Validation of Transparency in e-Health – Turning Information Visible Through Design

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Abstract. This paper presents a proposal, a Model, Knowledgeable Intersection of Virtual Communities (KIViC), for the development of (online) Health Information Systems, grounded in the concept of Patient Empowerment (PE). In this proposal, Transparency in design is a crucial point to evaluate. In this special meaning, transparency is about turning information visible by means of design. The model, and an imaginary implementation in the shape of a "mock-up", is used in a study, performed 2006, to evaluate the usability of an empowering information system for health care. From the study, it is possible to conclude that there exists a tendency is towards a desire for openness and visibility of information and information flow in health care. Advantages and disadvantages with the (e-health and transparency) approach are finally discussed.

Introduction

The most significant trend in Health Care of today is Patient Empowerment (PE). The Active Patient (Ådahl 2003; Degoulet et al 2004 in Nelson & Ball 2004), as a cooperator in opposition to an inactive receiver of care, has spontaneously arisen as a concept during the last decades, growing stronger by the entrance of the Internet open for common people. This phenomenon was first identified by Dr. Thomas Ferguson who later, in a conference 1993, *Consumer Health Informatics; Bringing the Patient into the Loop,* coined the expression "Consumer Health

Informatics" in computer science, comprising IT systems specifically designed for patients (Nelson & Ball 2004).

But old routines in Health Care are still not always fit to accomplish these new actions. Literally spoken patients are, by old routines and a remaining lack of suitable artifacts for new information structures (Tan 2005), forced into being patient. For example, some of the information flow in health care is invisible from the patients view, and to some extent also from professional health care providers view. Visibility into the flow of information, in health care structures and systems, should possibly increase patients' ability to obtain PE: A patient that knows what is happening also often knows when to act and how.

Anyhow, the former passivity of patients is connected to questions about responsibility in Health Care as well as questions of traditional ownership of knowledge. A professional worker in Health Care can not delegate tasks and responsibility to the patient. Nevertheless, it is fully conceivable to cooperate with the patient to agree on a treatment. The future Physician is becoming rather a "teach support" than an authority for the patient (Nelson & Ball 2004). However, even if it is realistic to overcome some of the obstacles, the development of digital health care systems does not keep pace with the new direction in Health Care in a satisfactory way (Sands & Halamka in Nelson & Ball 2004).

Consequently, referring to some preliminary results from the study presented below, patients do have difficulties in being as active as they want in order to be kept informed about their illness or health status, towards self-initiated action. Hence, and as the main research problem for this paper, it should be of most importance to make information, information processes and information flow in health care more evident to the user of e-Health information systems. Perceptible information processes are especially important in situations when patients, at the time, do not directly communicate with treating units inside health care institutions. Being a patient is not a static state. For example, a patient may be in hospital, an outpatient, waiting for answers and information about medical examinations, or living with chronic diseases. In most of these states, the patient should be informed about his/her status and actions taken by health care.

Furthermore, information as a concept is not simple. It must be understood (Devlin 2001), and used more carefully, in order not to cause information disasters: That is, for example, mistreatment derived from misunderstandings, that will adventure the prognosis of illness. Therefore, the information should be interpreted and visible, as must the information process itself. Transparency in health Care structures will promote this understanding, but also transparency in the systems, providing this information.

In this paper, a scenario, cut out from a real case, will enlighten the problem with invisible information structures in health care. A solution is suggested in the shape of an implementation (mock-up) of a model: Knowledgeable Intersection of Virtual Communities (KIViC) which is used in a study on information and which

will highlight an aspect of validation of invisible information flows. The study (ongoing at the time this paper is written), grounded in the model, will in part bring out some issues of validation connected to transparency issues. Furthermore, information, as a unit of understanding and knowledge, will be analyzed with reference to the notation and terminology of Situation Theory (Barwise & Perry 1999; Devlin 2001) to clarify its role in transparent information processes and systems.

