ABSTRACT
Personal health records (PHRs) are on the rise in recent years. To understand why and how people use (or not use) PHRs, it is critical to understand what they value. This paper reports preliminary findings from a thematic analysis of journal articles related to PHRs. Our analysis identified six values with ethical import as being particularly salient to the use of personally identifiable information in this literature: privacy, confidentiality, security, transparency, trust, and human agency.

Keywords
Human values, personal health records, usability, privacy, confidentiality, security, transparency, trust, human agency

INTRODUCTION
Personal Health Records (PHRs) are electronic health records controlled, shared, or maintained by patients (or designates) to support their care. PHRs can be tethered to health organizations’ information systems, such as Electronic Medical Records (EMRs), where subsets of information are provided by health organizations. PHRs can also be standalone and only the users themselves enter and manage their health data (Anker, Reinhart, & Feeley, 2011; Jones, Shipman, Plaut, & Selden, 2010). The functions of PHRs may vary widely (e.g., viewing medical test results, making appointments with providers), but they all intend to improve patient and family access to knowledge for self-management and to reduce health care costs. Thus, PHRs have been promoted by the government, policy makers, as well as health care organizations (Anker et al., 2011). Evidence also suggests they are valued by health consumers (Turvey et al., 2014).

However, despite millions of dollars spent on PHRs, the adoption rates remain low (Logue & Effken, 2012). One of the major barriers is usability (Turvey et al., 2014). A usability study of VA’s PHR system, MyHealththeVet, found that more than 75% of the participants could not successfully complete registration and one-third had difficulties entering information to track their health activities (Haggstrom et al., 2011). Usability may present as an even larger barrier for users with low socioeconomic status and low health literacy. A recent study found that the majority of the participants had difficulty performing routine health management tasks using any of the three PHRs systems deployed in the study (Czaja et al., 2015).

In the use of PHRs, an important yet understudied area is human values. Human values are enduring goals that influence behavior and attitudes (Fleischmann, 2014; Hitlin & Piliavin, 2004; Rokeach, 1973; Schwartz, 1994; 2007). Human values are interdisciplinary, spanning, for instance, human-computer interaction (Friedman, Kahn, & Borning, 2006), management (Bernthal, 1962), advertising (Kahle, Poulos, & Sukhdial, 1988), forestry (Bengston, Webb, & Fan, 2004), and politics (Templeton & Fleischmann, 2011). Value conflicts such as honesty versus convenience, innovation versus reliability, and timeliness versus completeness influence decision-making (Fleischmann & Wallace, 2010).

Human values play a critical role in the design and use of information and communication technologies (ICTs) (Friedman, Kahn, & Borning, 2006). Over the past two decades, there has been an increasing emphasis on making ICTs more user-friendly (Nielsen, 1999; Preece, 2000; Rubin & Chisnell, 2008). Typically, this has played out in terms of an increased focus on usability, or how usable a technology is. However, ensuring that technologies are user-friendly requires not only making them usable but also making sure that technologies are sensitive to users’ values. Human values are related to, but distinct from, usability. Friedman and Kahn (2008) provide several examples of systems that are usable, but actually undermine human values. For example, they cite Tang’s example of a personal computer designed for voice input (Tang, 1997). Turning the microphone on and off turned out to be cumbersome, and thus, to improve usability, the on/off switch was removed and the microphone was permanently on all of the time. As a result, this more usable system might undermine the privacy of the user, and thus go against their values. Thus, it is important to consider the impact of human values on ICT adoption and use in general and on PHRs in
particular. Specifically, this paper focuses on the role of human values in the use of PHRs. Our primary research question was: What human values were invoked in existing studies about the usability of PHRs?

METHODS
Thematic analysis is a qualitative method used in a wide range of fields, including anthropology (Ryan & Bernard, 2003), psychology (Braun & Clarke, 2006), nursing (Tuckett, 2005), and information science (Kuch, 1982). Thematic analysis involves analyzing texts to identify salient themes that occur across multiple documents. This approach has previously been successfully applied to analyses of human values in interpersonal communication (Koepfler & Fleischmann, 2011). This paper involves a thematic analysis of human values invoked in articles about the usability of PHRs. We completed the process in 5 steps:

Step 1: to select a database to search. Since the topic was health-related, we selected PubMed for this initial analysis. The freely available PubMed database contains more than 24 million citations including all records in MEDLINE.

Step 2: to create a query to find relevant articles. One of the planned applications of this analysis is to inform a content analysis of a larger study examining human values in patient portals (see the Future Work section). We selected PHRs because they are related to patient portals, but distinct. Patient portals often provide users with a way to access their medical records (including but not limited to PHRs). To identify relevant articles without invoking any particular values that might bias the results of the analysis, we looked for articles about the usability of PHRs. The final query used was: ("personal health record"[Title]) AND usability NOT portal. Using this query to search in PubMed in June 2015, a total of 10 articles were found.

