# Capturing and Representing Values for Requirements of Personal Health Records

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**Abstract.** Patients' access to their medical records in the form of Personal Health Records (PHRs) is a central part of the ongoing shift in health policy, where patient empowerment is in focus. A survey was conducted to gauge the stakeholder requirements of patients in regards to functionality requests in PHRs. Models from goal-oriented requirements engineering were created to express the values and preferences held by patients in regards to PHRs from this survey. The present study concludes that patient values can be extracted from survey data, allowing the incorporation of values in the common workflow of requirements engineering without extensive reworking.

**Keywords:** Personal health record, basic value, health care, goal-oriented requirements engineering, business/IT alignment.

## 1  Introduction and Purpose

To provide those goods or services which consumers desire in the method and manner which they prefer, thereby fulfilling their value proposition, it is necessary for a business to create a supporting infrastructure. Key components of such delivery mechanisms are often information systems, and as such, methods need to be developed which elicit and capture their values and preferences during the system design process, while finally presenting these to the business in such a way that they can be executed upon during the system development. The state where the goals and strategies of the business are in harmony with its IT systems is called *alignment* [1].

In this study, the business is the Swedish healthcare system, with its many-layered purposes and customers. Among these, we focus on the part of a healthcare system where the consumers are the patients, and our goal was to learn what values patients have in regards to Personal Health Records (PHRs). In the specific instance of developing a successful PHR, it is important for the business (Swedish healthcare

system) to engage its consumers (patients) on a number of levels, e.g., capturing user requirements for PHR systems during development processes and user studies, as well as in the marketing process. Consumer buy-in is important for the success of any product, but in particular an individualized and deeply personal one like PHRs. Engaging a consumer's values is a crucial step towards success.

The present research utilizes results from a survey aimed at capturing patients' feature and functionality requests in a PHR system. These are then analyzed through goal-oriented requirements engineering techniques to express the values and preferences held by patients in regards to PHRs.

The paper begins with a short section to frame the general argument, and proceeds to clarify that in §2 Story. Background is provided in §3 to ground the reader in the concepts not common to enterprise modeling, specifically PHRs, business/IT alignment, and Schwartz's Value Theory. §4 presents and analyses the survey that was used for the basis of the artifact found in §5. The work concludes with a brief summary and future work in §6.

## 2 Story

Health records are abundant with detailed medical information including medical terminology, and are also complex in their structure. It has been shown that patients find it difficult to navigate and understand the information in their own records [2].

Electronic health record (EHR) systems are physician-oriented and do not include patient-oriented functions [3]. One problem with medical records is that they contain a lot of data which is usually kept as unstructured text in narrative form; this information overload needs to be structured and presented in a manner that patients understand. Hence, the EHR information cannot be presented directly to patients but needs to be adapted to patient requirements when exported to patient portals or PHRs. Furthermore, for the PHR to be a supporting tool for patients there is a need to identify which key functions should be implemented to support patients. Usage of PHR is highly dependent on the information offered and that functions available meet patient needs. However, few studies focused on the features that make health records comprehensible for lay audiences [see 2].

Several evaluations of the usage of patient portals have shown a decrease of patient visits and increase of online prescriptions as well as telephone and e-mail consultations [4]. These numbers of operational efficiency are presented as benefits of PHRs, as they have positive economic implications for the health care business. Also, patients report quicker access to health care by means of e-mail and telephone as positive. However, less face-to-face communication and increased online communication of sensitive nature or bad news may not be seen as a positive value for patients.

# 3  Background

### 3.1. Electronic Health Records (EHRs) and Personal Health Records (PHRs)

EHR systems were initially developed for accounting purposes and still the basic structure and vocabulary of business management is evident in the record systems. Today, EHRs are one of the most important tools for physicians and other health care professionals and are a means of communication within health care, not aimed at communication with patients. Due to the confidential nature of the content, the language in the EHRs has developed within a closed professional community and is rich in terminology, abbreviations and jargon. Many EHRs also have a structure that encourages double documentation of symptoms and events, resulting in an overload of information.