An e-Health Paradigm Shift in Health Care

Patient Empowerment and Health Information Systems

In the last decades a new movement has developed among health care consumers and health care providers worldwide. From being a patient in a passive position, roles are changing towards patient activity and responsibility and the physicians' roles are changing from authority to supervisor (Nelson & Ball 2004). *Patient Empowerment* (PE) is the concept emerging from this progress, which can be defined as "the increasing ability of patients to actively understand, participate in, and influence their health status" (Bruegel 1998; Degoulet et al 2004 in Nelson & Ball 2004). Moreover, empowerment embraces to "providing on-line users of e-Health systems, including e-consumers and other major e-stakeholders, with self-directed education, allowing them to participate actively in the decisions that affect them and their health" (Tan 2005).

With the Empowerment paradigm, new demands on functionality will be made by patients for the design of future Health Information Systems (HIS). This might be to make these systems more collaborative; i.e. interactive and communicative, which, more close to reality, will match the nature of health care work (Johannsen & Kensing 2005). The Internet has radically contributed to the empowerment of health care consumers in the last decade. But nevertheless, there is much more to wish for in HIS-design, as well as the development of online applications and services for e-Healthcare. Joseph Tan claims that *Integration* is crucial in future e-Health development (Tan 2005). He states that we are inside a paradigm shift as e-Health is developing, and to keep pace with the development, there must be a radical change of HIS in the future. Knowledge is power and towards knowledge development for Empowerment, "creation of integral e-health knowledge and dispensing system and an integration of intelligent agents among humans and machines" must be executed (Ibid). Integration is, according to Tan, a key to the creation of a practical solution for e-consumers, in which various subcomponents of e-health care is brought together. Such subcomponents could be stakeholders; hardware, software, and interface technology; and processes, tasks, and work designs. Integration needs to be achieved from several perspectives; for example,

integration between or among e-stakeholders, integration of e-technologies and integration of e-health processes and services.

The Nature of Information

Situation Theory

In this paper, Keith Devlins version of situation theory will be used, in the way he interpret Information, to clarify what Information really is. He uses an equation to explain the components of the word "information", which he simply calls the "information equation" (Devlin 2001):

Information = Representation + Constraint (Procedure for encoding/decoding)

Information with meaning to an interpreter is written "Information" with a big "I" (capital letter). Data, that is representations, is written "information with a little "i". Therefore, the equation also could be written like this:

Big-I Information = Little i-information + Meaning

Consequently, regarding information in this paper, interpreted information is written with a capital "I" and representations (data) is written with a lower-case "i". The difference is important. The point is that we negligently and from a general point of view use the word "information" as if the information that is flowing is completely clear to everyone receiving it. For example, in design this put emphasis on *being situation aware*, that is to be aware of the context in which the information appears. Devlin speaks about "*conversations*" that is communication and cognition between (idealized two) participants. In a conversation, the participants use personal experiences and knowledge (*background* of the conversation) to build a *common ground* for conversation, creating an increasing common understanding for the topic of the conversation (Devlin 2001).

This should be crucial to the design of information systems, as the point is which information can be formalized or not. The relation between how to build interaction facilities and how to use them in real world information environments is delicate. Situation Theory presents a tool to deal with this relation, as well as design tasks, systematically, rigorously and publicly accountable (Devlin & Rosenberg 1996). As a result, in the analysis of complex interactive phenomena, the view should be how to formalize real world communication for system development. This can be done mathematically, by logic: In situation theory, information is regarded as kind of a commodity that flows by way of different representations, and comes in discrete units named "Infons"; items of information (Ibid). Cognition and Communication are means in the process and are described as the acquisition of information (flow) by an agent from its environment and the flow of information from one agent to another respectively. Devlin & Rosenberg claim that

> "…situation theory is regarded as a resource. It is needed to show the way of dealing with the problematic relation between knowing how to build interaction facilities and knowing how they can be used in a real-world information environment." (Ibid).

As information in situation theory is considered as coming in the form of infons or compound infons, the theory should be especially suited for analysis in studies of situated language and situated action (Suchman 1987). To make it more clear, Devlin & Rosenberg (1996, 2006) claim that infons are items of information related to the situation in which they appear. This can be analyzed mathematically by using a relation, where an infon σ, given a situation s, is written as s |= σ ("s supports σ"). This approach treats information as a commodity that flows. Consequently, and finally, information is interpreted in relation to situations. Information must also be analyzed and processed mathematically, by logic, to be automated and processed in systems. Therefore, Situation Theory offers a tool for analysis and design, towards systems for transparency of information.