Step 3: to download the full text of each article identified through the search query. Four of the 10 articles were available as open access articles (Chiche et al., 2012; Ennis et al., 2014; Haggstrom et al., 2011; Krist et al., 2011), three were available via subscriptions by the authors’ home institution (Luo, 2013; Luo, Tang, & Thomas, 2012; Luque et al., 2013), and the remaining three were requested via interlibrary loan (Lee, Delaney, & Moorhead, 2006; Monkman & Kushniruk, 2013a, 2013b).

Step 4: to identify invocations of human values in these 10 articles. The first author, who has extensive experience conducting thematic and content analyses of human values in texts (e.g., Cheng et al., 2012; Fleischmann & Wallace, 2010; Koepfler & Fleischmann, 2011), read each article and coded portions of the text referring to values, which spanned from a word to a phrase to a clause to a sentence to a paragraph. Step 5: to thematically analyze the invocations of human values to identify salient values within this dataset. The first author developed a set of themes, which was then reviewed and approved by the other authors.

RESULTS
The values we identified fall into three general categories. First, values related to health care and outcomes, such as the effectiveness and efficiency of care (Monkman & Kushniruk, 2013). Second, values related to usability of the interface, including ease of use, and utility (Ennis et al., 2014). Third, values with ethical import (Friedman & Kahn, 2008) related to the use of the information itself. Given the scope of this paper, we focus in this paper on values with ethical import. Specifically, our thematic analysis identified six values of ethical important related to the use of the information itself. These included: privacy, confidentiality, security, transparency, trust, and human agency. We report each of these in detail below.

Privacy is individuals’ freedom to keep some aspects of their lives to themselves without unwanted invasion, intrusion, or interference (Buckovich et al., 1999). For example, Krist et al. (2011) note that “Only three patients have asked to have their accounts deleted because of privacy concerns” (p. 8). Similarly, Haggstrom et al. (2011) found that “individuals preferred prescription numbers over names, sometimes due to privacy concerns” (p. 113). Finally, Chiche et al. (2012) note that “Sanoia has developed a web tool integrated with electronic personal health records, which offers full privacy protection using an innovative anonymity technique” (p. 726). Thus, privacy was a major focus of both the designers and users of PHRs.

Confidentiality is the need to protect specific sensitive information (Buckovich et al., 1999). For example, Luque et al. (2012) note that one barrier to PHR adoption is “Fear of disclosure of one’s HIV status” (p. 117). Lee, Delaney, and Moorhead (2006) point out that “the concept of the PHR includes an electronic application enabling individuals to access and manage their own lifelong health information, and to share all parts of such information with other individuals or care providers or authorized persons in a secure and confidential environment” (p. 25). Confidentiality was thus another major value, and was frequently invoked alongside security.

Security is the ability to protect sensitive information (Buckovich et al., 1999). Haggstrom et al. (2011) mention “Consumer focus groups suggest that the security of patient data is a primary concern regarding health information systems” (p. i16). Monkman and Kushniruk (2013) explain that “PHRs are used to access, share, and manage personal health information, privately and securely” (p. 179). Thus, while the values of privacy, confidentiality, and security are distinct, they are all closely interconnected.

Transparency relates to the importance of two-way information flows between a user and an ICT (Brin, 1999). Ennis et al. (2014) found, “In response to the results from our scoping exercises, the primary components to be included were care plans and patient reported outcome measures (PROMS), allowing service users to self-monitor their health (p. 3). Haggstrom et al. (2011) note, “PHRs add
value to users’ data by making information more accessible and understandable, and healthcare organizations should build trust for PHR health content” (p. i13). As indicated in this example, greater transparency can lead to greater trust.

Trust is an expectation arising in a regular, honest, and cooperative society (Fukuyama, 1995). Haggstrom et al. (2011) assert, “Consumer trust in online health information is also critical” (p. i17). Monkman and Kushniruk (2013b) provide the example, “HealthLinkBC provides trusted health information on over 5,000 health topics, symptoms, medications, medical tests and tips for maintaining a healthy lifestyle” (p. 310). Building trust is thus a critical consideration for the designers of PHRs.

Human agency is a person’s capability to act (Giddens, 1984). Luque et al. (2012)state, “Self-management means that patients assume an active and informed role in key aspects of their condition in collaboration with their personal clinician” (p. 117). Krist et al. (2011) write, “PHRs should provide support to allow patients and clinicians to act on recommendations” (p. 2). Monkman and Kushniruk (2013a) note, “health consumers act as curators of their PHRs and thus, decide what health information is and is not included” (p. 179). Human agency occurred frequently throughout the set of articles, and builds to a degree on transparency and trust, as these values all empower users.

DISCUSSION
Our thematic analysis found six values in existing studies on PHRs. It is important for designers to consider human values in the design of PHRs. Values related to usability and to health outcomes are rather obvious, but PHRs also touch on values with ethical import. Thus, it is important to consider the values of privacy, confidentiality, and security, along with the values of transparency, trust, and human agency, to ensure that PHRs will not only meet the needs of users but also be sensitive to their values.

FUTURE WORK
As noted earlier, PHRs are a related technology to patient portals, which are typically the mechanism through which patients interact with their PHRs (along with providing additional functionalities). The value inventory developed through this thematic analysis will be applied to conduct content analysis of a larger study of human values in the literature on patient use of patient portals.

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REFERENCES


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