

Trusting Digitized Patient-Related Information: The Need for a New Approach

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Abstract

Trust is receiving increasing attention nowadays, particularly since new technology enables communication and collaboration like it has never been seen before. However, trust is a fuzzy concept that needs further examination and attention from multiple levels. For example, security is very important from a user's point of view in trusting that technology will function in accordance with the user's intended and requested function. This paper reviews the concept of patient safety, which thus far has been discussed and defined from a narrow technical perspective. We demonstrate that it is much more complex, and that it is not primarily the technical issues that are problematic, but rather the cultural, process-related and personnel issues. Our results point to a need for a new approach, which takes the patients' view of healthcare and the patient-related digital information as its focus. The discussion is made from a Swedish perspective, but the issues are international. The needs for information and knowledge in healthcare are obvious. Without clear definitions of concepts and roles, a good information flow or process cannot be designed. Our discussion shows that trusted digital patient information gives an opportunity for a patient-focused healthcare. Multidimensional trust must be addressed on all levels; organization, person and technology. More empirical research into trust in digital patient-related information is necessary, to develop a model for patient safety from a trust perspective that encompasses all levels of trust.

Keywords

Trust, information security, patient safety, electronic healthcare records

1. Introduction

"Trust is like the air we breathe. When it's present, nobody really notices. But when it's absent, everybody notices." (Warren E. Buffett)

Trust has become a focal point of interest for researchers and industry, in particular since new technologies have done away with previous barriers to trade. Trust is a fuzzy concept in the sense that it is defined and used differently in various research disciplines. There is the psychological angle, where trust concerns user willingness to risk time and money on expectations of other people's intentions or behavior (Luo, 2002), and the technical angle which is associated with technological solutions (Brogan & Armstrong, 2007). This paper takes the discussion of trust from multiple perspectives into the realm of healthcare, in particular focusing on trust in patient-related, digital information. The concept of patient safety has been discussed and defined from a narrow technical perspective, not taking the full complexity of the

subject into account. However, the technical issues are not the most problematic, but rather the cultural, process-related and personnel issues. Instead of focusing on the patient process, healthcare looks at the needs and requirements placed by the healthcare providers. This needs to change. This paper aims to take a step in this direction by discussing requirements and challenges for a new approach, and points to some necessary future directions for both research and practice. The discussion is made from a Swedish perspective, but the issues are international. It is based upon three pillars: patient information (including the patient process), patient safety, and trust. We will present each of these areas and then discuss the road ahead and the focal issues to address.

2. Documenting patient information

To understand which activities a patient goes through during for example a hospital visit, we discuss it as a patient process.

2.1. Patient process

A patient process in healthcare includes diagnostic, treatment and care. The way of working with processes has been well established since long ago (Elg et al., 2011). A patient process shall solve the problem that patients have to visit several departments to receive their diagnosis, treatment and care (Eriksson, 2005). However, the methods vary between the different units and the same activity is repeated over and over again (Jaakko et al., 2006). Repetitions can also depend on a desire from the personnel to perform all investigations themselves before a treatment. By doing so they are secure on that the investigations has been done in the best and the right way. People who come to the hospital expects to receive treatment for their illness. They passed between personnel with specific knowledge and expertise in a specific medical specialty, which has been collected in one unit.

The personnel have practiced specific working methods to perform care activities that differ between departments. It is in general a lack of consensus about how the healthcare activities shall be performed even in identical situations (Hellström et al., 2010). The situation is just the same as with common goals for which quality a specific care activity should have. Weakly developed communication between staff and units who are involved in the patient process, means that the patients may go through the same investigation several times because of the diversify performance between the units. Nevertheless, the care which focus on the patient activities is superordinate's other activities (Rivers and Glover, 2008). Nurses and doctors are deeply engaged in their medical work, and it conforms to their norms and values about how good care is being conducted (Bellou, 2010). They have also strong interest in that patient activity works well.

2.2. Digital patient information

Everything healthcare personnel do with a patient shall be documented in something like a patient journal. Nowadays, this is often digitalized (Greenhalgh et al., 2009).

Where patients are located can be seen in a digitalized patient overview. The journal contains everything from the personnel's first inquiries about a patient's previous diseases and problems to the actual treatment for the current health problems. The law also prescribes that all personnel shall keep a journal that is incumbent to write what they are doing and decide with the patient. Since a journal system often is unique to every organization, it causes communicating problems (Jensen and Aanestad, 2007). For example, few hospitals are able to exchange digitalized information with the primary care (Jerlvall and Pehrsson, 2006). The same applies to units within a hospital, who have problems sharing information for example since they can have a unique ways to document.