Transparency in Design

Transparency is a concept with multiple meaning depending on the domain that is using it. In computer science, transparency means invisibility of actions, in the system, i.e. actions that are taking place outside the field of vision of the user. (Tanimoto 2004). This is considered to be good, as the aim is to shield the user from the complexity of the system. Consequently, transparency means simplicity. But there are pitfalls; if the complex reality is simplified at the expense of functionality (Bolter & Gromala 2003). Bolter & Gromala express concerns in that transparency design would, paradoxical, end in invisibility of processes that should be visible. For example, in that "the interface will mask the operation of the system exactly when the user needs to see and understand what the system is doing" (Ibid).

This basic meaning of transparency, derived from computer science (Tanimoto 2004), could be associated to the traditional course of treatment in health care. From the patients view, the processes (actions) in the health care system are hidden and invisible, to simplify and put emphasize to some predefined aspects that, from a hierarchal view, are allowed to inform the patient. But the peril is when the process is not fully functional, or when the patient should be able to contribute but could not as he is only exposed to information that health care, with respect to a patient as a passive entity, has stated long before.

The other meaning is found in the humanities, which uses the word to describe openness, communication and accountability. There is a global trend that revolves around insight and control in healthcare, preventing corruption in the health care area. Transparency is here used to describe the openness and visibility of

processes behind administration of the health care business, according to what the concept stands for in the humanities. The humanity view on transparency should suit the intention behind the model, briefly presented in this paper, and be possible to integrate in systems design. Consequently, the concept Transparency is, by the author, with inspiration from a PhD-student course at BTH, Ronneby (Eriksén 2005), further on used to describe information processes that in design are made explicit to the user of a system: The user should, by means of the system, look through the hidden health care processes and be able to view information flows that could support Empowerment.

Nevertheless, this does not imply that transparency in design, addressing the computer science view (Tanimoto 2004), is less important. The use of a system should not be suppressed by complexity, but also, the system should not be simplified to the point that functionality will decrease (Bolter & Gromala 2003 in Eriksén 2005). It seems to be important to try to strike a balance, to find reflectivity, where the computer reflects the user, or different levels of transparency to choose, in design (Ibid).

As a result, a system built on the model should bring out hidden information flows, reflecting the patients' needs, so that they will be visible and open. Also the system should be invisible to the user, emphasizing the use and purpose without the expense of functionality.

A Model for Communication and Cognition

Outlining the Model, Using the Set Theory and Situation Theory

Using situation theory, a Model for e-health information systems development was created in 2005 by the author, upon experiences from patients, relatives, and professionals activities in an online discussion forum for parents (Ådahl 2003). The authors own personal experiences as a "bilateral participant observer" (for further explanation, see under the headline The Study) was the foundation for the design. The Model, named Knowledgeable Intersections of Virtual Communities (KIViC), is a description of virtual communities, forming an *intersection* where "conversations", due to situation theory (Devlin 2001), can occur. Furthermore, the foundation for the KIViC model is directly comparable to the set-theory, where each virtual community in a KIViC should be regarded as a set, and the actors within each set as elements of that set. The intersection of the sets is common for each set. The diagram in Figure 1 explains the KIViC visually:

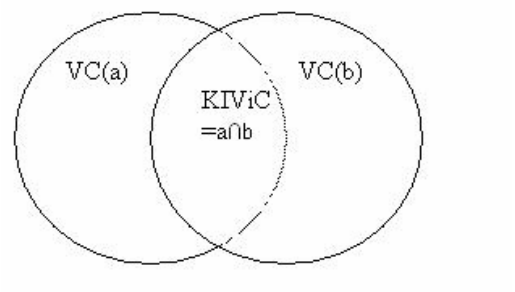

Figure 1. KIViC (Knowledgeable Intersection of Virtual Community)

