The Role of Patients and their Health Cards in Integrated eHealth Environments

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Abstract. Communication and co-operation processes in healthcare and welfare require the involvement of all parties involved, including health professionals as well as patients. Generally, professionals can and will easily communicate via trusted health networks. To enforce both communication and co-operation between professionals and patients and to guarantee the required degree of involvement of patients in shared care environments, smart cards are widely used. They serve as person identifiers on the one hand and as security token on the other hand. Acting as storage media and portable application systems, patient data cards enable patient-controlled exchange and the use of personal health data for specific purposes such as prescription and disease management. Additionally, patient status data such as the emergency data or the immunisation record may be stored in and communicated by patient data cards.

Keywords. Health Network, Health Cards, Security, Infrastructure, Patient Data Cards, Policy, Electronic Health Record System, Patient Integration

Introduction

Knowledge accumulated in the recent decades proved that information that flows within a domain and its transfer between domains is the very basis of human progress. Professional knowledge becomes more valuable when shared with other professionals. This is also true for healthcare and welfare. In order to increase quality and efficiency of healthcare, health systems in developed countries throughout the world tend to move towards distributed collaborative and coordinated care of patients in the sense of shared care. Additionally, health care administration and management focus more and more on preventive care which the citizen himself/herself is responsible for. Regardless whether integration of information is considered for domains like bio-informatics, biomedical engineering, applied and clinical informatics, or for information systems and informatics education, it is always collaboration and exchange of knowledge that counts [1].

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Patient empowerment and patient involvement in the healthcare and welfare processes are important pre-requisites for achieving the positive outcomes hoped for. Health cards can play an important role. They allow developing an integrated eHealth environment by integrating medical informatics, health informatics, patient integrity, and patient integration. Keywords to foster these processes are card, security token, and card technology. The role of the card in the process of patient integration and the security functionality for data integrity and patient integrity and the problems concerning access rights, and related data protection and privacy aspects are also vital [2].

1. Patient Empowerment and Patient Involvement

From the aforementioned point of view, healthcare systems will increasingly profit from engaged citizens while engaged patients will have better outcomes. New health policies, increasing patient needs and decreasing health budgets necessitate empowerment of the patient. The involvement has to take place at different levels within the healthcare process at the level of care as well as at the political level [3]. At the level of care, the interest in citizen engagement is presently changing from past practices where the patient’s involvement meant that the patient had to go along with the physician’s advice to a collaborative partnership where the citizen is considered a partner within the medical workflow. At political level patient group representatives are increasingly considered valuable allies [4], [5].

Patient empowerment means that citizens have to take on responsibility. Citizens have to realise that healthcare is a concern of theirs even when they are not in need of it. This means they have to understand the system. Only if they understand the system and know how to influence the healthcare process, will the citizens build up the necessary confidence in the new system and will be ready to accept any change of behaviour that might be required. Health care providers and politicians, on the other hand, have to realise that healthcare systems and services can only be improved with actively participating citizens.

A dedicated patient health card (PHC) as a means to strengthen the role of the citizen has multiple functionalities [6]. It can be used for purely administrative reasons, but also support the communication between care providers and improve data security. In either case the patient has to support this process – at minimum – by presenting the card whenever required. This means that the patient has to be involved but is in the same time empowered. However, this kind of involvement asks for a certain level of process understanding (awareness, confidence, acceptance), too [7]. How can a card support this?

2. Patient Empowerment by Standardization in the Patient Health Cards Domain

Open, interoperable and scalable solutions for empowering and involving citizens and patients worldwide especially if they are to include respective cross-border activities must be based on international standards [8]. Otherwise a French health professional, for example, will not be able to read the health card of his/her German patient and vice versa.
Regarding the aforementioned requirements for interoperable patient data cards, a series of standards have been specified at international level by ISO TC 215 “Health Informatics”. After having identified both needs and requirements for such cards, the standardization experts defined a framework of card-related specifications of medical and administrative content. ISO TC 215 does not intend to standardise the card-related technology itself but only the health-related structures of such types of cards.

Person-related data carried on a data card can be categorised into three types: identification data (of the device itself and of the individual the data it carries relates to), administrative data related to the card owner, and the respective medical (clinical) data. It is important to realise that a given healthcare data card "de facto" has to contain device data and identification data and can contain, in addition, administrative and clinical data (see figure 1 below). Furthermore, patient data cards may support the collaboration with network-based systems. For that purpose, any type of link information was specified. Person-related cards can also enable the use of established security infrastructure services.

Developed under the rules of the so-called “Vienna Agreement” for allowing the European Standardization Body CEN to easily adopt existing ISO standards, ISO TC 215 WG 5 “Health Cards” has started developing standard 21549 “Health Informatics – Patient health card data” [9]. This new standard has started replacing the former European pre-standard ENV 12018 adopted by CEN in 1995. ISO 21549 consists of eight parts describing structures and roles within a common framework.

3. International Standard ISO 21549

A data card essentially provides specific answers to definite queries whilst at the same time there is a need to optimise the use of memory by avoiding redundancies. Figure 1 shows the overall structure for patient health card data according to the described 8 parts of ISO 21549 [9] using a UML Class Diagram.

