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ABSTRACT

In this paper we describe a generic model of a patient health portal, which is suitable to implement patient access to the evolving German healthcare telematics infrastructure. The portal uses the telematics as a communication infrastructure to ensure the concise and secure exchange of medical data between professional medical personnel and patients. We aim at providing patients an application platform model for using and enhancing their data by processing or extending them with medical services offered via the internet or with local medical appliances. We show that a) specific functionalities (such as data import/export from/to the telematics) for patient health portals can be derived from the legal foundation in the German law b) the portal is conceptually suited to provide a link between the public health information infrastructure and other (maybe commercial) applications in the e-health environment via Personal Health Records (PHR) and c) patients' rights can be mapped with a common data model.

Keywords

Patient Data, Healthcare Telematics Infrastructure; Electronic Health Record; Telemonitoring; Seamless Healthcare

INTRODUCTION

German health authorities are building a nationwide telematics infrastructure to centralize the storage of health data and harmonize interactions of all actors in the German health system. Universal accessibility of data across the public health system without institutional boundaries aims at reducing healthcare cost by avoidance of redundant examination and administration (Bundesministerium für Gesundheit, 2008). Unified Telematics specifications should ensure high data security standards, a standardized access process and common data formats throughout the national health system (Sunyaev, Leimeister, Schweiger and Krcmar, 2008). Misuse should be avoided by mandatory encryption of health data and role based access rules for health care providers. A major goal of the project is the enforcement of extended patient rights (eGesundheit.nrw, 2008). Since data can only be collected, accessed or processed with the approval of patients, they become strongly involved in many medical processes. This enhances patients' data sovereignty and health knowledge (Sunyaev, Göttlinger, Mauro, Leimeister and Krcmar, 2009; Sunyaev et al., 2008). Consequently personal awareness in health matters increases, which improves individual prevention in many cases (Pawlowski, Gromadecka-Sutkiewicz, Skommer, Paul, Rokossowski, Suchocka and Schantz, 2001). According to the German ministry of health, the quality of public health services correlates directly with the contribution of patients to their electronic health documentation (Bundesministerium für Gesundheit, 2008).

Patients will need a tool, which is suitable for daily use, to play the vital role (i.e. active involvement of patients) in health system intended by the authorities (Heeks, 2006). Till now there is no specification for a dedicated patient access to the telematics infrastructure; we therefore develop a model of a web based portal, which is intended to fulfill this need. It aims at a connected healthcare system without media frictions (Schweiger, Leimeister, Niggemann, Feussner and Krcmar, 2006; Schweiger and Sunyaev, 2007). As patients increasingly seek health information autonomous from the public health sector (Luo, Tang, Yang and Wei, 2008), health portals should be evolved to patient information systems, by making them the patients' hub for medical information collection and documentation as well as for communication and cooperation. It is essential to include patients into the whole picture of future healthcare landscape (Haux, 2005). Patients need the possibility to use their data and process them within additional applications (such as sports training programs (Knebel, Leimeister and Krcmar, 2007) or patient communities), regarding the trend that people are eager to scrutinize their medical records and personal health theories individually (Sillence, Briggs, Harris and Fishwick, 2006).

THE GERMAN HEALTHCARE TELEMATICS INFRASTRUCTURE

In Germany the telematics infrastructure is used as the backbone for the mandatory electronic health card (eHC) system (Fig. 1). This infrastructure, specified by a government controlled institution called gematik, connects existing information systems of care providers via a common network with shared data storage locations (Fraunhofer Institut, 2005). These storage locations provide services; the primary systems (e.g. clinical information systems) of medical institutions can consume them to communicate with other care providers and maintain, review or share medical data objects. A local component, called "Connector", encapsulates all local services as encryption or card access and establishes a secure virtual private network (VPN) connection to the central services if needed (gematik, 2008a). All individual related medical and administrative data uploaded to the central services have to be encrypted, using a hybrid encryption method. A symmetric key, which is only accessible by using the private key of the health smart card owner, is created for every data object. Private keys are located on the smart card chip of the eHC and cannot be extracted from there. Decryption of the access key happens within the microchip of the smart card after authorization with a Personal Identity Number (PIN). Patient can create a new version of the symmetric key, encrypted with the public key of a care provider they want to grant access rights to. Therefore they need to access the health care provider's smart card, the so-called health professional card (HPC), over the local Connector infrastructure, to obtain the desired public key.