Analysis of data from the participatory observations in the forum mentioned above (Ådahl 2003), confirms that common grounds for learning and understanding are built on conversations between participants. Using this conclusion, in addition to a situation theory view, we can apply the understanding on the model and be able to expect common grounds to be built on the information flowing within the intersection. As it is bilateral from a user perspective, the *background* (Devlin 2001) for these conversations is extended to comprise different groupings of participants. The Intersection is incubation for knowledge development, ideas, real world actions and PE, as communities of practice and learning are in cooperation towards knowledge development. Nevertheless, the same types of activities (conversations) are occurring in both communities forming the intersection, but the idea is that the common platform should pollinate each others conversations further on.

The Model should be used as a foundation for design of online e-Health information systems. Central to this design is the conclusion that information must be interpreted to be understood (Devlin 2001). In e-health and PE, it is a problem to deliver Information to the public without a great deal of misunderstandings. In Figure 2, patients and professionals meet in the intersection for interaction and cooperation (conversations) which should serve as a resource for understanding and clarification.

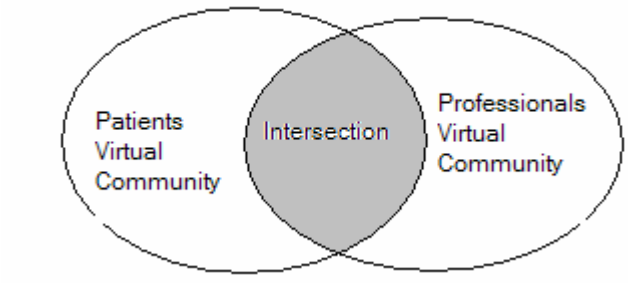

Figure 2. An e-Health KIViC

Essentially, the model is applicable for other implementations than a common and open virtual community. For example, a common artifact (Health Information System) for secure communication between an outpatient and health care, built on the aim of Transparency, can be developed on the bilateral concept. This paper is, after a description of the view on the users as part of a Multi Agent System (MAS), i.e. the system itself, further on focused on Transparency of information processes in such a system, handled by a Tracking subsystem and evaluated in a study during 2006.

The Model viewed as a Multi Agent System

By now, it is concluded that the model is outlined by means of the set theory and by analyses of data from participatory observations, on the idea of the Situation Theory, which means that its use is defined. But the *actors* within the model have not yet been in focus. According to Situation Theory, situations are parts of the world perceived by a cognitive agent (Pinheiro & Lopez 2002). An actor in the model could be "a human actor" or "a software actor", as an actor in this view is equal to an agent. Consequently, the actors must not automatically be the users of the system, which may be the intuitive reaction to this aspect. Instead, the actors can be viewed as a part of the system itself, where some of them are the users.

The model comprises this apprehension and uses the concept of a Multi Agent System to describe it. An actor is viewed as an *agent*. Agents could be *software* agents or *human* agents. A software agent carries information in the system, but a human agent is a user, as well as a carrier of information. Therefore, the implementation of software agents could be of interest to support information flow within the system, and between other information sources on the Internet and the system.

The BDI-architecture (Belief, Desire and Intention) is used in the model and views the agent as a system entity, having particular mental attitudes, determining the systems behaviour (Rao, Geogeff 1995). Michael Bratman, a Professor of Philosophy at the Stanford University, was the first source of inspiration for the concept, developing a planning theory of intention in which intentions are treated as elements of partial plans of action, plays a significant role in practical reasoning and cannot be reduced to beliefs and desires (Bratman 1987): The BDI Model, based on the mental attitudes belief, desire and intention, was first introduced as a philosophical model for modeling rational (human) agents, but later adopted and transformed into an execution model for software agents, based on the notion of beliefs, goals, and plans by Rao and Geoff (1995). The KIViC model approves to both, and uses them to describe a system design with human agents in the center, using software agents and each other. It is important to raise a flag of warning concerning transparency and the use of software agents. As agents are developed to make the system invisible (transparent, according to computer scientists) (Bolter & Gromala 2003), it should be of importance how

they are implemented; to make information visible without impoverish the system.

