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Systematic inquiry for design of health care information systems: an example of elicitation of the patient stakeholder perspective

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Abstract

The electronic health record (EHR) has evolved as a tool primarily dictated by the needs of health care clinicians and organizations, providing important functions supporting day to day work in health care. However, the EHR and supporting information systems contain the potential to incorporate patient workflows and tasks as well. Integrating patient needs into existing EHR and health management systems will require understanding of patients as direct stakeholders, necessitating observation and exploration of in situ EHR use by patients to envision new opportunities for future systems. In this paper, we describe the application of a theoretical framework (Vicente, 1999) to organize qualitative data during a multi-stage research study into patient engagement with EHRs. By using this method of systematic inquiry, we have more effectively elicited patient stakeholder needs and goals to inform the design of future health care information systems.

1. Introduction

Health care information systems design has traditionally incorporated direct stakeholders working for organizations, including clinical practitioners and administrative staff. These information systems support clear objectives for patient data management, treatment protocols and workflows, and targeted outcomes in the organization. Clinician-facing health care information systems are informed on a top-down design basis by organizational performance measures informed by national benchmarks (e.g., Health Plan Employer Data and Information Set (HEDIS); see [18]). The performance measures approximate the quality of patient care through normative standards, and are then used to evaluate the information systems, a process that pointedly excludes patients as direct stakeholders in the system. Patients are, instead, acted upon by the systems they encounter in managing their health, including EHRs. Doctors, nurses, and other clinical practitioners are the heavy users of health care information systems, and often input and retrieve information on behalf of the patient. For this reason, we argue that from the standpoint of systems development and interaction, patients have been traditionally viewed as indirect stakeholders in health care information systems development, improvement, and evaluation.

New modes of interaction with health care information systems, such as online patient portals, EHRs, and even social media-based patient sites change the patient experience. Patients can no longer be described as indirect stakeholders. In many online patient portals, the user can now enter personal data directly into the system, correspond with clinicians over

secure messaging services, access historical data through shared portions of the EHR, or read through health education content to inform decisions. Patient access to EHR data is also a requirement in Stage 1 of the Centers for Medicaid & Medicare Services meaningful use requirements ([3]), which affects government payments to health care providers – a strong incentive to build the capability for increased direct patient-systems interaction.

In addition to the new, direct interaction with the system, the patient also brings information system use into new contexts. All aspects of a health care information system are no longer predictably used in the confines of a doctor's office, with trained medical professionals to mediate information from the system. New contexts of use for patients "in the wild" include use in the home, through computers or mobile devices, and in situations where just-in-time information could affect a patient's decision making regarding medical conditions or concerns. Due to the changes in use contexts and new modalities involved in patient direct interaction with health care information systems (and specifically EHRs) described above, future health care information systems functions may incorporate very different requirements to successfully engage patients. In this paper, we describe our method for structuring a qualitative exploration of the patient experience to envision future information systems at the intersection of clinical care and chronic illness management. We explain our method of theoretical framing to organize a systematic inquiry that can articulate and segregate the limitations of normative requirements applied to current EHR design. This approach gives us an advantage in eliciting useful and actionable information about current patient engagement and possible futures for EHR design. In this way, we are better able to use our qualitative data to guide design work in the future.

2. Related Work

First, we give a brief overview of the EHR as an organizational tool, dictated by the normative requirements of the health care industry, and its broadened use today as a patient communication medium between doctors and patients. Then we examine patients as direct stakeholders of health care information systems, arguing that the patient experience is an essential factor for future health care information systems design. Finally, we introduce the theoretical model used in our method - Vicente's [20] requirements model - as one tool to structure inquiry for gathering qualitative information about system engagement from patients.

2.1. The Electronic Health Record (EHR)

Electronic health records are a subset of health care information systems, and the content of EHRs is dictated from a top-down, normative point of view largely designed by health care payers such as Medicaid and Medicare [3]. Standards for the development of EHRs are also informed at the national level according to applicable law and patient privacy regulations enacted in parallel jurisdictions [10]. With regard to EHR implementation in the United States, Gunter and Terry [10] point to four major drivers in the shift to electronic records:

1. A shift from inpatient to ambulatory care;
2. Demands by payers for performance measures;

3. The emergence of the “shared care” notion, whereby patients are active participants and partners with their doctors; and
4. Error reduction in medical practice.

