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ABSTRACT

Personal Health Records systems are envisioned as a user-centric and user-controlled means for individuals to track health status over a lifetime, consistent with the Institute of Medicine's recommendations for health care improvement in the U.S. These systems represent a new model of information system design in that they are voluntary, longitudinal over long periods, may have varying degrees of affiliation with institution-based records systems, and must be designed to serve all individuals, regardless of the individual's health status. Deriving and documenting user requirements is essential to systems development. Because user-centered designs are specifically intended to serve the end user's needs, unlike system designs in which the needs of an organization are served, *a priori* understanding of the users as fully as possible is even more essential. Using a multi-method approach, this study seeks to systematically classify potential PHR users and describe their attributes.

Keywords

User-centered design, personal health records, PHR, electronic medical records, taxonomy, cladistics

INTRODUCTION

Personal Health Records systems are the natural companion to health care provider-based Electronic Medical Records. PHR systems are envisioned as a user-centric and user-controlled means for individuals to track health status over a lifetime, consistent with the Institute of Medicine's recommendations. These systems represent a new model in that they are voluntary, longitudinal over long periods, may have varying degrees of affiliation with institution-based records systems, and must be designed to serve all individuals, regardless of the individual's health status. Understanding the users as fully as possible is essential in designing a user-centered system appropriately and for gaining user participation in the final implementation. Theorizing about and describing different classes of users provides a better understanding about broad systems design principles and raises the understanding of the "user" construct from the situationally specific to a higher level of abstraction useful in making generalized decisions about system design. As technology has become more sophisticated and ubiquitous, the need to keep the user uppermost in our design concerns has assumed great importance in system design. The information systems community has a long history of taking a user approach to systems design, a research stream, Human-Computer Interaction (HCI), which is still very active today. As designers, concerned with constructing useful artifacts, (Simon 1999) we are reminded that the way to understand user requirements is to study the users and meet their needs (Lazar, Hanst, Buchwalter and Preece 2001; Norman 1988). The research undertaken here will deepen our understanding of users, extending beyond the workplace environment of mandated usage and into the sphere of voluntary, yet essential, system use. Creating a user taxonomy that will facilitate the sound design of a universal PHR infrastructure can make an important new contribution in healthcare.

OVERVIEW AND METHODOLOGY

Our project aims to provide insight into the nature of PHR users, taking an inductive approach to classifying them and describing their attributes. In seeking both to understand and to classify, this project employs both an ontological approach to understanding the characteristics of users, and a taxonomic approach to classifying users in ways that are useful in meeting their specific needs. To develop this understanding, two methods are used: (1) quantitatively-oriented survey research over a broad spectrum of health care consumers, and (2) qualitatively-oriented in-depth interviews with a group of consumers purposively selected as representative of the three main user groups we have contingently identified, the well, the unwell, and

the disabled. The quantitative survey is based on a set of 17 PHR dimensions identified in previous work (identifying reference). These dimensions include the key concerns of privacy, security, consumer control and interoperability. The survey data provide insight into how the consumer's life situation (age, gender, health status, family structure) influence information behavior and information needs in the context of a PHR system. The survey data are analyzed using the tools of cladistics, an empirical, testable, systematic method suitable to the organization of comparative data. Although cladistics is most often seen in biological systematics, its use is uniquely suitable for taxonomy construction in any domain of inquiry. The qualitative data provide an opportunity to examine in depth the themes that emerge from the broader-based surveys, as well as an opportunity to uncover additional themes using a bottom-up approach as opposed to the necessarily top-down approach of the quantitative survey. These two approaches meet in synthesis, providing the basis for an empirically-informed ontology and the taxonomic classifications that will allow us to put the conceptual knowledge to practical purposes.

This research makes a unique contribution in taking an empirical path to understanding users and their needs, performing true, basic user-centered design research to aid in the development of a comprehensive, national PHR resource that citizens will be motivated and encouraged to use. By doing so we can help to avoid the pitfalls of intuitive or prescriptive system designs that too often fail to meet user needs.

