winkelman presented research on the user needs of a chronically ill population in his talk, "The Technological Transformation of Self-Care." He proposed several factors that affect the needs of chronically ill users and discussed the impact of those factors, particularly with respect to the Technology Acceptance Model (TAM). He suggested that the TAM model may be inappropriate, at least in its ordinary form, for studying user acceptance of PHR in the chronically ill population. He cites three reasons for this:

1. TAM assumes that the user is a rational actor; this assumption may not hold with respect to PHR systems and users suffering from chronic illness.
2. TAM applies in the context of users as members of organizations, using technology that the organization wishes to have adopted; chronically ill potential PHR users are not functioning as members of an organization in choosing to adopt the technology.
3. TAM holds that system features and characteristics are what motivate users to adopt the technology *for their jobs*; chronically ill individuals who are considering PHR adoption are not acting in a job-related context.

Winkelman described a grounded theory of patient-perceived usefulness based on four elements:

- Illness ownership
- Patient-driven communication
- Personalized support
- Mutual trust

These elements (further elaborated in [Winkelman et al., 2005]), should, he proposes, augment our understanding of TAM when applied to the case of the chronically ill. To adapt TAM to this use case, we should consider that:

- Successful utilization is dependent on shared participation and reciprocal understanding.
- Trust is the currency of healthcare discourse; it is an emotionally-driven currency of primary importance in patient interaction with health services, including between patients and PHR.
- The formative evaluation of PHR must take into consideration both the rational and emotional-affective characteristics of the patient-user and the fiscal and geo-political restrictions (power structures) that define the healthcare social context.

There was general agreement among the participants that much of the body of user research on electronic health records has focused on the needs of the unwell, and that this has perhaps created an unbalanced view of PHR as an illness-focused concept. Yet several participants also

pointed out that the needs of the unwell have not been studied in depth and that the unwell should not be perceived as a unitary body of PHR users. Robert Jenders pointed out during the concluding research roundtable that a major use for PHR systems is as a health care decision support tool for individuals. He suggested that one of our research goals should be to better understand how health status (wellness, unwellness, or disability) affects individuals' abilities and interests in using PHR systems.

THE DISABLED

Two participants spoke to the use case of the disabled and PHR: Steeve Kay and David Stapleton. The disabled present a special class of PHR users because they may share characteristics with either or both of the well or the unwell groups, and because the disabled have their own unique characteristics resulting from their health status of disability. Additional medical data collected specifically for disability evaluation may also have a place in an individual's longitudinal PHR.

In discussing the dynamics of disability, Steeve Kay termed the disability spectrum a "complex hybrid" that is distinctively different from wellness management and from either acute or chronic health care. He traced this difference to the nature of the information used in disability cases: the information users and the end purpose of the information. Information collected for disability purposes is primarily used for the evaluation of disability claims and not for treating the disabled individual. As such, the information is medical evidence, but of a different sort than evidence related to ordinary health care. The key difference being that *disability evidence is used in an adjudicative role*. The primary use of disability information is to determine whether an individual claiming the right to disability benefits from, for example, the Social Security Administration or the Department of Veterans Affairs will have that claim accepted, and, if so, what the level of compensation will be. However, unlike cases of medical treatment and wellness care, there is an inherent tension between the disability claimant and the payer, one of whom rationally wishes to maximize the benefit and the other of whom rationally wishes to minimize it. An issue of importance for PHR is determining what the proper contents of the record will be, when the claimant may have an interest in selectively presenting the medical evidence as a means of maximizing his claim, while the payer has an interest in surfacing data that would have the opposite effect. Kay contrasted this with the role of medical evidence in health care. In treating illness or injury and promoting wellness, it is in the individual's best interest to have all relevant data available for evaluation. Complete and accurate data is required, for example, to avoid adverse drug interactions, avoid unnecessary procedures, or prevent potentially deadly allergic reactions.

Kay described the body of medical evidence that supports disability claims as being a separate entity, a collection of records used for a discrete and finite purpose: rating a disability claim. He presented this body of records as a collection from among many sources of medical data, much of which overlaps in purpose with wellness and illness PHR scenarios.