The factors identified here are all essential to the motivation of organizational adoption of EHRs, but with the exception of the third element (emergent notion of “shared care”) largely disregard the patient as a direct stakeholder. These normative requirements shaping EHRs have more recently stipulated patient- centered initiatives, such as timely electronic access to patient information. However, current EHR design does not go far enough in addressing patient information and interaction needs.

The changing nature of the medical record is largely an artifact in medical care workflow, with normative values embedded in its design and use. When we examine the values that emerge strongly from assessments of EHR implementation, we find that clinician and health care organizational priorities are amplified, while patient goals and priorities are less prominently represented. Berg and Bowker [1] noted that clinicians required both a medical record and interaction with the patient to create meaning out of the medical record. In addition, the design of the medical record supports normative organizational conditions, such as shift work for nurses and doctors. The context of medical work is also emphasized by Berg and Goorman [2], who note that with the use of EHRs, the context of data may get lost when information is aggregated (e.g., in “big data” initiatives), utilized by third parties, or segregated from knowledge the patient possesses about his or her health (see also [7]).

Within the medical literature, some authors have expressed concern about the consequences of challenging normative requirements and encouraging greater patient access to medical data. They state that this change in interaction can lead to deterioration in the patient-clinician relationship [19]. However, research can also integrate the patient point of view with that of the clinician as it is executed in current health information systems. DelBanco et al. [4, 5] opened physician notes in an existing EHR as part of the Open Notes project to thousands of patients. Patients reported feeling more in control of their care and sharing the content of notes with others, with no significant increase to physician workload among the physicians volunteering for project. This exploratory study expanded patient information access and allowed patients to use the information as they saw fit (as evidenced by the sharing of information in the notes).

In general, attitudes with regard to inclusion of patients in design and functionality of health care information systems have enjoyed more influential support since the 1990s and the mid-2000s. The Institute of Medicine [13] included “patient-centered systems” as one of six central tenets for increasing the quality of medical care for all patients in the United States. A 2014 report by the National Committee for Quality Assurance [16] called for increased patient participation in the design of health care information systems. The report describes the current state of patient-centered systems, proposing a taxonomy of devices to use in engaging patients with the ultimate goal of “empowering” patients and caregivers to promote engagement in managing chronic illness and increasing transparency around medical decisions. An important first step for empowering patients is positioning their claim on

health care information systems as direct stakeholders. We describe the patient shift from indirect to direct system stakeholders in the following section.

2.2. The patient as direct stakeholder

As patients and caregivers begin to interact directly with health care information systems through EHRs, it becomes increasingly important to understand their stake in the operations of the health care organization. Stakeholder theory originates from organizational studies, and has traditionally defined stakeholders in the broadest sense as “any group or individual who can affect or is affected by the achievement of the organization’s objectives” [8], regardless of reciprocal interest in the stakeholders from the organizational perspective [6]. Although the broad definition of a stakeholder assumes that all stakeholder interests are equally important because all stakeholders have equal moral standing [11], the literature has dealt extensively with narrowing this definition and differentiating normative stakeholders who have legitimate interests or claims on an organization from those whose interests are derivative and to whom managers have no moral obligation [17]. In the context of health care, we argue that the moral obligation to the patient is an important factor in the patient-stakeholder position.

Although the moral obligation to patients is paramount, there are good reasons why the patient-stakeholder perspective is not fully realized in health care information systems design currently. This disconnect can be explained by the lack of power in the patient-stakeholder position. One of the most influential and comprehensive equations of stakeholder interests is Mitchell et al.’s [15] dynamic theory of stakeholder identification, focusing on the salience of stakeholder claims to organizational priority. Mitchell identifies and classifies stakeholders by three attributes that influence their salience within the corporation: power, legitimacy, and urgency. The Mitchell framework is applied to understand patients as dependent stakeholders who may have, at any given time, two attributes within health information systems – legitimacy and urgency. Crucially, patients lack power through which their legitimacy might gain voice. Introna and Pouloudi’s [14] work describes the underrepresented nature of the patient-stakeholder regarding decision-making about privacy measures in EHR design; Introna and Pouloudi come to the conclusion that patients lack the power needed to make their claims hold.

Although patients have traditionally lacked power as indirect stakeholders in health care information systems, their stakeholder position is shifting due to increased direct engagement with their health management information (i.e., from indirect to direct system stakeholders, [9]). This is an important reason to apply rigorous methodology to understanding the patient stakeholder point of view and current use of existing information systems. Freeman [11] highlights the importance of understanding stakeholder needs, and describes a “bridging” approach that involves forming strategic partnerships between the organization and its stakeholders to lower barriers to participation in the organization. This “bridging” approach motivates our inquiry into the current patient engagement with the existing health care information systems.