The Study

Reconnoitering study and Main study

A preparatory reconnoitering study was performed during 2000 and 2005 where participatory observations and interviews have been made, ad hoc, to find material for scenarios and reflections. This method is pure qualitative and the findings are grounded in personal experiences in the area. Derived from this preparatory study, three cases were written. All of these cases are realistic, taken place in Swedish health care and homes, and two of the scenarios were enacted within a period of six months.

Complementary, the reconnoitering study comprises the creation of a model and a mock-up, built on that model, to be used as a foundation for the questionnaire used in the main study. The author has used experiences from a professional life as a nurse (since 1983) and as a mother to a child with a severe congenital heart disease (since 1986) to construct this mock-up-example.

Finally, during January-April 2006, the main study was conducted; a bilateral study performed within two communities of health care. The first area is the Professionals, in this investigation the Department of Paediatric Cardiology and the Department of Cardiology/GUCH (Grown-Up Congenital Heart Disease) section at the University Hospital in Lund, Sweden. These two specialities are representing a “virtual community of practise”. The other area is the Patients. For this study, participants were traced by an advertise in both the periodical and at the web-site of The Swedish Heart-Children's Association, but also by a call for participation in the “All For Parents” discussion area for children with special needs/heart children. The participants are representing parents (and relatives) to children, as well as grown ups, with congenital heart diseases.

The study is ongoing when this paper is written and by now there are 15 participants from the patients’ community and an unknown number of participants from the professionals. Nine answers from the patients’ community and one from the professionals (a physician) have been collected until now. In this Paper, the participants are “double-coded”, to be able to be referred to completely anonymous. First, when answering the questionnaires, they have received the first code to make it possible for the author to get in contact for further interviews. Second, the codes have been transformed into letters A-O, in random order, with the prefix A for Professionals and B for Patients/Relatives, to be referred to apart from each other in papers etc. Consequently, the author is the only person who knows who is who.

Method

Qualitative research methods originate from the social sciences, where researchers aimed to study social and cultural phenomena, trying to understand, not only what and how people do, but also the social and cultural *contexts* which they live within. Therefore, a qualitative approach was preferred in the main study, as knowledge about context and background knowledge is crucial to how information is interpreted (Barwise & Perry 1999; Devlin 1991, 2001). This is clearly obvious in participatory observation methods, where the observers' participation in an activity is used to understand the activity itself and the actions taken in it. What is actually happening is that the participating observer, in the activity that is to be studied, uses background knowledge to understand what is mediated in the situations occurring and simultaneously builds a common ground for understanding (Devlin 2001).

Nevertheless, participatory observations were not possible to perform in the main study, as the participants are scattered over the entire country (Sweden) as well as working in differing services at different locations. The varying communities of practice and learning (Wenger 1999; Lave & Wenger 1991) have a "virtual part", but are only seeds to the virtual communities in the model, which makes them difficult to capture: There is no physical place to enter, as the use of information occurs in so many places, different to every single participant. Consequently, the virtual surroundings that are to be studied do not yet exist!

Bruce Mason writes that "Virtual Ethnography is an ethnography that treats cyberspace as the ethnographic reality" (Mason 2001). The first to be done is to identify the ethnographic context, but how to identify something that is not there? As the context does only exist in a model, this problem was solved by a mock-up, which was created preparatory. Consequently, the model and the virtual environments were made concrete to the participants through this mock-up and could be used for imaginative reflection.

Secondly, an ethnographic methodology is needed and ethnographic tools must be generated. The method used for this investigation is a triangulating method, where a questionnaire (most often part of quantitative studies) is used to collect information. In this case the questionnaire is to be regarded as an "interview in writing", as the questions are formulated very open. The questionnaire is completed with follow-up interviews, written or oral, specific on questions where there is a need for further explanation. The questionnaire is similar in both communities (patients and professionals), to find a bilateral perspective on the area of the investigation. The mock-up is central and also three realistic cases; scenarios.

Compared to this, the reconnoitering study was performed as a participatory observation, most as a result from circumstances, and performed completely opportunistically, as it was a result of the authors own double membership in the patients- and a professional community (both mother to a child with a severe heart condition and Registered nurse since 1983).