In the information age, it is quite natural that new means of communication between health care consumers and providers have evolved. Patients of today want to read the information about themselves in EHRs to follow their health care process, and want to keep their own records as PHRs. A variety of systems have been developed for this growing market, ranging from freestanding smart phone applications for e.g. vaccinations to EHR-integrated patient portals with online access. The International Standardization Organization (ISO) has defined the key features of the PHR as "it is under the control of the subject of care and that the information it contains is at least partly entered by the subject (consumer, patient)" [5]. A PHR can, as per the ISO definition, be one of the following "(a) a self-contained electronic health record (EHR), maintained and controlled by the patient/ consumer, (b) a self-contained EHR, maintained and controlled by a third party such as a web service provider, (c) a component of an integrated care EHR maintained by a health provider (e.g. general practitioner) and controlled at least partially (i.e. the PHR component as a minimum) by the patient/ consumer, or (d) a component of an integrated EHR but maintained and controlled by the patient/consumer".

Systems giving online access to (parts of) the EHR will inevitably export the problems of EHR, such as double documentation and suboptimal navigation, to the patients, if care is not taken in the design and functionalities offered. Also, to function as a means of communication, functionalities for the patients to add information and e-mail the care giver are needed. In an attempt to make EHR language more stringent and transferable between different EHR systems, international efforts have been made for a joint health care terminology, SNOMED CT [6]. However, using professional language and SNOMED terminology, which does not include layman vocabulary, will leave patients disempowered and voiceless [7].

### 3.2. Alignment

According to Kotler [8] consumer value plays a crucial role at the heart of all marketing activity: it is in effect a catalyst for the value exchange and refers back to

the value proposition. This describes how the business will create differentiated, sustainable value [9]. This unique offering of a business demonstrates the "overall view of one of the firm's bundles of products and services that together represent a value for a specific customer segment" [10].

More recently, evolving these ideas, Kotler et al. [11] have stated that the next phase of marketing will be values driven, an evolutionary step from the original product-centric and the latter consumer-oriented types. They claim that collaborative consumers, savvy in the tools of the Internet that rapidly evolved in the past decade, and living in the age of globalization as part of a creative society, are driving companies to design their propositions around values.

Accordingly, the solutions presented in this work focus on capturing basic values and introducing them through a variety of means into the development of PHRs that support the health care system who intend to provide goods, services, and experiences to satisfy both patient and practitioner needs, based on their basic values, thus providing a core example of business-IT alignment.

### 3.3. Values

*Value* has a number of accepted meanings, with the choice of usage primarily one of context within one of two categories. Quantitative or *economic* is the type of value most commonly used in business to denote an object that can be offered by one actor to another [12] often where the worth or desirability of something is expressed as an amount of money [12]. Economic values are generally understood as an amount in goods, products, services or money, considered as a suitable equivalent for something else: the material or monetary worth of a thing [13]. These are also how companies differentiate themselves by providing a value object in a particular way [10], their *value proposition*.

In *contra poise* are values with a qualitative nature, detailing how a good, product, or service is delivered to, or perceived by, the consumer. These have been termed non-economic values [9] internal values [14], or consumer values [15] among others.

While the impact of quantitative values on IT is readily seen and acknowledged, particularly within software engineering, (e.g., value-based software engineering or VBSE [16]), qualitative values have been researched to a much lesser degree, in particular basic values. The business/IT alignment community has made several attempts such as c3 [17], e3 [18], and BMO [10], to address this deficiency, although never through the explicit use of basic values. It is through this subset of qualitative values that this research demonstrates how development of PHRs can be improved.

**Basic Values.** Schwartz's Value Theory (SVT) [19] adopts the definition of value as a belief that a specific mode of conduct or end-state is personally or socially preferable to its opposite. Values serve as criteria for judgment, preferences, choices, and decisions as they underlie knowledge, beliefs, and attitudes.

According to Schwartz, all the items found in earlier value theories, including religious and philosophical discussions of values, can be classified into one of the following motivationally distinct Basic Values (Table 1): Power, Universalism,

Achievement, Benevolence, Hedonism, Tradition, Stimulation, Conformity, Self-determination, and Security. SVT emphasizes the profound nature of values, but at the same time offers the possibility of a consumer research approach by concretely combining these value structures with an analysis of human motivation. This integrated structure of values can be summarized with two orthogonal dimensions (Table 1).