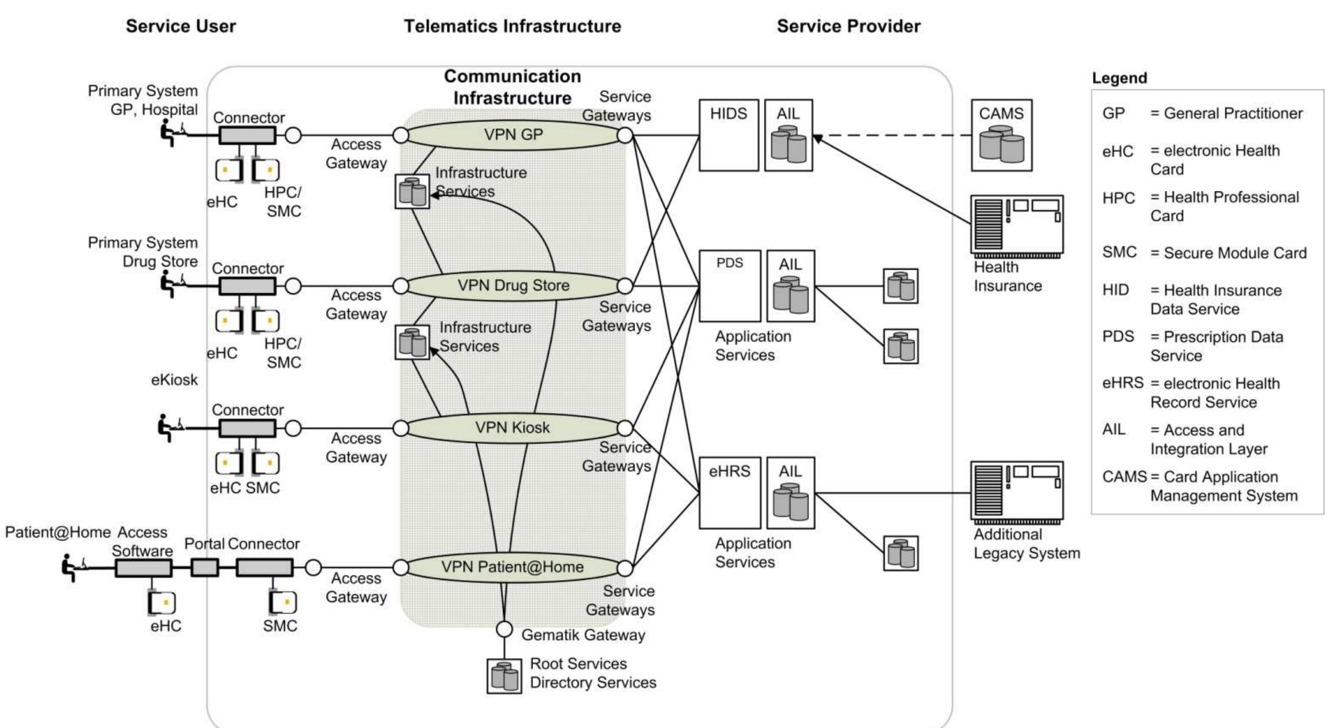

Figure 1. Architecture of the German Health Telematics Infrastructure (gematik, 2008a)