Nevertheless, the experiences gathered during this preparatory study constituted a foundation for further investigation and was used to design the main study. In this reconnoitering study, participatory observation and interviews, i.e. conversations (Devlin 2001), was used to construct the questions in the main study. The model (KIViC), and the mock-up implementation of the model that underpins some of the questions was originally constructed as a proposed solution for the need for information in the area of PE. It was initially built on a foundation of the authors former experiences in the area, but will be further evaluated and developed on the basis of the study.

Scenario on Invisible Information Structures

From the reconnoitering, preparatory, study during 2000-2005 (participation from patients/relatives view, observations and interviews), three scenarios were outlined. The scenarios were used in complement with a Mock-up on the KIViC-model and formed a base for reflection to the questionnaire. This section will present one of the scenarios, the proposed mock-up-solution for it and some reflections from the participants in the study.

Scenario

This realistic case took place in the fall 2005 and will exemplify an obstacle towards PE actions that lurks in invisible information flows or work flow structures.

> A GUCH-patient, 21 years old, arrives at the Emergency Ward at the Local Hospital (LH) with unspecific symptoms of Arrhythmia. He has experienced periods of exhaustion and hard and rapid heart rate (tachycardia), specifically in situations of exertion. ECG wave has changed since last checkout, 6 months earlier. The changes are ST-elevations that are typical signs of ischemia (lack of oxygen) in the heart muscle. The physicians decided to keep the patient at the Heart Division with telemetric-ECG and routine samples for Myocardial infarction (Heart attack) even if the most reasonable cause is NOT Myocardial infarction. But the Heart Clinic at the LH has most experience in heart conditions that is *not* inborn, and most recently they began to learn about inborn heart conditions. Therefore, there must be an *information flow* between the GUCH-unit at the Specialist Hospital (SH), which has the extended expertise, and the LH. The aim of the LH is, on the one hand, to treat the patient and, on the other hand, to learn about congenital heart diseases. Unless this does not work satisfactory, the patient must be sent to the SH for further investigation. The critical information flow between the two hospitals, LH and SH, in this case was ECG findings and information about earlier surgical operations on the heart, as LH grounded on information they got from the anamnesis and medical case book. There was also a great need for information exchange with GUCH-physicians by telephone, but some problem in getting in immediate contact with the desired GUCH-physician at the SH, occurred. Some week later, the patient was able to leave the Heart-clinic at the LH, but with no diagnose. Instead he got two answers from two different LH-physicians. The first was that there was a problem as the heart muscle referring to the ECG did not receive enough oxygen and behaved as there was a case of Angina Pectoris. This should be a probable consequence of an earlier open heart surgery, where the aorta valve was replaced with a biologic prosthesis. The second answer was that there were no differences between the last ECG 6 months earlier and the new ECGs. When the patient was able to go home, he had to wear a Holter-ECG for 48 hours that also must be sent

> to SH for evaluation later on. The patient felt anxious to know nothing for sure about the causes of his illness after all these controls. Also, he felt frustrated that he had to wait until SH has analyzed the ECGs made, and the other examination results (cat-scans etc that was performed during the week) and that the LH after this would give him information about his symptoms. After a couple of weeks, a letter from a doctor at the LH informed him that the tests were normal. No explanation to his symptoms or the ST-elevations at the ECGs was given, but the patient chose to trust the answer in the letter. Therefore, he went back to his normal life, but still suffering from the periods of arrhythmia and exhaustion. Two months later, a letter suddenly arrived where a time was booked for a new Exercise ECG. There was no explanation to why this new test was necessary, so he made a phone-call to the ward for clinic physiology where the test is performed. He was informed that the test was a mistake; that two letters of referral by mistake were made two months earlier and that the second Exercise ECG was not booked until now. Therefore, the test was voluntarily and by a deep psychological desire to stick to the second answer, that there were no changes in the ECG-Waves from the last check-out despite his symptoms, he choose to refrain from the test.