**Table 1.** Schwartz's Basic Values as per their Classifying Dimensions, with examples (italicized).
**Hedonism shares elements of both Openness and Self-enhancement [1] [22]**

| Dimension | Basic Value | Dimension | Basic Value |
|---|---|---|---|
| **Openness to Change** (independence of action, thought, and feeling, and a readiness for new experiences) | Self-determination *(Creativity, Freedom)* Stimulation *(An exciting life)* Hedonism[1] *(Pleasure)* | **Self-transcendence** (concern for the welfare/interest of others) | Universalism *(Equality, Justice)* Benevolence *(Helpfulness)* Hedonism[1] *(Pleasure)* |
| **Self-enhancement** (pursuit of self-interests) | Achievement *(Success, Ambition)* Power *(Authority, Wealth)* | **Conservation** (self-restriction, order, and resistance to change) | Conformity *(Obedience)* Tradition *(Humility, Devotion)* Security *(Social order)* |

Reading from the upper left, Openness to Change (combining Self-determination and Stimulation) opposes Conservation (combining Conformity, Tradition, and Security). These dimensions reflect the conflict between an emphasis on independent thought and action and a preference for change in opposition to self-restriction, preservation of traditional practices, and protecting stability. Moving to the upper right, the dimension Self-Transcendence (combining Universalism and Benevolence) opposes Self-Enhancement (combining Power and Achievement), where in the former one finds acceptance of others as equals, coupled with a concern for their welfare, while in the latter lies the pursuit of one's own relative success and dominance over others.

The values of an individual have an effect on their behavior as consumers through their attitudes, which in turn impact on their choices within the value exchange [14, 20, 17, 21]. Additionally, it was shown that values relate to real-life choices, and may also influence behavior through different manifestations, such as habits [22]. Therefore, the use of values—in particular basic values—makes a solid foundation for which to develop complex and heavily laden systems such as PHRs.

# 4  Study Design

A study was conducted to generate requirements that would be expressed through goal-modeling techniques. For this, the results of an existing survey [23] were further analyzed from the perspective of value modeling for requirements elicitation.

## 4.1. Survey: PHR-functions preferred by patients

To elucidate patients' requests on a future PHR system, a thematic analysis of interview data from five participants was used to design an online survey.

A five-point Likert scale was used to perform a descriptive analysis of the respondents' attitude to 18 statements, categorized in five themes: 1) overview of the content, 2) help to understand the content, 3) help to understand screening results, 4) communication/interaction with healthcare and 5) additional functions. Each statement also included the option for the respondent to comment in free text.

The survey was distributed to members of five patient organizations, and it was also made available in an online article published by a Swedish newspaper. 201 respondents participated in the survey.

## 4.2. Value model creation

Respondent comments were processed using a textual analysis technique from requirements elicitation—SVO (Subject Verb Object)—to discover the key actors and activities, as well as the patients' values and goals. The textual analysis was performed by three researchers (one clinician and two computer scientists).

The i* framework and language was chosen to formally express the discovered requirements [24] because it assists in examining and understanding the relationships among social actors [25]. Based upon the idea that a system aims to improve the relationship that some actors have with other actors, i* was directly in line with the focus of this research: improving PHRs through an exploration of the values and relationships of the actors within the system. Additionally, i* possesses a more complete set of concepts and primitives than similar goal modeling techniques such as c3 [12], e3 [18], and BMO [26].

Both Strategic Dependency (SD) and Strategic Rationale (SR) diagrams for the patient actor were fully developed, but due to space constraints only the SR is included herein, see Figure 1.

# 5  Results

The typical survey respondent was a female aged 54 years 7 months who suffered from some kind of illness and had good computer skills.

The survey revealed explicit answers to patients' attitudes toward suggested possible future functions in PHRs. The Likert scale responses revealed that almost all the answers were at the level of "agree" and "strongly agree".

Foremost, functions such as overviews, fact boxes and search functions were requested both in regards to screening results and medical record content. Moreover, the respondents wanted a clear overview of their illness and medication through timelines. Explanations illustrated with pictures and videos, access to a medical dictionary and text simplification were also highly requested. Also, they wanted the possibility to add information to the PHR.

For communication with caregivers, e-mail was preferred over video calls. Chat bots were least popular, as well as possibility to view PHR content in another language.

In the analysis of the free text comments some key issues were discovered: Computer Security, Anxiety, Limited Resources, Control and Fairness. Patients expressed concern about the security of their data, not only in its transmission electronically, but also in terms of access: is a family member, acting in the role of a care provider, able to read the complete file, or can certain sections be secured? Anxiety was discussed in terms of a lack of information about medical terminology, specifically whether the records would be understandable and useful to the patients.