Patients Role in the new German Health Care System

The patient related requirements for the development of the telematics infrastructure are derived from legal terms given in the German code of social law (Bundesrepublik Deutschland, 1988). Following the political goals of achieving high patient involvement to medical processes, patients are in full control of their data. They have to agree on collection, usage and processing of their medical data for each service and care provider, before the services can be used by health care providers. To achieve this, data is at first only visible to the patient (gematik, 2008a), since it is encrypted with the public key of the owner and therefore just accessible with the private key stored on the patient's smart card. Further it is mandatory that patients can view all their data and a record of its usage. The telematics must additionally support adequate processing of data, which is provided by patients or for them. To ensure that patients can exercise their legally granted rights in the telematics, the gematik suggests three types of patient interfaces. All primary systems using the telematics at the medical sites will have dedicated patient front-ends, implemented via a separate trusted viewer and a card reader. Further shared patient interfaces are provided as Point of Information (POI) terminals set up in hospitals, surgeries or common locations. The initial architecture also suggested an internet-based front end for home usage, called Patient@Home (Fraunhofer Institut, 2005). While the initial architecture suggested to access the infrastructure via a portal and a Connector, with full support of the eHC, the current architecture only indicates an access gateway with support of the eHC (gematik, 2008a). To date (02/2009), no specification is released, the cost analysis for the telematics indicated that the eHC will not be supported (Bernnat, 2006); hence the mandatory patient transactions cannot be supported via this interface. The telematics is currently an isolated system, which on patients' side, can only be accessed from dedicated locations.

Problems of the Current German Telematics Approach

An average physician-patient contact lasts only about 7 minutes (Kurt, 2001), which highlights the difficulties carrying out the authorization, document and audits review within this time span. In the current approach authorization can only be performed, when patients and physicians smart cards are connected via the same connector, which means they are in the same location (gematik, 2008a). Care providers, who have not been in contact with a patient, cannot view encrypted medical data, unless the patient physically visits their facility to grant usage rights on the addressee's system. This requires extra visits in case the physician needs time to review the medical documentation before the treatment can be started. Online pharmacies are not usable with this approach either, since the patient's smart card needs to be present for the pharmacy to decrypt the prescription. Therefore there is a need to build a fully fledged patient access to the telematics, allowing patients to perform all transactions without additional efforts from home, as announced in the specification (gematik, 2008d). This helps to overcome the described problems and achieve the information logistics principle, according to which the right information needs to be provided at the right point of time, in the right quantity, at the right location, and in the right quality (Augustin, 1990).

HEALTH PORTALS AS PATIENT INTERFACES

E-health is driven by patients (that with their interests push new services even in the healthcare field, mostly for their empowerment through access to information and knowledge (Della Mea, 2001)) and stands for the application of Information and Communication Technologies (ICT) across the whole range of functions that affect the health sector (Europäische Union, 2008). A paradigm shift leads towards patient centered healthcare (Bobel, Norgall and Pharow, 2006), consequently patients should be engaged in relevant fields of health related ICT. Therefore Patient Information Systems generally need to enable access to the most important technologies, supporting individual prevention and information retrieval, as patients are the central focus of future e-health landscape. To achieve a centralized access, we evaluate a portal as a central application from where all e-health services are accessible and adequately conditioned to support patients' decisions and data handling (Moon and Burstein, 2005). Much functionality as document management, browsing, navigation, a directory service for authorization, search engines, personalization and internet communities can be implemented into medical portals (Tushkar, 2000).

Due to the missing definition for patient health portal's architectures, suitable to match all the demands of the German healthcare environment, the paper derives a formal definition from a general portal definition as given in (Fraunhofer-Institut für Arbeitswirtschaft und Organisation, 2004) and extends it for the main purposes of the healthcare usage. Therewith, a patient health portal describes a generic application platform from which a patient can access the telematics with its data objects and can execute all patient related processes. Further health services and applications, which are offered outside the boundaries of the telematics, can be accessed, either as web services or local interfaces at the client side. The portal, as a combination of telematics and integrated health service modules, builds a patient information system, which has to ensure semantic and syntactic interoperability with primary systems of health care providers over the telematics infrastructure. The user interface displays the processes of the heterogeneous applications and provides all the handling for all patient processes.

Fig. 2 includes the major trends Home Health Monitoring, Personal Health Records, E-Prescribing and Health Monitoring Tools from the Gartner medical hype cycle 2007(Runyon, 2007), which are relevant to patients and prove to deliver added value (AHIP, 2008; Leimeister, Krcmar, Horsch and Kuhn, 2005; The Boston Consulting Group, 2001) into a model, implementing the previous health portal definition. Regarding the correlation of declining trust in the medical system (Wendt, 2007), the growing percentage of internet users (BITKOM, 2007) and the developing e-health environment, e-health applications are likely to gain importance in Germany quickly (Bagchi, Udo and Kesh, 2005). Patient health portals might contribute to a) more intensive integration of patients in medical treatment processes (Schweiger et al., 2007) b) communication and collaboration of patients in the form of communities (Leimeister and Krcmar, 2005), ideally building up confidence between patients and/or provider with the aid of trust-supporting components (Leimeister, Ebner and Krcmar, 2005). E-health services are often available globally, while telematics mostly covers national healthcare ICT. This approach is a first step in linking e-health services with national telematics to connect the field of public services with commercial e-health offers to allow portals to implement processes of both fields.