Wider use of healthcare information systems and easier integration and sharing of patient clinical information will focus on patients to access their medical record (Cauldwell et al., 2007). This can be beneficial for both patients and doctors, since it enhances communication between them whilst helping patients to better understand their health condition (Hassol et al., 2004). Several advantages in terms of security solutions can come into place, as well as improving the correctness and completeness of the patient records (Ferreira et al., 2007). Such systems are complex and expensive and of great importance to estimate what benefits it will achieve both for the personnel and the patients. Different systems must be integrated to allow patient related information to cross healthcare borders. Results from different sources supplement each other and healthcare personnel presume that the patient information is reliable, available and understandable to them.

3. Patient safety

The goal of healthcare according to Swedish law is to provide good health and care on equal terms for all Swedish citizens. The care should be provided with respect for all humans' equal value and for the dignity of the individual. The one with the greatest need for healthcare should be prioritized (2§ HSL, 2§ TL). This is the basis of systematic quality work within healthcare, and a prerequisite for reaching requirements of patient safety, patient satisfaction, and cost efficiency (Ministry of Health and Social Affairs, 2010). Patient safety is defined by the National Board of Health and Welfare as "protection against healthcare injuries", which is clarified as the result of actions against risks, mishaps, and negative events.

According to the patient safety investigation (SOU 2008:117), "patient safety" is a cross-disciplinary knowledge area for example within technology, philosophy, medicine, sociology and psychology. Patient safety is affected by the current attitudes between people in organisations, i.e. patient safety culture. Both WHO and the European Council have published recommendations to their member countries regarding how to structure their work on increasing patient safety. Most advice concern how to work to prevent healthcare injuries, for example via political directions, a cohesive and complete patient safety strategy, event management systems, and so on. Patient safety literature is currently focused on preventing healthcare injuries, and primarily those that are purely physical or medical. There is however little understanding and insight about injuries related to the patient's own

suffering and to respect for the individual. There is also little research on how to secure the information in order to increase patient safety, even though statistics show that lack of or flawed information is a large cause of healthcare injuries. Patient safety is often preventive against injuries that are highly related to healthcare costs.

4. Trust

Trust can be described in different ways. It is *subjective* since it concerns party's beliefs about one another. This embraces trust as non-objective (Pavlou, 2002). It is also *asymmetric* since two parties need not have the same trust in one another, and *context-dependent* in the sense that trust in one environment does not transfer to other contexts automatically. Finally, trust is *dynamic*, and can as such be reduced after misconduct and increased from good behaviour. All parties need some level of trust in the other(s), but that does not mean that the set of expectations is the same for all involved. Expectations derive from concrete experiences tied to the past, person or societal structure (Kumar & Becerra-Fernandez, 2005). Trust exists in the presence of risk, for example when there is uncertainty (Ba, 2001), a risk for opportunistic behaviour (Hoecht & Trott, 2006), difficulties in achieving cooperation due to different objectives (Langfield-Smith & Smith, 2003), or different cultural and national locations (Li et al., 2006). Trust in another party is defined as a multi-dimensional construct with two inter-related components—trusting beliefs (perceptions of the competence, benevolence, and integrity of the vendor), and trusting intentions—willingness to depend (McKnight, Choudhury & Kacmar, 2002).

4.1. Trusting beliefs

Trust represents, or can be characterized by, each partners perceptions of the other's ability, benevolence, and integrity (Murphy & Blessinger, 2003; Al-Diri, Hobbs & Qahwaji, 2006). Together, these three constitute the trusting beliefs, and they are often referred to as "trust" (McKnight & Choudhury, 2006). Trusting beliefs are in this sense perceptions of the competence, benevolence, and integrity of the vendor (McKnight et al., 2002). They denote the extent to which one principal believes that another principal is willing and able to act in the trusting party's best interest (Gray, Jensen, O'Connell, Weber, Seigneur & Chen, 2006). When information and experience that have been gathered from the environment are processed, the result can be new trusting beliefs about parties (Gray et al., 2006). The constituents can be defined as follows: *Ability/competence*: includes a set of skills, competencies, and/or characteristics that enable either party to exert influence within some specific domain of expertise (Murphy & Blessinger, 2003). *Benevolence*: the extent to which a either party believes that the other acts in a positive manner or will do good to the other party/-ies with regard to their interactions, excluding egocentric considerations or profit motives (Pavlou, 2002; Lumsden & MacKay, 2006). The partners are thus genuinely interested in the other partner's welfare and joint gain (Marshall, 2003). *Integrity*: either party's perception of the others' devotion to a set of generally accepted principles (Murphy & Blessinger, 2003). The three constituents in trusting beliefs are related, but separable, and together explain much of the variance in trustworthiness while maintaining parsimony (Murphy & Blessinger, 2003). For

example, perceived ability and integrity standards should be established especially if no prior benevolence data is available (Sherer & Adams, 2001). Also, competence/ability and integrity refers to credibility while benevolence refers to goodwill (Pavlou, 2002).