2.3. The Vicente theoretical framework

For the purpose of organizing our participant data into a valuable stakeholder perspective, we used the Vicente theoretical framework [20] to order our data and inform the design process in a systematic way. The Vicente theoretical framework [20] defines information systems as engineered artifacts and is based in cognitive work analysis. Its theoretical perspective calls for analytical methods to identify the assumptions inherent in information systems design and grounded in empirical observation of work tasks (p. 13). Vicente designated three types of requirements models for information systems: normative, descriptive, and formative. They are defined as follows (adapted):

Normative models prescribe how a system should behave.

Descriptive models describe how a system actually behaves in practice.

Formative models envision requirements that must be satisfied so that the system can behave in a new, desired way.

Normative requirements are those that already inform the system in place; they also give insight to the assumptions underlying the current information systems and its task flows. Use of the Vicente framework helped us to identify and isolate normative requirements of the existing system. By focusing our attention on the other two framework requirement types, we were able to focus on understanding how patients and caregivers engage with the current system (descriptive feedback). We then identified constraints affecting engagement specifically for patients as users (formative feedback).

Further, using the Vicente framework to organize our data enabled us to acknowledge what we already knew about the existing system and how it acted on the participant and consider separately the participant workflow and opportunities for an envisioned, future system. In this way, we imagined patients as direct stakeholders: specifically, with patient goals, priorities, and technology use patterns forming a feedback loop with the healthcare information system, rather than a system informed by the normative requirements of top-down productivity goals (e.g., HEDIS) and evaluation standards (see Figure 1).

2.4. Ensuring rigor in systematic inquiry

Our application of Vicente's [20] systematic design framework to successive stages of our inquiry with patient stakeholders is a practical application of Iivari's [12] prescription for rigor in information systems as a design science. Iivari calls for a "constructive research" approach that "would make Information Systems as a design science more proactive, attempting to lead the evolution of [Information Technology] and not merely react to it" (pp. 50–51). The proactive approach is essential in establishing the patient experience as one of a direct stakeholder, rather than an object of the system to be acted upon according to system norms.

Demonstrating rigor in our methods is important for validating our empirical findings leading to inputs to the future design process. Our research team was composed of design scientists, information scientists, and medical doctors – all of whom approached the essential problem of helping chronically ill patients to achieve better outcomes from

different perspectives. From a practical standpoint, our approach using a structured theoretical framework to negotiate design decisions helped the research team to 1) consistently refocus our discussions on the patient as a direct stakeholder and 2) overcome differences in professional training and background. This approach kept us from “fighting” with the data as a reaction to difficult feedback – often in the context of chaotic, real-life experiences of patients who are managing serious diseases – that does not fit the normative or current descriptive viewpoint of healthcare information systems.

3. Overview of Study

The study objective was to design an open standard for patient reminders and notifications within existing health care information systems. Our data collection and study objective focused in particular on patient reminders and notifications from the system designed to engage patients with tasks dictated by the current EHR that supported ultimate (organizationally- and normatively-defined) goals of improving health outcomes for patients. Examples of reminders and notifications include annual exam reminder letters, e-mail messages announcing the availability of the annual influenza vaccine, or phone calls from the doctor’s office to confirm an upcoming patient appointment. These reminders and notifications are in turn connected to management of chronic conditions, and requirements for frequency of notifications and reminders are dictated by factors exogenous to the health care organization (e.g., regulatory requirements, national benchmarks) which are nonetheless important to classify in the framework.

To understand how patients and caregivers interact with the existing information system to manage chronic illness and preventive care needs, we separated data collection procedures into three stages. The stages include: (1) a first, exploratory interview with 40 participants, (2) a second, follow-up interview with as many of the original stage participants as possible, as well as new participants to achieve another 40 interviews, and (3) a set of participatory design sessions with patients or caregivers and clinicians who use the health care information system. In the first stage, two of the authors (JE and LK) conducted 40 interviews with 20 mothers of children with asthma and 20 adults with Type II diabetes in their homes. Our sample was designed for maximum variation in the experience of health care information systems users, particularly regarding use of and comfort with technology. The qualitative data gathered after the initial interviews amounted to approximately 800 pages of interview transcripts, and we sought a method to analyze the first stage of data to inform the interview schedule for the second stage of data collection.