![Figure 1. ISO 21549 Data Set](image)

3.1 Part 1 – General Structure

The first part is more or less an overview on what needs to be tackled by such a series of standards (see figure 1). Part 1 is the introduction to the multi-part standard that defines data structures kept on patient health cards compliant with the physical dimensions of ID-1 cards as defined by ISO/IEC 7816. Therefore, this part does not
apply to multi-application cards. It defines a general structure for the different types of
data, which are defined in the other parts of the standard, using UML notation. ISO
21549 Part 1 has been in place since May 2004. Several countries are basing their
national health card implementation strategies on this standard.

3.2 Part 2 – Common Objects

Part 2 is dedicated to data items and structures that need to be present on each and
every single health card to be addressed and accessed. Thus, part 2 establishes a
common framework for the content and the structure of common objects used to
construct other data-object data held on patient healthcare data cards, or references
thereof. This part specifies the basic structure of the data but does not specify or
mandate particular data-sets for storage on devices. The latter will be done in the other
parts. Part 2 of ISO 21549 has been in place as a standard since May 2004.

3.3 Part 3 – Limited Clinical Data

Part 3 defines and describes the limited clinical data objects used in, or referenced by,
patient-held health data cards using UML, plain text and abstract syntax notation
(ASN.1). Part 3 specifies the basic structure of the data contained within the data object
“Limited Clinical Data” but does not specify or mandate particular datasets for storage
on devices. In particular, the data contained within the data objects in “Limited Clinical
Data” are intended to aid the delivery of emergency care, but are by themselves neither
intended, nor suitable, for the provision of all information required. ISO 21549 part 3
has been in place since May 2004.

3.4 Part 4 – Extended Clinical Data

Part 4 specifies the basic structure of the data contained within the data object
“Extended Clinical Data”, but does not specify or mandate particular data-sets for
storage on devices. In order to facilitate interoperability, whenever an application is
built for use in the healthcare domain in compliance with this standard, data items
required for that application shall be drawn from a defined list of objects. These shall
then be used in conjunction with other data defined in other parts of this standard.

3.5 Part 5 – Identification Data

Part 5 establishes a common framework for the content and the structure of
“Identification Data” of the device-holder held on healthcare data cards. It specifies the
basic structure of the data, but does not specify particular data-sets for storage on
devices. Its structures can accommodate suitable data objects specified elsewhere

- Security functions and related services which are likely to be specified by
  users for data cards depending on their specific application, for example
  confidentiality protection, data integrity protection, and authentication of
  persons and devices related to these functions;
- Initialization and issuing processes (which starts the operating lifetime of any
  individual data card, and by which the data card is prepared for the data to be
  subsequently communicated to);
• Access control services which depend on active use of some data card classes such as microprocessor cards.

3.6 Part 6 – Administrative Data

Part 6 specifies the basic structure of the data contained within the data object “Administrative Data”, but does not specify or mandate particular datasets for storage on devices. In order to facilitate interoperability, whenever an application is built for use in the healthcare domain in compliance with this standard, data items required for that application shall be drawn from an existing list of objects (some of which are extensible). These shall then be used in conjunction with other data defined in other parts of ISO 21549. For delimiting the administrative data set of this standard from the identification data set of ISO 21549-5 the administrative data set shall contain health insurance data only.

3.7 Part 7 – Electronic Prescriptions

Part 7 specifies the basic structure of the data contained within the medication data object. It defines the structure for electronic prescriptions. This is on top of the priority list of most European countries as this use case seems to be the most promising concerning acceptance and cost savings [10].

3.8 Part 8 – Links

Part 8 is of specific importance for the future use of health cards as this part intends to bridge card and network. Cards will not be able to bear complete information (plain text, structured information, images, other multi-media information, etc.) regarding a patient’s health status. Networks will easily communicate this information within a very short time. Cards will therefore act as keys to this information. To allow for all these functions, links and other pointers need to be stored on the card (URL, URN, tickets, etc.). Part 8 of ISO 21549 will define and standardise this kind of structure and both EFMI WG “CARDS” and EFMI WG “Electronic Health Record” will play an important role in these processes [11]. Draft versions of Part 8 have been extensively discussed during 2007.

4 Conclusions

Shared care solutions all over the world have to be based on trustworthy communication and application security services. Patient Identification Cards (PIC), Patient Data Cards (PDC), and Health Professional Cards (HPC) will play an important role; either as personal ID token, as professional ID token, or as health data carriers. Cards have an impact on the related security infrastructure, the certification of processes, on process interoperability (workflow), and on the certification of state and relations of principals in longer terms. This is especially true for the upcoming developments on Electronic Health Record (EHR) architectures, their requirements, their design, their policy details, and their instantiation and implementation strategies.
Citizen involvement and patient empowerment are based on awareness, confidence, and acceptance. An adequate level of awareness can be achieved by the respective level of information, education and training measures. This will lead to confidence with regard to shared care, the new healthcare paradigms but also the health card. With the regular use and based on the patients’ respective behaviour, the level of acceptance is going to grow leading to an even higher level of awareness at the end of the day. Additional applications like the electronic signature, as a first step towards a real multi-application card, can foster these processes.

The more information citizens and patients do have regarding different procedures and processes in healthcare and welfare, the more they are able to significantly play their dedicated role within this partnership. Cards can and will contribute by allowing citizens and patients to get controlled access to administrative and medical data stored either on a card or in the network but also to determine who else shall have access to this data.

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