David Stapleton's talk addressed EMR/PHR as a means to both better serve the disabled population and potentially to rationalize government spending on disability through more efficient use of resources. He stated, "The disability process is broken" and envisioned some of the changes that could result if complete medical data were universally available and accessible by both disability claimants and evaluators:

- The applicant could give a disability examiner immediate access to PHR.
- Records would always be complete and updated in real time.
- Data standardization could be optimized for use in evaluation protocols.

He also identified public health benefits that would derive from the ability of public health researchers to study the accumulated, comprehensive disability records, as well as benefits for

managing disability spending at the national level through a better understanding of the population and the better planning that this increased knowledge would permit. On the other hand, Stapleton cautioned that the disabled population is diverse and that EMR/PHR solutions and other disability system reforms may need careful tailoring to meet specific needs and to avoid compounding the problems that many in the disabled population already face. Fundamental to this concept is the idea of consumer control of PHR, a basic tenet of IOM's recommendations for health care reform [Institute of Medicine, 2001]. In the end, he sees PHR systems as performing a critical role in the transformation of current disability programs to ones that place an increased emphasis on self-sufficiency and consumer choice.

CROSCUTTING CONCERNS

User-driven categories have crosscutting concerns that interact with many of the dimensions of interest in defining a user-centric PHR system. Identified in the symposium background paper [Lafky et al., 2005] were 17 dimensions to user-centric PHR; four of these dimensions were discussed in depth in the symposium's opening sessions:

- **Privacy.** Privacy of medical information is commonly ranked as the number one concern of individuals with respect to electronic health records [Westin, 2005]. To the individual, privacy of medical records means protection from unauthorized access and use. Individuals' views of privacy may differ from that of the medical community by excluding unconsented use of any kind [Browning, 1998]. Other privacy concerns include protection from unauthorized use during legal proceedings, especially in employment litigation regarding health and disability discrimination [Bernabei and Schroeder, 2004; Bishop et al., 2005].
- **Security.** Security measures guarantee privacy by preventing unauthorized access and use. Individuals may express concern for information security, especially in the era of heightened awareness brought on by widespread fraud. However, individuals cannot be expected to have a high degree of sophistication with respect to security implementation [Ackerman and Cranor, 1998].
- **Portability.** Portability relates to changing relationships between individuals, their health care providers, and third-party payers. Changes in location, employment, employment status, or employer health plans often trigger changes in provider and payer relationships. Further, when Americans reach eligibility for Medicare, their provider relationships may again change. Portability design must include provisions for mobility in space, social relations, and time.
- **Interoperability.** Interoperability is the ability of health information systems to work together, regardless of their location, design, and other technical constraints.

In keeping with the interactive nature of the symposium, the participants rank ordered the 17 implementation considerations introduced in the background paper. The results of the survey indicate that the top four dimensions at the implementation level are: Privacy, Control, Interoperability, and Security.

The research recommendations that emerged from discussing these many faces of PHR, as well as those represented within the speakers' presentations will help to identify ways to address the needs and issues identified in these user perspectives.

IV. RESEARCH PERSPECTIVES

PHR-related research findings present interesting information from the front lines of PHR design, development, and implementation. At this time, they represent the leading edge of the adoption curve, as well as designs, models, and prototypes that will help shape the PHR world to come.

The research papers presented at this symposium provided several samples of this current research:

- Evaluating user satisfaction,
- Deploying PHR on a large scale, and
- Comparative information systems studies.

UNDERSTANDING USER SATISFACTION

Vance Wilson argues, "Satisfaction with e-health depends substantially on patients' experiences with technology and to a lesser degree on experiences with provider services offline." With colleague Nancy Lankton, Wilson developed a model based on an initial survey of 111 users of an e-health prototype system. They administered an online survey to assess antecedent characteristics and initial expectations of e-health services, followed 90 days later by a second survey to assess performance perceptions and satisfaction. Their model "explains over two-thirds of the variance found in satisfaction, and direct prediction of satisfaction by antecedent characteristics explains 41% of variance in satisfaction" [Lankton and Wilson, 2005]. Predicting user satisfaction is highly relevant to PHR system design because of its immediate practical application. If user satisfaction can be predicted accurately for EHR/PHR systems, it can help "organizations and patients obtain maximum value from their e-health investments" [Lankton et al., 2005]. Accurately predicting user satisfaction can also help researchers, system designers, and system sponsors to avoid the kind of situation that prevailed in the early days of IS research and design. As Wilson said, IS had been "burned and burned badly", when systems failed spectacularly because "users simply rejected them." A focus on user acceptance and a predictive model that can help to assess it prior to full-scale implementation will be key factors in the ultimate success of any broadly available PHR of the future.