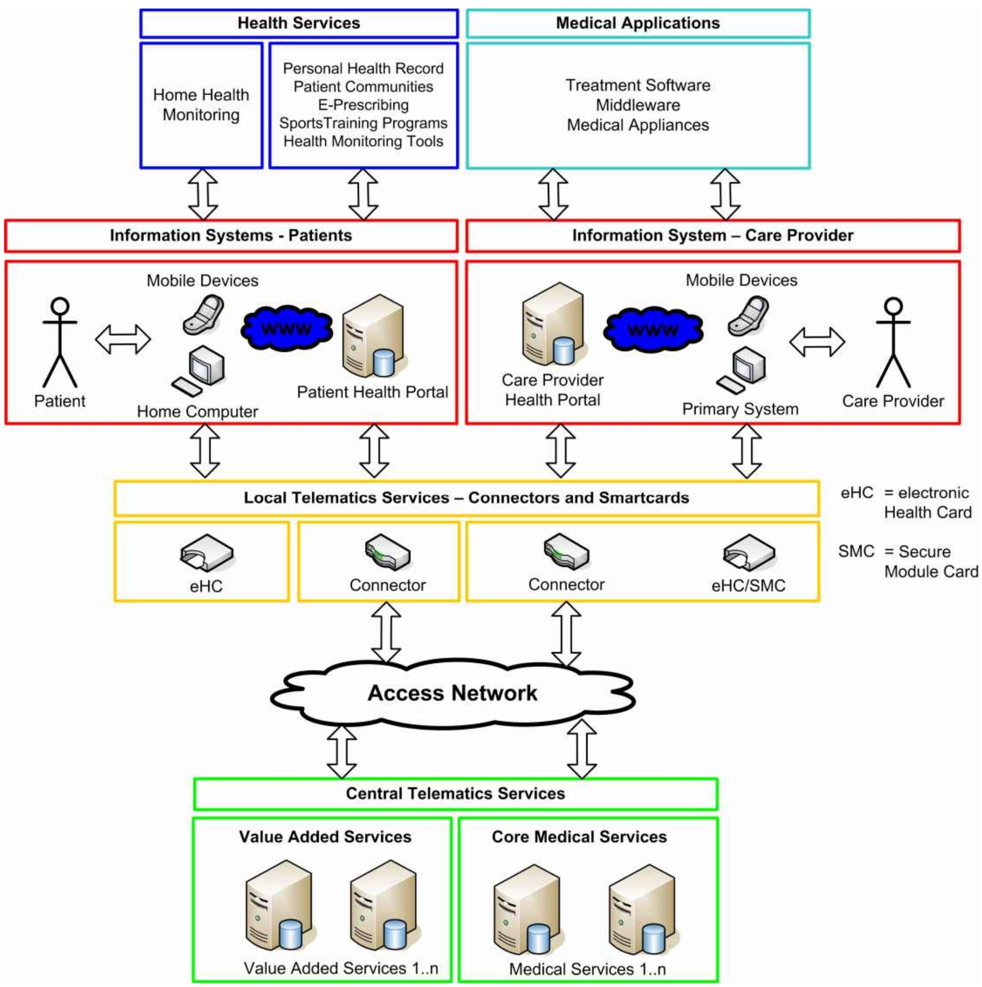

Figure 2. Integration of Telematics with other e-health Technologies via Portals

REQUIREMENTS ELICITATION AND ANALYSIS

Functional Requirements

The definitions for patients' role in medical processes in the German code of social law lead to mandatory functional requirements for nationwide telematics. Using the given legal conditions, every usage right patients have on their medical data can be seen as a usage scenario. To achieve minimal functional requirements, which can guarantee a complete administration process compliant with German law, all usage scenarios can be converted into use cases. These can be extended and implemented by health portal providers, following a common software development approach as given in (Brügge and Dutoit, 2007). The use cases in figure 3 can be refined to an analysis- and system model for implementation. Further functional requirements result from the authorities' specifications, which requires e.g. role based authorization and granting of long term access rights for professions. The following use cases can be derived directly from the German code of social law and the current specification of the gematik. They should be generally valid for all medical services in the e-health environment, when patients are intended to receive full control right for their data and an exchange of medical data objects should be possible between the public health sector and the patient. All use cases are defined generically to guarantee that they can be transferred to newly offered health-services in the telematics without redefinition. Nonfunctional constraints result from the technical architecture of the base ICT-Infrastructure. The minimum functional requirements can be extended later when modeling the process in order to offer a higher level of details or add functions, specific to a certain service.