EMPIRICAL VS. INTUITIVE TAXONOMIES

The need for better taxonomies in health care information systems research has been recognized for some time (Collen 1991; Hasselbring 1999). This need has recently been re-stated by Tang and Lansky, who suggest that, "a research agenda should be developed and funded to guide the evolution of PHR technology, including the development of a taxonomy...(Tang and Lansky 2005)." The importance of clear terms for things and specific mappings of the relationships among them is evident in the wide use of taxonomies in science. Taxonomies help to bring order to research, especially in emerging fields, such as PHR. By classifying and systematizing knowledge about the subject entities in a domain, taxonomies create a common language and understanding among researchers in that domain. Systematics in general, and the cladistic approach in particular, are valuable in information systems research as it seeks to align itself with the three major criteria of the scientific method: classifiability, generalizability, and predictability (McKelvey and Aldrich 1983). In presenting a cladistic approach to taxonomy development, this study seeks to move beyond the more intuitive approach to taxonomy seen in much recent research (Clarke 2001; Huang 2002; Karlsbjerg and Damsgaard 2001; Lehmann and Lenher 2002; Meso and Madey 2000; Methlie and Pedersen 2002; Mohamed and Irani 2004; Rodriguez-Abitia, Vidrio and Montiel-Sanchez 2004; Tarmizi and de Vreede 2005) and illustrate the power of the cladistic approach to generate taxonomic theory in information systems.

ONTOLOGY AND TAXONOMY IN PHR: CONCEPTS AND OBSERVATIONS

Gruber (Gruber 1993) calls an ontology "an explicit specification of a conceptualization." What this means in practical terms is a systematic setting out of definitions, terms, and relationships for some knowledge domain. These definitions, terms, and relationships are defined in the abstract, i.e. theoretically, as opposed to being empirically derived. In formal terms, a taxonomy is a type of ontology as well, in that its goal is to systematize knowledge. One role of taxonomic work is to observe objects or phenomena and determine where within an ontological structure the observed is to be classified. This type of systematization assumes an existing ontological structure which, by definition, is established *a priori*, a top-down approach to classification. Such an approach is inconsistent, however, with user-centered system design. If a system is to be designed according to users' needs, then it is incumbent upon the designers to learn *from the users* what those needs are—the design must proceed from the bottom up. Therefore, a user taxonomy in a user-centered system design builds an ontology inductively from classifying users by their attributes or, in cladistic parlance, *characters*. This study will observe (survey, interview) users, ascertain their attributes (characters), classify them into related groups based on the similarities (homologies) among their characters, and merge them into tree structures (cladograms), working from branch terminals inward to branches and trunks.

ONTOLOGICAL/TAXONOMIC HYPOTHESES

It is clearly not possible to begin a PHR user taxonomy *ex nihilo*. Instead, this study uses an iterative method, first hypothesizing a contingent ontology, then studying users and learning their actual characters. This is followed by classification of the users and comparison of these classifications with our hypothetical ontology, adjusting the ontology where necessary, and possible further user study to verify the resultant hierarchy, as seen in Figure 1.

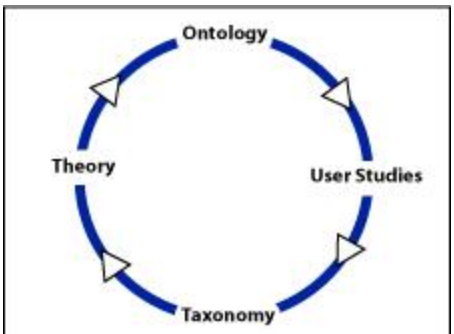

Figure 1. Ontology—Taxonomy Cycle

As a starting point, we propose a broad segregation of users into three groups based on health status (identifying reference 2006), shown in Figure 2. While health status is only one dimension among several that help to inform our picture of the PHR user, it is believed that this particular dissection of users will yield one of the most informative sets of distinguishing characteristics.

