An electronic health record to support patients and institutions of the health care system

Eine elektronische Gesundheitsakte zur Unterstützung von Patienten und Institutionen des Gesundheitswesens

Abstract

The department of Medical Informatics of the University Hospital Münster and the Gesakon GmbH (an university offspring) initiated the cooperative development of an electronic health record (EHR) called "akteonline.de" in 2000. From 2001 onwards several clinics of the university hospital have already offered this EHR (within pilot projects) as an additional service to selected subsets of their patients. Based on the experiences of those pilot projects the system architecture and the basic data model underwent several evolutionary enhancements, e.g. implementations of electronic interfaces to other clinical systems (considering for example data interchange methods like the Clinical Document Architecture - standardized within the HL7 group - and also interfacing architectures of German GP systems, such as VCS and D2D). "akteonline.de" in its current structure supports patients as well as health care professionals and aims at providing a collaborative health information system which perfectly supports the clinical workflow even across institutional boundaries and including the patient himself. Since such an EHR needs to strictly fulfill high data security and data protection requirements, a complex authorization and access control component has been included. Furthermore the EHR data are encrypted within the database itself and during their transfer across the internet.

Zusammenfassung

Im Jahr 2000 initiierten das Institut für Medizinische Informatik und Biomathematik der Universität Münster und die Gesakon GmbH ein Kooperationsprojekt zur gemeinschaftlichen Entwicklung einer Elektronischen Gesundheitsakte (EGA), genannt „akteonline.de“. Seit 2001 wurde diese EGA bereits von verschiedenen Kliniken des Universitätsklinikums Münster bestimmten Zielgruppen aus ihrem Patientengut als zusätzlicher Service im Rahmen verschiedener Pilotprojekte angeboten. Aufbauend auf den Erfahrungen dieser Pilotprojekte wurden die zugrunde liegende Systemarchitektur und das Datenmodell mehreren evolutionären Weiterentwicklungen unterworfen. Unter anderem gehörte dazu das Design von Schnittstellen zu anderen medizinischen Informationssystemen (hierfür wurden sowohl der von der HL7-Gruppe definierte Standard der „Clinical Document Architecture (CDA)“ als auch die in deutschen Arztpraxissystemen vielfach schon etablierten Lösungen wie VCS und D2D berücksichtigt). "akteonline.de" unterstützt zurzeit sowohl Patienten als auch Gesundheitsbetreuer und hat es sich zum Ziel gesetzt, als „collaborative health information system“ diagnostische und therapeutische Prozesse auch sektorübergreifend und selbst den Patienten unmittelbar einbeziehend zu unterstützen. Aufgrund der hohen Sensibilität der in einer solchen EGA zu speichernden Patientendaten wurde eine umfangreiche Autorisierungs- und Zugriffregelungskomponente implementiert. Zusätzlich werden die Daten der EGA sowohl während ihres Transports über öffentliche Netze als auch in der Datenbank selbst verschlüsselt.
Introduction

Today efficiency, productivity, and quality of healthcare institutions depend very much on the information technology which is applied in the patient care process. As mentioned by Itkonen and in similar words by many other authors "The future of information technology is about developing new relationships between health care practitioners and patients. Information technology programs must work collaboratively with doctors to develop new ways of delivering health care that overcome the deficiencies that have beset the traditional doctor-patient relationship."[1]
The value of empowered patients having at least partial access to their own medical data is already known to and proven in the literature [2], [3]. As an example one can think of the patient's better understanding of his health condition with all the concluding advantages [4].
The potential advantage of a secure and transparent connection between information systems in hospitals, doctor's practices, pharmacies and other health care provider sites is overwhelming. However, most of the existing projects to establish such integrated networks still neglect the patient's right to be an empowered partner in all his care decisions and to control the communication of his medical record (or parts of it) between his health care providers. In our opinion, an electronic health record (EHR) in the possession of the patient with free definable levels of access authorizations to the EHR contents will enhance the patient's role in the care process and offer new opportunities of networking and electronic data interchange between his health care providers. Therefore the objectives of the EHR akteonline.de are:

- to give the patient the possibility to manage his own medical data electronically,
- to support the management of those data via internet independent from time and place,
- to incorporate data from different medical applications and systems (e.g. Hospital Information Systems, General Practitioner Systems) automatically and integrate them into one personal health record,
- to make personalised health care information available to the patient,
- to serve as a medium for the communication of health care information between health care professionals, and finally
- to support preventive medical treatment through integrated reminder functions, which can be a basis for advanced disease management.

The advantages of an electronic health record directly depend on its capabilities to bring together data, manually entered by a patient, with the scattered pieces of information (or an aggregated epicrisis of those data) in other electronic systems. As an example, it is highly desirable that a patient can integrate his referral letter and his blood values into his EHR directly after a hospital stay without any additional manual efforts.