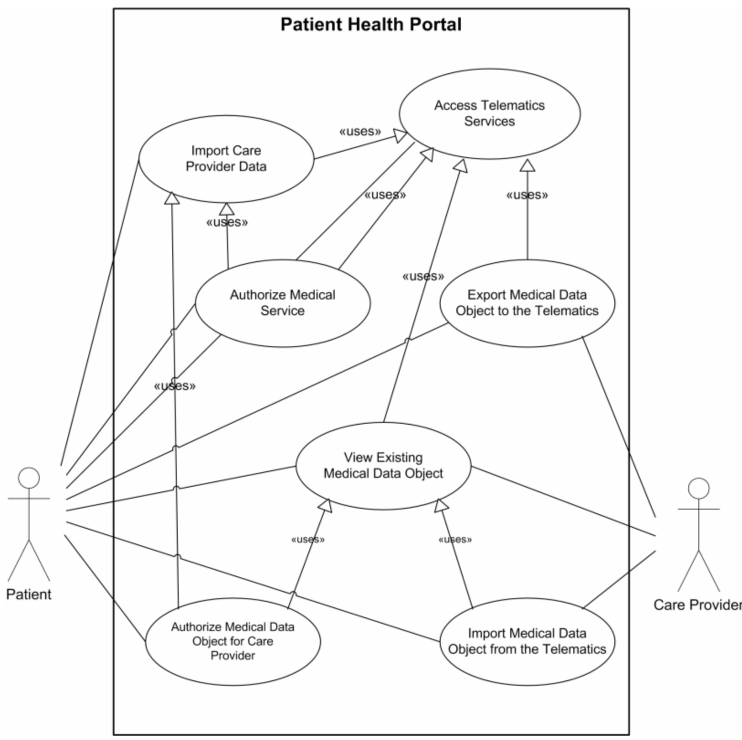

Figure 3. Mandatory Telematics Related Use-Cases for Patient Health Portals

Non-functional Requirements

Non functional requirements result mainly from the definition of personal health portals and the existing gematik specifications. As the portal should be accessible with standard web-technology all transactions need to be executable from a standard web browser. Further the usage of a common smart card reader must be supported, as well as a connection to medical appliances and web services for processing of medical data. Further certain standards, as the HON Code (Health on the net foundation, 1995), must ensure that the application is a trustable medical platform. For security standards the guidelines for care providers systems should be carried over to portals to ensure minimum data security (gematik, 2008c).

IMPLICATIONS FOR THE EXTENSION OF THE TELEMATICS SPECIFICATIONS

At first, there is a need for a clear statement on whether the access Patient@Home to the telematics will be realized as suggested in the first architecture specification (Fraunhofer Institut, 2005). Further it is important to define which parts of health portals have to follow a committing guideline purported by the gematik specification and which parts can be freely designed by the implementing party. The authorities have to define compliancy conditions, as they have done for systems of medical care providers (gematik, 2008c), to evaluate whether the portals can be approved to function as a patient administration tool for the eHC. All service consumer systems are currently not part of the telematics specification (gematik, 2008d). To guarantee that portals can be implemented to fulfill all mandatory requirements and consequently implement all use cases, the telematics has to offer the necessary services to build a data model supporting the patients' transactions.