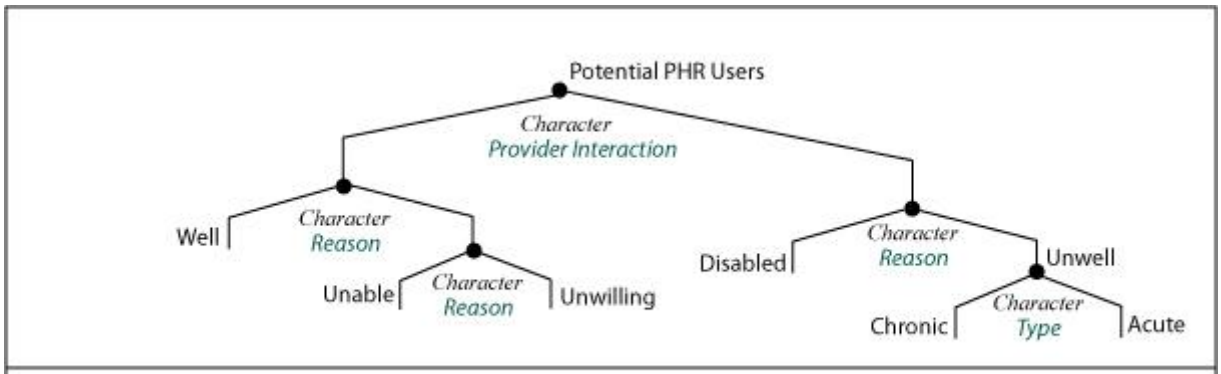

Figure 2. Possible PHR User Hierarchy

RESEARCH PROGRESS AND REMARKS

Phase 1 of this project consists of a round of qualitative interviews with purposively sampled subjects. Among these are a sample drawn from an active retirement community, including subjects who self-classify as well, unwell, and disabled. Other subjects are expected to be drawn from a graduate university student population, from a population within a disability study center, and others to be identified. This first round of interviews commences in April, 2006 (pending IRB approval) and is expected to be concluded by early May. Quantitative surveys are currently being designed and a random sample being identified. The quantitative survey will be conducted primarily online, however to include responses from the full range of users, other methods may be used.

Conducting an empirical taxonomic study using cladistics requires specific methods of collecting and coding data. In particular, it requires the definition of characters (attributes) that define groups and the elucidation of character states, which are attributes of individuals (Kitching, Williams, Forey and Humphries 1998). These characters and their associated states must then be coded so as to "identify as accurately as possible those features that ultimately diagnose relationships of taxa (Kitching et al. 1998)." Selecting a coding method and developing a coding schema are non-trivial tasks and ones which are presently under study. It is anticipated that coding characters of potential information system users will be somewhat more straightforward than coding homologies in the biological domain, however this assumption may turn out to be over-optimistic. The selection of analysis tools will depend on the results of the survey data, while the exact specifications of the survey data will depend in part on the outcomes of the first round of qualitative interviews. There are several open source

resources available that we believe will allow the analysis of the PHR user characters and construction of appropriate cladograms.

At a recent symposium convened by the authors, several dimensions of the potential PHR user were discussed in a preliminary fashion. One of these is the nature of individuals', as compared to their social support systems, interactions with their own medical records; for instance, in some use cases (e.g."well") there may principally be direct interaction between in the individual and the record, whereas in other use cases (e.g. "disabled"), there may typically be an entire social (and legal/custodial) network of interactions. Our study hopes to uncover, in an inductive manner, how health status (well, unwell, disabled) affects such interactions: how do individuals alter their interaction patterns based on health status, what other factors influence this interaction, and how do those factors work together to produce the medical records interaction?

CONCLUSION

The research in progress presented here takes an innovative approach to obtaining user requirements from an un-studied population and applied to a new and important artifact: the PHR. While there are many unknowns to conquer in the definition of a national PHR and its role within a National Health Information Infrastructure, we view the development of a user taxonomy as an important step in guiding PHR as the United States seeks to implement a new health care agenda (Markle 2005). With this tool, the IS community, as designers of information systems, can further realize its potential to make a major contribution to the advancement of health care.

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