While electronic communication within the hospital, e.g. between departments, is largely solved based on HL7 ("Health Level Seven") messages, electronic communication between hospitals, outpatient clinics and general practitioners is still an open problem (at least in Germany). The main reason for this seems to be heterogeneous approaches and system architectures which are pursued by vendors of hospital information systems on one side and general practitioner (GP) system vendors on the other side. No reliable standard has been established yet for exchanging structured information between such systems. Diverging communication standards between German ambulatory care environments ("xDT" comprising message types such as LDT ("LaborDaten-Träger", laboratory data carrier), ADT ("AbrechnungsDaten-Träger", accounting data carrier) or BDT ("Behandlungs-DatenTräger", treatment data carrier)) and German hospital environments where mostly HL7 is used form a considerable barrier which must be overcome. In order to solve such cross-sectoral communication problems the German project "Standardized Communication of Information Systems in Physician Offices and Hospitals using XML" (SCIPHOX) [7] has applied the "Clinical Document Architecture" (CDA) [8], developed by the HL7 group [9] and based on XML [10], [11], as a promising new approach for structuring and exchanging medical data between institutions. In our opinion it offers an ideal way for spanning bridges between institutional information systems and the personal EHR of a patient.

Materials and methods

According to the above described goals which were pursued with the development of akteonline.de its functionality is much more comprehensive than other EHR implementations, especially in the US [12]. Beyond its basic functionality to provide a web-based user interface for the empowered citizen to access his internet-based personal electronic health record, it has been designed from the beginning to include additional functionality, to increase the benefits and usability for the patient.

The EHR contents

The contents of the EHR comprises basic demographic data, a record of all outpatient and inpatient visits, diagnostic findings (including also radiology images), diagnoses and performed procedures, a lifelong medication record, personal risk data (e.g. allergies), vaccinations, and clinical referral letters. Figure 1 shows an exemplary
Figure 1: View of a patient's medication record in akteonline.de. Context sensitive links like the shown "search in several internet search engines" to access further drug information for a selected drug have been established.

Figure 2: Detailed view of a multimedia data object (in this example DICOM radiology images) with thumbnail preview within akteonline.de.

dscreenshot of a citizen's medication record. Figure 2 illustrates the capabilities to include multimedia objects such as radiology images in various image formats.

Patient information

As additional service information for users as well as health care professionals a medical knowledgebase with medical information on clinical topics has been included, focusing on the specific diseases (e.g. breast cancer, leukaemia) which our pilot projects have focused on. Further to the medical information directly included within akteonline.de, links have also been established to relevant internet based information resources (e.g. a link to drug information systems which is directly integrated within the drug data entry form; compare Figure 1).

Supporting preventive care

The concept of akteonline.de has been extended to include not only "passive knowledge sources", but to provide active reminder functions. Such reminder functions can inform a citizen about necessary vaccination dates or remind him to follow-up visits, e.g. in case of chronic diseases.

Integration with other clinical information systems

One of the most important steps during the development of akteonline.de was to provide additional ways to enter clinical data not only manually by using web-based data entry forms. A patient would not accept, that a referral letter which is electronically created within a hospital information system can not be automatically transferred into his EHR after his discharge from a hospital. Therefore it was a major issue to establish standardized and open interfaces to integrate data from the hospital information system (HIS) of the University Hospital of Muenster. The HIS possesses an extensive programming interface to design new forms and to link external application components. This features have been applied to define an electronic form within the HIS environment for the creation of a referral letter which gathers most of the needed data, like personal data, lab results and other examination
results, diagnoses and procedures, from the HIS database itself.

In addition an external process has been implemented which may be initiated by the HIS from within the referral letter module. This process receives the contents of the letter and converts it into a CDA based XML-structure (Figure 3).

A CDA document is typically made of a header, which contains general standardized information about the document (e.g. the actors like the physician, the patient, and the institution), and the body, in which the detailed information is included in a structured form. In the current CDA specification unfortunately the granularity of structured information is not yet detailed enough to extract structured parts of a letter, such as diagnoses, procedures, or recommended future therapy in full detail.

If the respective patient possesses an electronic health record account within akteonline.de, a third process establishes an upload link to the EHR and imports the referral letter. In another project the same conceptual approach has been applied to import clinical documents in CDA format also into a GP system [13].

Security and authorization

Data encryption, secure authorization, and comprehensive, but flexible access regulations are basic requirements when such an EHR shall be used as an internet-based system. Therefore much effort has been put into this area. The complete security and access model has been published in an earlier paper [14]. Here we will only emphasize some major issues which have been tackled during the design of akteonline.de.

In theory, every citizen can open an akteonline.de account in order to create his/her personal electronic health record. Since the majority of akteonline.de pilot projects are centered on juveniles, children, babies, and newborns (these patients typically do not have the necessary knowledge and may be too young to manage an own EHR), a deputy model has been implemented, where every user can define one or more deputies, who have full access rights to maintain the EHR instead of the original record owner.

Health care providers may be defined as "users" within akteonline.de. They do, however, not possess an own record. Instead every patient can define access rights (on his/ her whole personal record as well as on selected sub-items) for such a health care provider, either on a permanent basis or for a single access.

Authentication for one-time access to a patient's record is established using "transaction numbers" (TAN), similar to online banking methods.