Syntactic and semantic interoperability have to ensure that content can be processed and viewed on both, primary systems in the public health service and the patient portals equally. This is a necessity to fulfill the requirement of importing and exporting data from the health portal to the telematics. Hence the data formats to be stored on the telematics servers must be defined and limited by the authorities. To date there are XML-Schemes and XSLT-Stylesheets (Extensible Stylesheet Language Transformation) for most medical services of the telematics, documents can be created and displayed according to a common standard (Warda and Noelle, 2003). Using common standards as Health Level 7 Clinical Document Architecture (HL7 CDA) ensures that data processed within the telematics can also be used by patients outside the system boundaries of the telematics e.g. in a PHR (Bobel, 2008; Waegemann, 1999). Common documents should be wrapped in those formats when provided by patients to care providers via the telematics infrastructure. Access mechanisms to the telematics have to be adapted to ensure that patients can access their data and use all the services according to the basic requirements (Warda et al., 2003). This can be achieved by adjusting the local access components and providing a functioning smart card terminal for the usage within multi user portals. Administrative, medical and value added services have to be extended that portals can use all relevant data and services. These are reference data, access rights for data objects and services, certificates of the care providers, audit records and the service directory.

ELECTRONIC HEALTH RECORDS

Since electronic medical records (EMR) are a key factor in the concept of centralized health data storage (Kim, Feng, Cai and Eberl, 2001), various types of EMR must be integrated into the concept of patient portals. The portal is supposed to work as the data exchange link between the EMR maintained in the public health system and those maintained by patients. The specification defines two kinds of health records within the telematics, the electronic patient record (EPR), a universal set of medical documents, and the electronic case record (ECR), a context oriented selection of data for specific care providers as medical specialists. Both are maintained by physicians and controlled by patients (gematik, 2008b).

The concept of the patient maintained PHR needs to be included into the formal application landscape to achieve the highest level of EMR, as defined by Waegemann (Waegemann, 1999), the Electronic Health Record (EHR), a record which contains livelong medical information of a patient. It is maintained by both, patients and health care providers. To achieve this level of medical documentation, it has to offer the transformation of data between all primary systems, the medical services of the telematics and the PHR. Patients must have the possibility to add personally generated data to the telematics. Data from storage location within the telematics must be transferable to the PHR and to various ECR (Fig. 5).