CUTTING-EDGE DEPLOYMENTS

One PHR implementation that stands out for its relative maturity in a still-emerging sector is the Department of Veterans' Affairs online PHR system: myHealth_eVet (MHV). Leonard Kleinman described the VA's experience with this system, which has been undergoing phased implementation since November 2003. According to Kleinman, it has been well received and has further empowered veterans to manage their own care. "However", he noted, "there have been important lessons learned and there are unresolved issues that merit further study. These include effective communication of plans to stakeholders (veterans, veterans' organizations, health care practitioners, and system managers), implementation of security protocols, coordination of national and local efforts, methodology for stakeholder feedback and formative evaluation, and management of the ever rising expectations of stakeholders." MHV has several properties that the VA sees as forming the basis of a PHR prototype. These include linkage to selected portions of the veteran's EMR held within the VA's VistA system, a user-controlled data storage facility with online trackers for health and service history data, data sharing based on user-controlled permissions, and designed-in HIPAA compliance.

In its capacity as a web portal, MHV also provides users with access to health education materials. Additional features soon to come include a complete one-screen portal to a patient's comprehensive personal health history: appointment scheduling/history, wellness reminders, prescriptions, hospital admissions, active health problems, allergies, and outpatient history. The key lesson learned from implementing MHV is that a web-based, robustly interactive PHR system is technologically feasible. Further research should consider whether MHV is suitable as a model architecture within a wider framework.

While MHV appears well accepted by its target users, not all systems can make that claim. Patients within the VA system are cared for within a vertically integrated environment. The government both provides and pays the cost⁶ of the services rendered. Relatively few Americans obtain their health care within this type of vertically integrated framework, however⁷ [Goldsmith, 1994]. By providing access to portions of the institutionally held electronic medical record through MHV, the VA leverages its vertical integration to provide a comprehensive PHR system.

DATA INTEGRATION AND INTEROPERABILITY

To deliver this level of service in other types of health care structures will require solutions tailored to the specific environment. One such means was discussed by Cynthia LeRouge in her talk, "Investigating Insurance Claims Data as a Data Source for an Electronic Patient Record." With colleague Gordon Wong, she investigated possible synergies between medical chart data and insurance claims data. LeRouge described claims data as a potentially useful source for PHR because these records, unlike provider-based EMR, span providers and time. Motivations to integrate these include better coordination of care and prevention of medical errors. LeRouge identified several challenges to achieving integration:

- Adaptation between the information models of providers and payers.
- Legal issues surrounding the custody and use of patient data.
- Standardization, including universal patient identifiers.
- Willingness of providers to share data.

Also relevant to the discussion on interoperability was Mark Gaynor's presentation of remote sensor input networks used in emergency medicine and how the information captured and transmitted may enhance evidence-based medicine, for example, through data mining. This led to further discussion of the importance of data quality in creating both EHR and PHR applications. As our participant poll revealed, interoperability is considered a key dimension in PHR development, a role effectively highlighted by research presentations and their discussants.

V. RESEARCH RECOMMENDATIONS

A major goal of the symposium was to delineate a PHR research agenda. Discussions of PHR concepts, particularly its user-centric nature, and the emerging taxonomy (e.g. well, unwell, disabled) of PHR served to ground this agenda, while presentations of pioneering implementations and of key socio-technical issues highlighted some of the barriers to be overcome and the means to do so. With these in mind, we turn to a summary of recommendations for the next stages of PHR research.

Drawing from his experiences with the Partners Healthcare PHR project, keynote speaker Blackford Middleton posed a set of key questions to be answered about PHR systems:

- Will consumers use PHR systems and how will they use them?
- What will be the providers' role in consumer-centric PHRs?
- How will consumer-directed care, facilitated by PHRs, affect clinical outcomes?