This case is used, as one of three scenarios in the main study 2006, to evaluate patients and professionals view on invisible information flow structures in critical situations, connected to congenital heart diseases, and the proposed solution for this problem. The study is not completed when this paper is written, but answers to the semi-qualitative questionnaire (written interview) are continuously incoming. Consequently, in this paper, nine answers from patients' health-community are available for analysis as well as one from the professionals.

Turning Information visible – for what reason?

In the scenario above, some obstacles towards patient activity are revealed. From the patients view, the absence of viewable signs from the information flowing between LH and SH, in connection to the lack of sufficient information flow between LH and the patient, seems to be crucial for the patients' impaired ability to act in cooperation with health care and to fulfill optimal self responsibility actions. Drawn from the answers in the Main Study, it is possible to conclude that Transparency in information processes is desirable. For example, one participant (B:J) stated that

> "..the patient has in this case no control over how the investigation is performed, neither if it works properly nor what really *has* been examined."
>
> **B:J**

Also, this participant concluded that the Mock-up-proposal, the Tracking subsystem mentioned above and presented in the Main Study as a solution for more transparent processes in health care, could function well to make invisible information flow visible. The following picture shows that proposal:

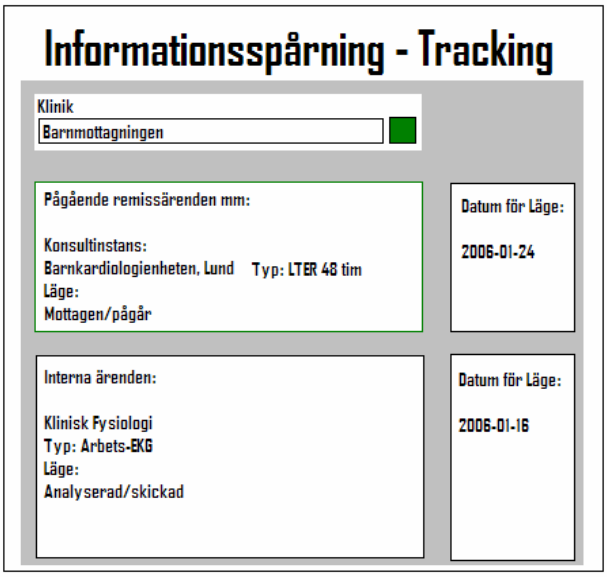

Figure 3. Information Tracking subsystem

In this example, the Mock-up on the "Information Tracking" subsystem (Figure 3) is used by an out-patient while he is, policlinically, examined for arrhythmia and exhaustion (as in the scenario above). The mock-up points at some crucial information steps in the information flow during an investigation. The first is that there is an ongoing ECG-investigation (what activity is going on). Second, the patient is informed about who is consulting who (who is active in what). Third, the patient is able to se when the ECG is sent and received (when who is active in what).

For example, the patient would be aware of where in the examination process he was if he could receive a receipt from the SH on the arrival of the ECG. This receipt makes the process transparent to the patient and put visibility to the information flow behind. If the patient wants to take some kind of action within this process, he is more prepared to do so even if the process probably will function anyhow. An action from the patient could in the scenario contribute to his own confidence in the care situation, knowing that the SH really has begun the analysis and has got essential and immediate vital information about his indications of illness. If there was no receipt to be found in the system, but it was expected to be, he would be able to contact health care in an earlier stage of the process. Consequently, in the scenario he did not do that as he trusted the invisible information process to exist and function without seeing it.

Conclusions on validation of Transparency in Design

The information-tracking subsystem, in the mock-up example of the KIViC-model, is designed to view hidden and invisible information flows to the patient,

just as to the physicians involved in the case. The primary aim is to provide Information about the state of the investigation, which would empower the patient to take active part in it. Regarding Information as commodities, using Situation Theory analyses on user cases towards automatization of information flows, it should be possible to design systems to deliver correct (the right and the needed) information and make it transparent to the user agent at the right moment of time (Pinheiro & Lopez 2002). Hence and moreover, as the model views systems for development of PE learning as multi agent systems, the BDI-agent-paradigm should be used in design to model behaviour of the system, a direction that could be compared to a traditional object oriented approach (Rahwan, Kowalczyk & Yang 2000).