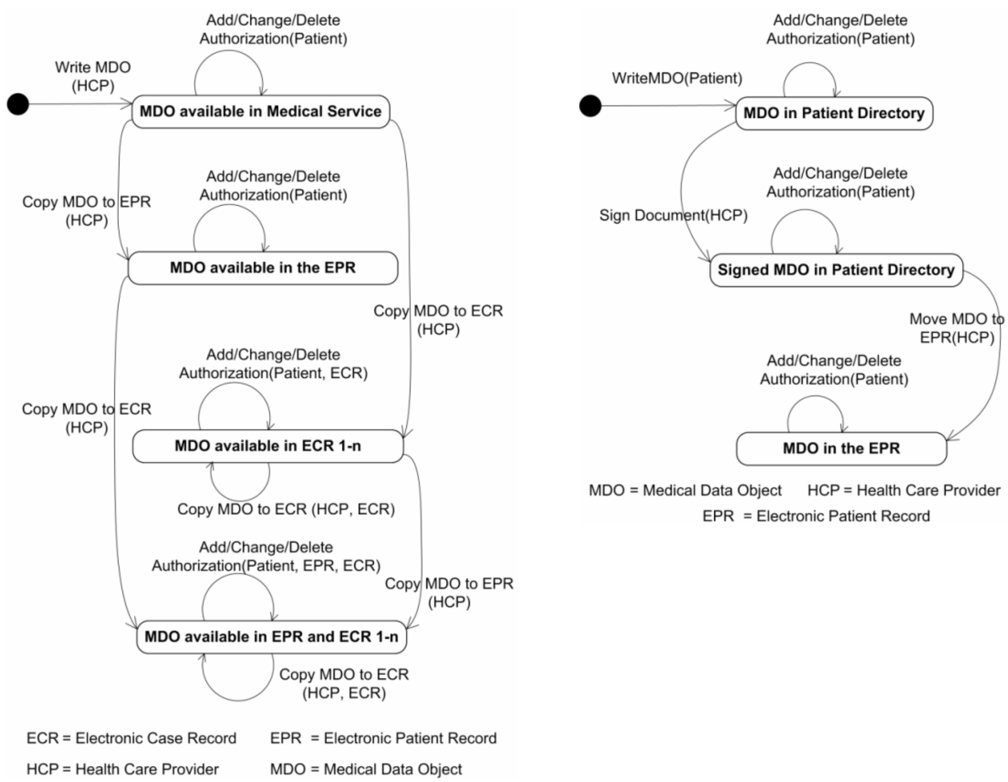

Figure 4. Adding Patients' Data to the Telematics and copying Medical Data Objects between Health Records

The patient directory is a concept, which is currently mentioned in the goals of the eHC as an exchange service for medical data objects (MDO) between physicians and patients. Location of the data and the data itself must be prepared in a well arranged way to ensure interoperability (Warda et al., 2003). As a result, the services in the telematics but the exchange directory would only contain medical data, reviewed or created by physicians. Data which is uploaded by patients to the patient directory can be published in telematics health records by digital signature of qualified medical personnel. This ensures that all data within the telematics is reviewed by appropriate health care providers and therewith suitable for further processing in the public healthcare service.

ANALYSIS MODEL

In the integration scenario an analysis model is created, which implements the requirements based on the specification extension. With a patient related specification extension, it is possible to build up a generic data and usage model valid for all medical services. The data model results from the mapping of the created interfaces, provided by the telematics to data entities of the portal. The interfaces were derived from physician related interfaces for medical services in the specification (gematik, 2008b). Authorizations achieved by the creation of Service- and ObjectTickets for care providers allowing process creation without requiring patients' presence.

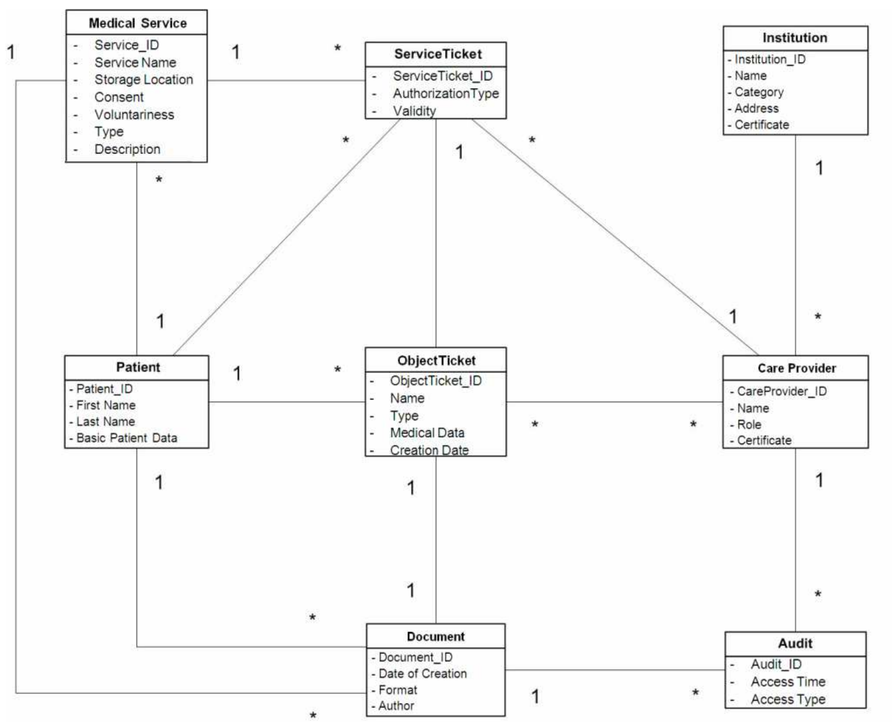

Figure 5. Data Model implementing legal Requirements for Patient Transactions

Whether the data model is written to a database or just created temporally and held for one access session is not relevant at first. In the portal data can be visualized in various ways in order to ease the handling of the processes and the access for patients. In the long term it should be possible to process data in the portal from various data sources or move it automated between them. Patient data and information can be feed from the central server directly back to the individual patient's home, as suggested in (Stroetmann, Pieper and Stroetmann, 2003).