This paper covers the method applied to our first, exploratory interviews and the process we applied to categorize normative, descriptive, and formative aspects of the existing information system according to Vicente’s [20] framework. We demonstrate how the organization of data systematically identified gaps in our knowledge of what was at stake for patients engaging with the healthcare system, including the personal health goals and preferences that motivated their engagement with the healthcare information system. Structuring data collection and analysis to probe patient goals, priorities, and technology use patterns helped us to focus on possibilities for systems design that would serve patient needs as direct system stakeholders.

4. Applying the Vicente framework

In preparation for the second stage of data collection, we organized data collected in the first round of interviews to write and revise the semi-structured schedule for the second interview. Specifically, we wanted to identify opportunities to inform design and envisioning for a system that better addresses the constraints acting on patients and caregivers when engaged with the health care information system of interest and its reminder mechanisms. We used the Vicente framework to analyze possible design domains for the health care information system according to the *normative*, *descriptive*, and *formative* requirements models that have or may act upon system requirements.

Having chosen the requirements framework to organize the past and planned data collection, we also thematically grouped design domains explored in the first set of interviews (see Figure 2). There were a number of ways to cluster themes from the first interviews; these themes were used as a starting point for discussion and were based on previous open coding performed by the core research group, including four of the five authors. Open coding was followed by a group affinity diagramming exercise to agree on data themes that could be used for analysis and discuss facets of the information system in more depth. The themes identified and used to organize content from interviews are defined below.

Health information needs

Statements where a patient articulated an information need from the health care information system or clinician.

Modality

Statements of use or preferences related to different information modes, such as digital or paper tools used to engage with the health care information system.

Medication task cycle

Participant activities around taking daily medication, particularly locational or routine-based reminders for taking medications.

Appointment task cycle

Descriptions of engagement with the health care organization for scheduling, remembering, and attending medical appointments.

Social

Participant descriptions of engagement with the health care system that involved a social component, such as needing human contact to remember an appointment (e.g., a phone call from the doctor's office) or using the information system on behalf of others (e.g., spouse, children).

The grid shown in Figure 3 was used to map out the three types of information we had or needed: (1) normative requirements present in the existing system (which we built from knowledge of the system); (2) data from the first round of interviews; and (3) participant

feedback we needed to elicit from the second round of interviews to gather enough descriptive and formative data to inform the participatory design sessions in the third stage of data collection. As shown in Figure 3, we had collected rich Descriptive requirements data in each of the design domains. We focused our attention on the data gaps highlighted in the figure, and we describe our methods for addressing each gap below.

Data gap 1

We found that Interview 1 data resulted in valuable information about discrete events in terms of task cycles; one example of this data was participant statements about motivation for responding to information like after-visit summaries or annual checkup reminder letters. However, we wanted to target more Descriptive requirements data in the “Health information needs” domain around relationship-driven information exchange between participants and clinicians. The focus for the second interview shifted to asking whether or not participants felt as though their information needs were being met. We formulated questions about participant perception to deepen descriptive data about interactions in which patients engaged with the health care information system or a clinician. Example questions we formulated for the second interview protocol include: *“When you have questions about your health, where do you go for information?”* and *“Do you believe you are given enough information to help you effectively manage your health? Why or why not?”*

Data gap 2

The second data gap left over from the first interview caused a significant shift in the framing of the participant interview. We intended to move away from questions that framed the participant as someone who is *acted upon* by the information system; for example, asking questions of participants about receiving annual checkup reminder letters. Instead, we centered the inquiry on the participant’s health goals, placing their priorities at the forefront of the interview. We structured the interview schedule to ask first about the participant’s health goals, moving on to phrase questions using their goals as a focal point. For this reason, the second interview schedule opens with the question *“What is most important for you to get out of your health care?”* The interview schedule then allows interviewers to recall the response to the participant goals question throughout the semi-structured protocol to center the discussion on patient priorities.

Data gap 3

Related to the previous data gap, we formulated the second interview schedule to move away from patient use of technology as the central interest. To achieve this goal, we wanted to elicit more Formative data related to the appointment task cycle. Interviewers in the first round (JE and LK) reflected on the difficulty they encountered in prompting participants to remember certain interactions with the existing health care information systems and/or clinicians. For this reason, the group decided to use an artifact (a list of recommended activities for the management of the applicable chronic illness and preventive care) in the second interview to elicit information from participants. Although this list is provided to guide clinician activities for reaching out to patients, we framed the interview to focus on the participant’s priorities in reaction to the list. Questions pertaining to the list of recommended activities probe the following four areas:

1. Recommended activities the participant considers to be important to meet health goals
2. Recommended activities that conflict with the participant's health goals
3. Recommended activities the participant finds challenging to fulfill
4. Recommended activities the participant is unsure are necessary to meet health goals

Although the list of activities for managing chronic illness and preventive care of interest (Type II diabetes or pediatric asthma) can be quite extensive, we have designed the second interview to help the participants reflect on the activities in the context of their own goals.