The scenario in the study could have been combined with a use case of the chosen example of a system implementation, further on translated into a situation theoretical approach. But to do so would be premature as the study is not yet completed. What also must be noticed is that it is not possible to find statistical evidence in a qualitative study like the main study. Consequently, there is no *evidence* of transparency in the design of the system, only *assumed* transparency. Neither can evidence of transparency be found in the results of the study. Furthermore, there is no *evidence* that the patient would act, even if that kind of Information was exposed to him/her. The study could only identify *tendencies*. In addition to this cautious view, the author has made every endeavor to remain objective in the design of the system, despite the double membership of both communities described. The problem is dual; on the one hand the double memberships constitute a foundation for a deeper understanding but on the other hand it could result in less objective analyses. A solution for this, the mock-up-example was chosen to be evaluated by both sides of the participants.

In the answers given until this moment, it is a convincing tendency towards a desire for more visible information structures. For example, all of the nine answering participants from the patient community agreed on the usefulness of an Information tracking subsystem as presented in the mock-up. The physician answered that it was of an interest also for the professional community, but was at the same time concerned over the risk that the process could be time-consuming. Consequently (s)he would like to be ensured of a very simple input process for health care. Furthermore, one of the nine patient participants could not immediately see in which situations the feature could be used, but was still interested. Nevertheless, (s)he agreed on the scenario case and its coupling to the Information tracking subsystem.

To summarize, the possibility of accessing and viewing information and structures, that before was hidden, should be significant in e-Health development, with respect to patients (and maybe also to professionals; that is too early to conclude). Therefore, this would constitute a starting point for future in-depth investigations on visibility of information and transparency in e-health design. It

should be one of the main questions to ascertain whether PE is supported by transparency aspects on information flow in health care, as well as transparency aspects on e-Health systems design.

Discussion

Obviously, Health Care itself is a *sign of trust* (Rindebäck & Gustavsson 2005). By tradition, we trust Health Care, but nevertheless there are frequent reports on fatal mistakes; sometimes they are grounded in broken chains of information flows, misinterpreted information and missed or mixed up information etc. HSAN (Medical Responsibility Board) is an authority in Sweden which manage reports from patients and the National Board of Health and Welfare and assesses medical negligence. The board can take disciplinary action (admonition or warning) against the person that has the responsibility for the fault that was reported.

Therefore, the responsibility issue is on the Health Care sector, but nevertheless the patient might have a strong interest in avoiding situations of misinformation etc. by an active cooperation in the process towards recovery and health. Some of the mistakes that HSAN must take disciplinary actions against, have had lethal consequences or caused more illness, suffering and even disablement. Also Health Care might also have an interest in such cooperation. Visualization and transparency of information processes, as well as (early) feedback from the patient within the process, would most probably prevent some of the complaints to HSAN and hopefully some tragedy caused by breakdowns in information processes and flow. For example, the Scenario emphasizes a critical situation that a possible disaster could be avoided with transparency into the processes behind patient treatment, not at least access to patient bound information from the patients view.

Also, transparency in (the management of) information flow in health care should most likely strengthen the patient in his confidence to be active and empower him to cooperate. When information processes are invisible, it is impossible to act because there is no obvious action to act upon. Therefore, using a system that reveal invisible information processes, and make health care actions visible to the patient, should probably be of importance for PE.

But at the same time, it is of great importance to raise a warning against the e-Health paradigm. Computers and online health information systems should never be allowed to supersede other communicative methods in health care! There is still a digital divide, excluding relatively large groups of citizens in society, and therefore traditional channels to contact health care in and receive information from must remain open. Neither should computer artifacts supersede the personal face-to-face contact with the doctor.

Another issue concerns the interpretability of online health information resources. It is concluded that misinterpretations occur, information overload is

overpowering the patients energy to act and that a new kind of hypochondria has appeared; Cyberchondria. This is opposing to the goal of PE but much of the solution should be found in transparency and interpretability of information processes and information. If the patient is shown the information that is useful for action, and also able to interpret the information into Information that is useful for knowledge development, PE should have a reasonable chance to develop in the future. The responsibility is solely on the health information systems designers.

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