4.2. Trust levels

The definition of trust is often made from the psychological or sociological point of view, i.e. from a people perspective. However, it is commonly discussed, or classified in literature from an organisational or technological perspective too. The definitions still are the same, but the level of application differ. Let us start with person trust, or *interpersonal trust*. This is the extent to which a person is confident in, and willing to act on the basis of, the words, actions, and decisions of another (Kanawattanachai & Yoo, 2002), thus increasing vulnerability to the actions of others whose behavior cannot be controlled. As can be expected given the nature of trust definitions, this is equal to the definitions of trust in general. This type of trust is cognitive (Ratnasingham & Kumar, 2000). Interpersonal trust relationships are very important for the success of for example outsourcing, which involves close cooperation between internal and external staff (Hoecht & Trott, 2006). Trust is also a basic ingredient of *organizational* functioning and underlies the sharing of for example vital systems knowledge (Kasper-Fuehrer & Ashkanasy, 2001). It is a governance mechanism necessary for conflict resolution, intra-organizational goal setting, and creation of shared values, to enable employees to work together more productively and effectively (Pavlou, 2002). Lastly, *technological trust* relates to an individual's belief that the underlying technology infrastructure and control mechanisms of a website are capable of facilitating the transactions (Lumsden & MacKay, 2006). Website quality, content, and appearance distills a perception of security and reliability which contributes to a consumer trusting an e-retailer (Lumsden & MacKay, 2006).

4.3. Trusting beliefs vs Trust levels

Trust differences depending on level can be analyzed using the trusting beliefs. Table 1 provides such an analysis. On the person level, the definitions of trust apply. As soon as moving to the organizational or technology levels, the degree to which structure and boundaries are needed increases, for example in terms of contracts or technology specifications.

	Ability	Benevolence	Integrity
Organisation	Collective set of skills, core competences, equipment	Collaboration partners want benefits for us	Commitment to contracts and agreements
Person	Skills, competences, characteristics	"Good behaviour"	Devotion to principles
Technology	Technology purpose and capabilities	Technology will respond to commands	Technology will function according to rules

Table 1: Trusting beliefs vs Trust levels

Furthermore, trust on the technology level concerns people placing trust in the technology, and not trust between technologies. The objective nature of technology and the fact that most technologies to date are not self-adaptive means that technology does not think or react as defined in trust, but are programmed and created to respond in certain ways. When technology becomes more adaptive, they will not only be able to recognize familiar situations and respond accordingly, but may draw conclusions and engage in actions also in unfamiliar cases. However, this is a future scenario and not relevant to date. Research into the difference between technology trust and “regular” trust should also be made, in particular to distinguish between trust and security mechanisms. If these two perspectives are treated the same, then why use two words for the phenomena? Confusion exists now, and clarifications will help focus on the real issues at hand. It may be that people and organizations do not place trust in technology per se, but rather in the organizations and people that own and operate the technology. In a sense, this is a form of transitive trust: organization A trusts organization B, organization B trusts its technology, and hence A trusts B’s technology. Future work should also consider group dynamics and elaborate on the meaning of trust from an organizational point of view and contrast it to that of interpersonal trust. For example, who is placing trust, and who decides when trust exists in the organizational perspective?

5. Discussion: The need for a new approach

Thus far in this paper, we have presented three pillars upon which the issue of trust in electronic healthcare records from a patient perspective is resting. Based on this knowledge, we will now discuss central issues in the target area, and point towards actions needed and issues to resolve. We are taking a Swedish perspective, which is affected by Swedish laws and regulations, but the issue has international relevancy. In fact, an international comparative study is one advised future direction.