De-emphasized areas of inquiry

Using the grid system to organize our data also led to de-emphasizing the Formative data inquiry for the medication task cycle. In relation to our primary study objectives, we found the descriptive data was sufficient to fulfill our information needs for the third stage of data collection (participatory design).

5. Benefits of systematic inquiry

The practical application of determining what data we had, and what data we needed to collect, according to the grid occurred in an iterative formulation of the second interview schedule. We used the grid in editing the interview schedule and as a point of discussion in regular research team meetings. This approach had three major benefits for the team. First, we were able to avoid spending time discussing normative requirements of the existing system; these were outside the scope of inquiry and included assumptions already built into the system, which saved us time.

Second, we could ensure that the information we needed was the main focus of the second interviews, as determined by the highlighted areas on the grid. We were able to proactively avoid repetition in inquiries between the first and second interviews by mapping data we already gathered, and focusing on effective questions to elicit the information needed in the gaps in data (highlighted areas). Since the second interview was based on a script in a semi-structured format, we were also able to prepare interviewers for the second round in time allotment for each question area. This is invaluable in the field when managing limited time with participants.

Third, and perhaps most importantly, we were able to focus the research team on gathering rich qualitative data for the purpose of envisioning new user engagement with the system. We set aside the current limitations of the existing health care information system, based in its normative requirements that largely ignore the direct patient-stakeholder, by identifying and separating normative requirements. In this way, we are able to focus on holistic participant feedback. For example, multiple participants preferred text message reminders for appointments, including doctor's appointments. This capability is currently excluded in the existing system due to normative requirements (e.g., practical application of the Health Insurance Portability and Affordability Act, or HIPAA); however, by structuring data using

the theoretical framework, we are able to present the patient stakeholder point of view with regard to message modality without censoring for normative limitations.

Thus, our ability to inclusively gather participant feedback to envision new system engagement models is a proactive – while still rigorous – approach for informing the third stage of our study, design work. In the third stage, we will integrate the wide range of patient experiences derived from our maximum variation sample, qualitative data collection, and systematic inquiry into patient preferences to emphasize findings related to formative requirements. This will expand the possibilities for eliciting ideas about new types of patient (and caregiver) interaction while shifting information systems to a more patient- centered stance.

6. Implications for future work

We have presented a method for systematically engaging the patient as a *direct* stakeholder in healthcare information systems design to support better notifications and reminders for the management of chronic illness. In addition to focusing our inquiry on what is at stake for patients, the method has provided a foundation for building consensus around constructive design decisions as an interdisciplinary team of practitioners (medical doctors and clinical researchers), information systems researchers and designers. Recalling Iivari's vision of information systems design and evaluation as a proactive process, we utilized the Vicente framework to shed preconceived notions about what the systems could and could not do based on existing experiences and beliefs about constraints and capabilities.

The Vicente framework improved content and face validity of our data collection instrument by helping us to identify the assumptions embedded in our interview questions. The framework helped us to formulate questions that encouraged narratives focusing on the patient as an active agent in the task cycle of receiving, using, and responding to a reminder, rather than exploring positive or negative feedback about the system engagement.

By using the Vicente framework to guide inquiry, and situating patients as direct stakeholders, we achieved a more proactive vision for the system's future capabilities. Just as clinical workflow has been evaluated in healthcare information systems implementation, we were able to systematically map patient workflows and their engagement with the system.

Specifically, we identified features of the information system that are dictated by each type of requirement. *Normative requirements*, informed by regulatory requirements or healthcare organization goals such as HEDIS indicators, shaped factors of the EHR we examined such as type of notifications and reminders sent to patients with particular diagnoses (e.g., A1C tests for adults with diabetes). These normative requirements operationalized processes to improve health outcomes from the organizational point of view, but were predictably not uniformly successful engagement methods with all patients in the sample.

To capture patient experiences with the system, we gathered information about *descriptive requirements* from patient narratives elicited in our interviews: we asked about how patients responded to notifications and reminders, probing preferences about message modalities and

the relationship between patient priorities and the standard notifications issued by the EHR system. In particular, patients were able to identify failures related to engagements with the system; these were areas where we were able to explore inconsistencies in current system capabilities and patient preferences.