⁶ Less certain specified costs for which patients are responsible, depending on their VA enrollment status.

⁷ Kaiser Permanente represents a notable exception.

- What will the structure of PHR be like? Who will host it; who will provide it, and who will own the data?
- How will adoption barriers be overcome?

Early research initiatives have provided some insight into the answers. For example, the experience of Partners Healthcare is that their patients do enthusiastically adopt PHR. Nevertheless, as Middleton noted, it is still early in the project and much remains to be learned.

Helga Rippen outlined a broad view of PHR within the health care matrix. Many sectors will influence the ultimate shape of PHR: consumers, providers, public health policy, and researchers. She noted that, up to this point, the national discussion on PHR has been “by experts and stakeholders with a non-consumer vested interest” and suggested that a consumer-centric model of PHR requires better representation of “the consumer as a consumer.” Among the research needs she identified are:

- How should PHR be defined?
- What will be the ultimate model for PHR?
- Who are PHR consumers, what are their needs, and how will those needs be met?
- Who owns the PHR?
- Will all sources of personal health information be available?
- What will be the role of research and public health?
- How will the “digital divide” be addressed?
- What role will PHR play in decision support and in creating an informed consumer?

Mary Jo Deering, in her talk “Toward interoperable personal health records” concluded with a grand research challenge to the IS community. “Academia is not bound by corporate and governmental political and financial concerns,” she said. Unbounded, academia is free to “break out and build as a research effort a very robust and complete PHR model.” Doing this, she argues, will overcome the widely held *a priori* objection: “it won’t work.” Deering sees four challenges to erecting a large-scale PHR enterprise:

- Confirming and acting on value propositions for PHR.
- Drafting policy to address issues of information access and control.
- Identifying the target of greatest strategic impact: separating the ‘glamorous’ from the essential.
- Achieving synergy through collaboration.

The closing roundtable on research directions took up Deering’s call for a bold consumer-driven approach. Ideas suggested for further person-centric research included: taking a bottom-up view of user needs rather than one dictated by abstract concepts; achieving a systematic understanding of how user needs vary as their lifetime health situations change; consideration of non-users and pre-users in the development of systems designs; and taking a broad perspective of the health information consumer. Providing insight from the viewpoint of scholarly publication, Wilson pointed out that the time of abstract conceptualizing about PHR is past: future research must proceed from empirical observation, including case studies and experiments. This implies that good working relationships must be established between the IS and the clinical communities. There was broad consensus among the group that the focus of PHR research must now focus on

studying consumers as the intended user base, including both quantitative and qualitative approaches.

In summary, the 2005 Symposium on "The Many Faces of Person-Centric Electronic Health Systems" explored many issues surrounding the developing domain of PHR. Clearly, the research agenda is long, challenging, and many-faceted. In keeping with the dynamic nature of the topic, the Symposium organizers and sponsors have planned on-going activities and opportunities for the community to begin engaging together in realizing the vision arising from the Symposium.

VI. FOLLOW-ON ACTIVITIES

The symposium was conducted by CGU as part of an ongoing research and outreach interest by its School of Information Systems and Technology (SISaT). During the symposium, the establishment of a new research center called "Kay e-health Research Center" was announced. This new center will facilitate research and other related activities on e-health including symposium follow-on activities listed below:

Symposium Website – The main location for symposium related materials is <http://ehrsymposium.cgu.edu>. PowerPoint presentations from all the speakers are posted on this website. Other supporting documents including multimedia materials will be posted as they become available.

Symposium Wiki – The Personal Health Records (PHR) space, defined only recently, is growing and evolving rapidly. As a way to capture both the themes drawn from the CGU-QTC symposia and to provide a forum for on-going discussion of them, we have established a collaborative Wiki workspace. To view the materials and participate, visit <http://www.phrwiki.org>. The Wiki contains the conference materials described above, provides a means to comment and to add to discussions, and includes supplementary materials not available elsewhere.

IS and health care has been a topic of increasing prominence among IS researchers. The authors are working with IS colleagues to enhance attention to user-oriented issues in electronic health through the following actions:

AMCIS Track —The 2006 AMCIS conference will include a mini-track, "Towards Consumer-Centric Health Information Systems in the 21st Century" dealing specifically with PHR, as well as consumer-centered EHR and EMR. [More information](#) is posted at the AMCIS 2006 web site.