Anxiety and Computer Security were personal goals for the individuals and are related to Schwartz's value Security.

Limited Resources and Fairness were an expression of the amount of effort the healthcare system and care providers would need to devote to maintaining such a system; not only were patients worried about care providers expending time in writing records in laymen's terminology, but also whether they would be able to treat patients as well as answer e-mails, etc. This was an interesting outcome, possibly indicating that a high number of healthcare professionals answered the survey, as this finding was also borne out in other research on the development of PHRs. These issues relate to Schwartz's value of Universalism.

The issue of Control related to patients' requests for being able to follow their own healthcare process, e.g. by transparency in the system for seeing which tests are taken and which clinicians are involved in making decisions, by having the possibility to choose treatment type, etc. This issue is related to Schwartz's value Self-determination.
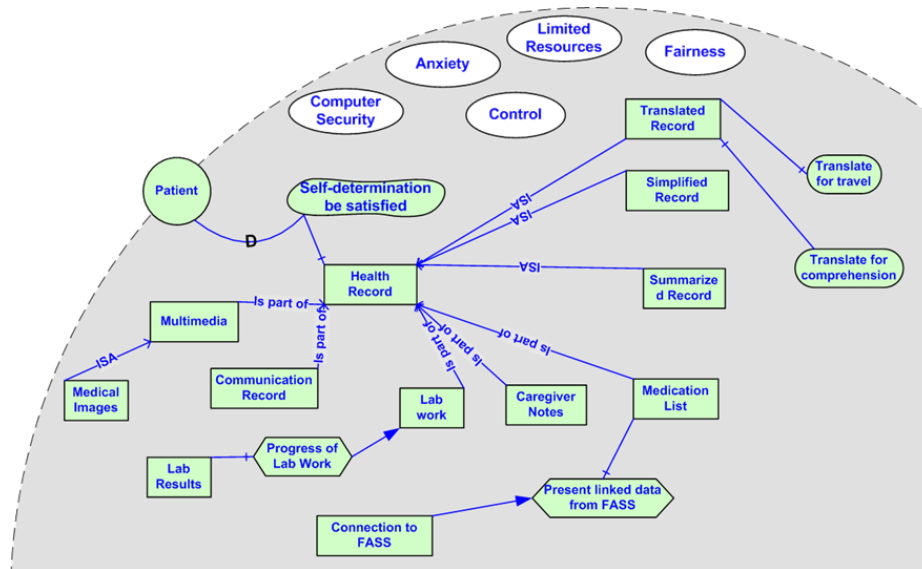
**Fig. 1.** SR for Patients regarding Patient Health Records

Figure 1 highlights requirements that would satisfice for the patients' softgoal "Self-determination be Satisfied". To capture, and stress the importance of, Schwartz's values, the i* constructs for a Softgoal Dependency were adapted for this SR, where the depender (Actor: Patient) depends on the dependee (Resource: HealthRecord) to perform some task that meets a softgoal (Self-determination be satisfied).

## 6 Lessons Learned and Future Work

Patient values can be extracted from survey data, allowing the incorporation of values in the common workflow of requirements engineering without extensive reworking. The importance of doing so should be evident from the references provided.

The textual analysis technique applied on the free text comments from the survey was useful for generating values linked to Schwartz's model, specifically Security, Universalism, and Self-determination. Our intention is to further analyze this material for identifying values in the remaining dimensions of Schwartz's model. Of course better results would have been obtained if using PVQ [21], but this study shows that it is possible to re-use survey material created for related purposes. Additionally, the i* [24] framework provided a suitable platform for modeling these values, possessing a more complete feature set than similar techniques such as c3, e3 or BMO, proved to be a sufficient choice for the goals of the study.

The current study aims to capture the patients' views, who usually want EHRs as a means of understanding and communication, while doctors usually use EHRs as a legally binding means of treatment and documentation (often even between doctors). Thus there are different requirements on medical terminology, ownership, etc. An

additional study exploring the values of health care providers has been completed to explore this population. It highlights significant differences between physicians and support staff, as well as those of patients. Due to the integrated nature of PHRs, this further exploration should prove fruitful for deriving additional requirements and for supporting the contention this research makes about addressing basic values.

In summary, this *a priori* approach should not only increase user acceptance, but will consequently drive down issues such as change requests and reconfiguration. Offering patients a tailored PHR based on their values facilitates high product acceptance and can activate participation, in turn leading to empowered patients.

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