We then identified elements that suggest an ideal future, where patients imagine a healthcare information system is incorporated into their chronic disease management workflow, using information and communication modality preferences that work most effectively for attaining personal health goals (*formative requirements*). Patients suggested such idealized interaction with their doctors as texting appointment reminders or lab results information – stating that the benefit to being able to receive text information outweighed their privacy concerns.

While the formative requirements challenge the status quo, the conflicts at the intersection of the three requirement types are, of course, where designers are obligated to make decisions about systems features tradeoffs. These insights allowed us to identify patient-centered values that contradicted normative requirements, but are nonetheless valuable in facilitating future participatory design work (in the future scope of our study), such as formulating personas to guide discussion and reflect on patient-user values. This will be the next phase in our research to suggest open standards for patient reminders and notifications.

7. Limitations

This research is presented with limitations imposed by the research context, our chosen sampling method for participants, and the exploratory nature of the framework application. In terms of the research context, we carried out our inquiry with participants who interacted with an integrated health delivery system, and therefore the normative standards we identified in the course of organizing our data may not reflect normative standards applicable to non-integrated systems and clinics. We also chose to draw our sample from patient populations managing chronic illness; although these users were chosen for their regular interaction with the health care information system, engagement with health information systems might be different among populations who interact with the health care system in a more episodic, ad hoc frequency. Finally, while applying the Vicente framework was intended to provide more rigorous structure and analysis to our three-stage inquiry than standard iterative qualitative interview design methods, we do not present here a standard prescription for applying the framework.

8. Conclusion

This study explores new ways to structure patient feedback and engage patient goals and technology use to inform the design of future health care information systems in the case of health reminders and notifications. In this paper we describe our method for using the Vicente theoretical framework to systematically structure our qualitative data analysis and collection procedures into three iterative stages. By adopting an existing theoretical framework for organizing our data from the first interviews, we were able to focus our efforts on writing the second interview schedule to elicit information for envisioning new

information systems, rather than limiting our inquiry to the capabilities of the existing information system. The systematic investigation of the patient and caregiver experience helped us to understand the participants as direct information system stakeholders. Our systematic inquiry method ensures rigor in the design of data collection and analysis activities for qualitative investigation of existing health information systems. This work demonstrates that utilizing a theoretical framework in collecting and organizing contextual information and user requirements can expand user-centered approaches for envisioning future systems at earlier stages in the interaction design process.

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Patients as indirect stakeholders:
the info system acts on patients uniformly;
system feedback informs adherence to
outcomes dictated by organizational
priorities

Patients as direct stakeholders:
patients are equal stakeholders, and their
priorities and constraints are built into
system interactions; outcomes are also
informed by patient health goals

Figure 1.
Patients as indirect versus direct stakeholders

Figure 2.
Affinity diagramming to coalesce themes in the first stage of data collection

Design Domain	Normative	Descriptive	Formative
Health information needs	Patient rights to EHR information, e.g. CMS meaningful use standards	Interview 1 – data gathered Pertaining to task cycle: visit summaries, lab test results Interview 2 – data gap 1 Probe relationship with doctor/other clinicians, e.g. verbal information or mediated information during face-to-face visits	Interview 2 – data gap 2 Frame information needs in context of patient health goals
Modality	Regulations dictate privacy of medical information and sharing (HIPAA)	Interview 1 – data gathered Use of phone, text messaging in every day life and to remember appointments, tasks	Interview 1 – data gathered Speculation about use of new modalities for interaction with healthcare information system (e.g., texting)
Medication task cycle	Administration of drugs dictated by safety regulations, diagnosed condition, doctor's orders	Interview 1 – data gathered Tools to remind used in the household, including location cues & integration to routine; includes narrative and photographic data	De-emphasized formative information N/A (medication reminders not focus of study)
Appointment task cycle	Recommended appointment intervals adapted from national guidelines and customized to patient characteristics (age, gender)	Interview 1 – data gathered Recording appointment, remembering appointment, setting reminders	Interview 1 – data gathered Speculation about increasing effectiveness of reminders/switching modes or changing content Interview 2 – data gap 3 Use artifact (list of recommended activities) for managing chronic conditions to probe patient priorities and health goals
Social	Regulations dictate privacy of medical information and sharing (HIPAA)	Interview 1 – data gathered Receiving reminders for others Receiving reminders from others	Interview 1 – data gathered Speculation about increasing effectiveness of reminders/switching modes or changing content

Figure 3.

Design domain data organized according to the Vicente theoretical framework