A popular saying in Sweden reads: “you must be healthy in order to have the strength to be sick”. One important problem to resolve is the issue of competence and knowing what information is needed to provide good care. There are a number of questions to answer within the frame of this problem, one of which is the lack of holistic patient information in the digital records. There is a need for a template for what patient information to collect and store. There is healthcare staff who document from fear, and who thereby document too much. The *right* information needs to be documented, not just to keep one’s own back safe. Several aspects come into play. Firstly, such a template needs to be built with the right competence on a national level. Secondly, the right competence is needed locally to be able to use the template. Thirdly, there is a need for cross-border information for collaboration and entirety, where there may be issues in competence transfer between healthcare staff, healthcare staff and patients and , different units and levels in organizations. Patients and staff also both have to complement information being *information carriers*, which results in fragmented information. It is important to have a synergy effect between top-down and bottom-up, or there cannot be a holistic view. It is hence essential to realize the importance of collaboration of the professional organization in everything, and to allow the professions to be standardized. Another aspect that

needs to be standardized is the healthcare plan. It needs to be standardised enough for healthcare staff to know what kind of information they need to gather in order to make good evaluations and provide good care, and is hence closely tied to the proposed template. The healthcare plan should be complemented in time and will thus provide coherent information. Depending on what condition the patient is seeking care for, the right information should be displayed without the staff needing to search in the masses of information.. There are also technical issues such as integration problems when systems are not communicating. This impacts the trust for the whole patient process. Patients often do not get any kind of documentation of their own, but usually only receive oral information. Many of them hence may forget what has been said, and if so cannot go back to any written information to get facts. Furthermore, medical prescription recommendations may in some cases be written on post-it notes, given to a doctor who puts them in his pockets. What happens to this piece of information? Systems for EHR need to be designed so that they support the people who are to use them. Today, this type of support is not there, and some people do not log out because it is too much of a hassle to log back in again. It is more difficult to follow existing rules and regulation since current systems do not support or facilitate that. Usability needs to be designed to enable easy conformance to rules, regulations and controls, for example concerning logging routines.

In addition to information, communication is another main area where there are issues to address that affects the patient perspective and trust in EHRs. There are clear regulations stating that there must be guidelines for how patients should be addressed, and it concerns meeting expectations and not experiences. This means that the patient's expectations need to be asked for, and need to be discussed when meeting with the patient. Healthcare managers are nowadays required to ensure the presence of routines. Many educational efforts have been initiated lately to educate healthcare staff in this issue (Wendy, Currie & Finnegan, 2011). The task is not to fulfill every expectation, but to address them. For example, at the dentist's office, a patient is never to be alone in a room. The dentist shows and walks the patient through what is to happen. Those who have followed a similar method of working have never had any complaints regarding lack of patient influence (Åhlfeldt, 2010). Electronic healthcare records have logging lists, and these must be structured to enable patients to get transcripts – should they request it. Patients have the right to know who accessed their information. It is easier to maintain patient privacy when persons who accessed the information are known by the patient, since unknowns may increase uncertainty for the patient. Listening to patients and making them feel they are listened to is a difficult matter, since what people experience and what actually happens not always match. Some influencing factors are variations in culture, norms, and values, how we treat other people and when we decide to trust them. Trust *is* subjective, and that part of trust is very clear in healthcare. The core of trust demands some type of recognition, and trust is for example that the doctor is listening. Truth is important, even if it may cause distress too.

Clarity in terminology is essential, and healthcare has a problem today. Terminology in this case refers to healthcare organizations, professions and sections using different names for concepts. For example, a patient can be called patient, care taker,

user, and customer, and care plans can be referred to as care plan, standard care plan, PM, and checklist.. The key is to have a description there to find. Without clear definitions of concepts and roles, a good information flow or process cannot be designed. A clear terminology is the basis from which information is generated from where, where it is stored, how it is stored, when and where it is to be sent and to whom (National Board of Health and Welfare, 2011).

The discussion clearly points to the need for a new approach, which takes the patients' view of healthcare and the patient-related digital information as its focus. The issues discussed are not primarily of a technical nature, but concern culture, work processes, and personnel issues. By taking a patient perspective, we get a trigger to change, and to achieve a working change that is acceptable for all. Having trusted digital patient information means that we can achieve patient-focused healthcare, which is natural since healthcare is there for the patients and not vice versa. By raising awareness of this perspective, the needs for information and knowledge become clearer. It is currently possible to pay for and get high technical security, which will spur trust that relate to technical issues. However, as we have shown in chapter 4, trust is multidimensional and must be addressed on all levels. It is essential for a healthcare organization to get the security and trust it needs, but there is still much to learn about how to structure work on security and trust issues on a strategic level that is concretely connected to processes and persons. If, for example, policies are not connected to actual work, they will not be powerful enough to have an impact. What is needed is more empirical research into trust in digital patient-related information, for example concerning case studies that investigate where trust issues really occur. This can for example be used to develop a model for patient safety from a trust perspective that encompasses all levels of trust.

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