HICSS 2007 Mini-track — HICSS 2007 will include a mini-track entitled Consumer Health Informatics, Patient Safety, and Quality of Practice. Additional information and call for participation are posted on the mini-track [web page](#).

In addition to these outreach activities, the newly formed Kay E-Health Research Center will be undertaking a range of information systems related research studies in the electronic health and PHR arena and will continue to work with information systems, social science, and medical informatics researchers. E-health represents an important and burgeoning area of information systems, and through these efforts and the efforts of a growing community of researchers, it is hoped that the principles of information systems can inform the development and utilization of user-centric health systems.

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APPENDIX I. PRESENTER INFORMATION

| Following is a list of symposium presenters mentioned in this paper. A complete list is available at the symposium web site: http://ehrsymposium.cgu.edu , as are downloads of the presentations. | | | |
|---|--------------------------------|---|---|
| | Presenter | Affiliation | Presentation |
| Academic | Thomas A. Horan, Ph.D. | Symposium Chair Claremont Graduate University | Conference Objectives: The Many Faces of Person-Centric Health Systems: A National Symposium to Examine Use-Cases for Healthy, Chronically Ill, and Disabled User Communities |
| | David Stapleton, Ph.D. | Cornell University | Implications of Electronic Medical Records for Disability Policy, Present and Future |
| | E. Vance Wilson, Ph.D. | University of Wisconsin-Milwaukee | Predicting Patients' Satisfaction with Provider e-Health |
| | Cynthia LeRouge, Ph.D. | St. Louis University | Investigate Insurance Claims Data as a Data Source for an Electronic Patient Record |
| | Warren J. Winkelman, MD, Ph.D. | University of Toronto | The Technological Transformation of Self-Care |
| | Mark Gaynor, Ph.D. | Boston University | An Intelligent Pre-hospital Patient Care System |
| Health Care | Blackford Middleton, MD, Ph.D. | Partners Health Care, Harvard Medical School | Connecting with Patients to Prepare for Care: The Partners Healthcare Patient Gateway |
| | Leonard Kleinman, MD | Veterans Health Administration | MyhealthVet (MHV): The Model Personal Health Record of the Future? |
| Industry | Steeve Kay | QTC Management/ Kay Family Foundation | A Hybrid Model for the Disability Benefit Industry |
| | Jose Lacal | Motorola | Seamless Health Record |
| Government | Mary Jo Deering, Ph.D. | National Cancer Institute Center for Bioinformatics | Toward interoperable personal health records |
| | Helga Rippen, MD, Ph.D. | U.S. Department of Health and Human Services: Deputy Senior Advisor, National Health Information Infrastructure | Personal Health Records: National Directions and Challenges |

ABOUT THE AUTHORS

Thomas A. Horan serves as founding Director of the Kay Center for E-Health Research. Dr. Horan is Associate Professor at the School of Information Systems and Technology, Claremont Graduate University. Dr. Horan has twenty years' experience in applying advanced technologies to societal and governmental issues. He has published numerous technical articles, as well as two books on technology applications. Dr. Horan has spearheaded research with QTC Management on disability informatics and related e-health applications. Prior to joining CGU, Dr. Horan conducted technology policy research for the U.S. General Accounting Office (GAO) in Washington, D.C. and served as Senior Fellow at George Mason University.

Deborah Beranek Lafky is a Research Associate with the Kay Center for E-Health Research at the School of Information Systems and Technology, Claremont Graduate University. She is currently pursuing foundational research in user-centered personal health records systems. She has recently published on the topic of health care information systems in the *International Journal of Healthcare Technology and Management* and serves on the editorial review board of the *International Journal of Technology and Human Interaction*. Previously, she directed several medical research informatics projects at the University of California (Irvine) and has a background in information systems applications in health care and industry.

Bengisu Tulu is a senior Research Associate at the Kay Center for E-Health Research and an Assistant Professor at Worcester Polytechnic Institute. Her research interests include medical informatics and telemedicine. Her recent publications on the topic of health care information systems have appeared in the *International Journal of Healthcare Technology and Management*.

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