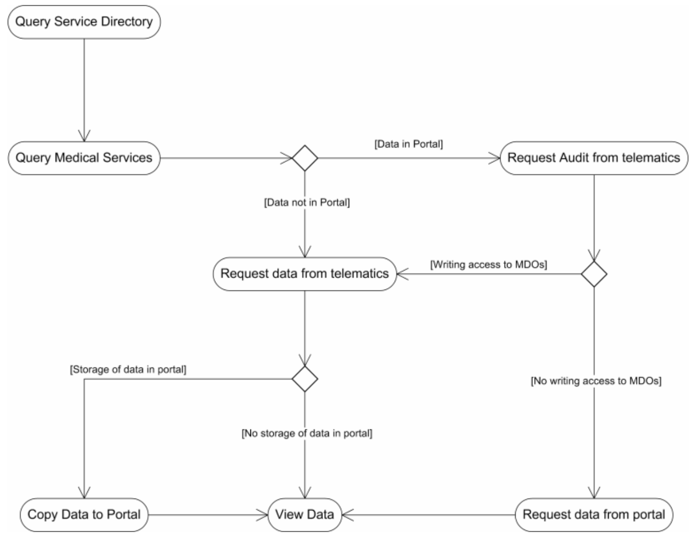

Figure 6. Synchronization Model for displaying Medical Data Objects

This could fulfill the desired elimination of redundant copies of data objects (Raghupathi and Tan, 2002). Patients as the owner of all medical documentation are the only user authorized to move data accordingly. This is done by the portal under his/her supervision. Transfer of big data objects, as X-Ray images; create huge data volume, hence redundant traffic should be avoided. An interaction between the telematics and the PHR, the lifelong documentation of a patient's health, would be considerable in this context. To reduce traffic between the telematics and the portals, data objects should not be transferred each time they are accessed, unless they have been altered. Data which is present in the PHR could just be compared with the state in the telematics by comparing the audit record. Patients could therefore hold data in their PHR, which is relevant to them; only additional data elements have to be transferred from the telematics to the portal. Coexistence of a PHR and data in the telematics infrastructure could be synchronized by the audit records (Fig. 5); the location of the data would not be a point of interest for the patient any longer. Patients can select data from the universe of information which is particularly relevant for them and access the data any time they want (Stroetmann et al., 2003). Since there is only one central access via the web interface anyway, data could be sourced according to security, performance and author criteria into a single web-based interface.

CONCLUSION

The future e-health environment will be patient-driven and consist of ICT across the whole range of functions that affect the health sector. Regarding the paradigm changes towards seamless and patient centered healthcare, health services have to be linked at the patients' side. Even though the use of portals in healthcare is disputed and security concerns are likely to be considerable (Glenton, Paulsen and Oxman, 2005), an integrated portal-concept for the telematics should be subject of further evaluation. It could theoretically puts patients in the center of the e-health environment and link telematics and commercial health services to implement processes for patients, accessible from one centralized access point. A telematics infrastructure, set up by national health authorities, can enforce standards in terms of data security, data formats as well as for communication and access processes by compliance conditions for vendors. Patients can then handle data from the public health sector as well as personal data to be processed in publicly implemented services as PHR.

By defining and implementing typical usage scenarios for patients, the mandatory part of patients' usage can be mapped as a universal model, based on the rights patients receive in the healthcare service and the technical constraints of the infrastructure. This can be implemented and offered as a part of a comprehensive e-health application, when the specification allows an appropriate access to the services. Related business models in this context could significantly differ from those of traditional health portals, as they are utilizable for more people. The systems should not be limited to the legal requirements of patient interaction but be extendable for future innovations in the e-health area. The patient access can be integrated into a holistic e-health concept. The patient health portal provides the application platform, which coordinates the different processes, holds a user relevant set of health data and provides a unified access. Opening the market for patient information systems by defining patient access conditions for system builders can help to close this gap and leverage innovations in the area of patient oriented information technology (Kuhn, Wurst, Bott and Giuse, 2006).

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