As an important difference to online banking, the owner of an EHR can himself define a one time access profile
Figure 4: TANs can be generated and printed from the "settings menu" of akteonline.de. Predefined access profiles are associated which each TAN.

(selecting the type of access, e.g. read or write, and the data subset of his record to which he wants to provide this access) and then generate an associated TAN (Figure 4). He may then choose to print this TAN and hand it to a health care provider during his next visit. This healthcare provider may use the TAN for one single access to EHR where he may just perform exactly the type of access which has been previously defined by the record owner. Thus the patient himself has the full control over the access to his/her personal record. Such a TAN can also be used as a one time key for the automated upload of electronically created documents, as described in the previous section.

Results

At the moment there are documents for exchanging lab results and referral letters on the basis of the CDA in routine use.

The lab device sends its data as HL7 messages to the HIS and a staff member can send the lab results encrypted over the internet from the HIS to the EHR (Figure 5, Figure 6). As usual for CDA documents, also the acting persons and the institution are embedded. The document is signed on receiving and akteonline.de prevents changing of the document in the future.

This feature is heavily used between the department of pediatric oncology and several of its juvenile patients. The physician in hospital as well as the general practitioner involved in the treatment of those patients can add laboratory data to the patient record when needed. Inside the hospital this is merely a click on a "send to EHR" button inside the regular lab report form, in GP practice it is mostly done via web access using a TAN number provided by the patient's parents. The clinical advantage is now that inpatient lab data as well as outpatient lab data, especially hemoglobin, hematocrit, and platelet count are available in continuous follow-up at a glance. Together with his GP and the responsible physician in the hospital the patient respectively his parents may look at those data and decide if the time for an additional chemotherapy, which is heavily dependent on those values (especially the platelet count must be within certain ranges), has come. Unnecessary visits in the hospital may thus be avoided.

So far a few hundred lab reports for hundred pediatric oncology patients have been stored. Thorough evaluation of the effects is planned.

The writing of a short referral letter within the HIS enables the integration with already existing data. The staff is able to automatically generate a CDA document from it and send it securely over the internet to the EHR of the corresponding patient (Figure 7, Figure 8).

The medical information in the documents can be automatically linked with further information for the patient and/or the next viewing healthcare professional (HCP). Furthermore a search in several internet search machines, like shown in Figure 1, can be triggered by the user.
Figure 5: Screenshot 1 illustrating the exchange of lab results from the HIS to the EHR

Figure 6: Screenshot 2 illustrating the exchange of lab results from the HIS to the EHR
Figure 7: Screenshot 1 illustrating the exchange of referral letters between the HIS and the EHR

Figure 8: Screenshot 2 illustrating the exchange of referral letters between the HIS and the EHR
Discussion

Discussion of technical issues

The department of Medical Informatics of the University Hospital Münster and the Gesakon GmbH (an university offspring) have established a working EHR which has proven its value. One of the specific features of our approach is the seamless integration between clinical information systems and the EHR based upon CDA as a method for structured data exchange. The described methods allow a CDA compatible exchange of structured data. For clinical staff the solution has been fully integrated into the normal workflow e.g. of lab data review or writing discharge letters. CDA has proven to be a suitable and flexible standard for the exchange of structured medical data. In principle, all content of a HIS can be mapped into CDA documents and could be exported. In contrast to the exchange of unstructured documents (e.g. PDF-files) the CDA documents can be machine processed at the receiving side. Speaking of the referral letters, in akteonline.de the diagnoses, the procedures and the medications can be extracted and may be used to trigger different actions. However, so far the actual CDA specification provide not yet sufficient granularity of information and they are not sufficiently adapted to the German health system. The SCIPHOX project [7] is developing several CDA conform extensions e.g. for diagnoses, insurance information and lab results, which helped us to overcome some of those barriers.

An EHR standing alone in the space of telemedicine does not make sense. "The consumer-driven products and services provided via the Internet are a potentially important and beneficial complement of traditional health services. They affect the health consumer-provider roles and require changes in healthcare practices" [5]. In Germany there are the communication methods called VCS (VDAP Communication Standard, VDAP = Verband Deutscher Arztpraxis-Softwarehersteller e.V.) [15] and D2D (Doctor-To-Doctor) [16] in routine use. They handle communication on a more technical level and can be expanded to exchange CDA documents. In this context, the EHR akteonline.de fits into the scenery very well, because both methods can be well combined with internet based technology.

Discussion of influence on patients and doctors

For the patient several advantages can be achieved with the help of an easy and modular expandable EHR with secure access management and extensive functions. They include

- evading unnecessary double examinations,
- offering personalized health information depending on the medical condition,
- retrieving high quality and reliable medical information in its proper context from web resources.

For the HCP the advantages are even more numerous. They include

- evaluating anonymously (with the permission of the patient),
- reducing the rate of ineffective therapies and therefore saving time and money,
- reducing information loss through more efficient cross-institutional diagnostics and therapies,
- offering a cheap and innovative service to the patient (or "customer" in this case), and
- offering personalized health information depending on the actual medical conditions of the patient.

Many scientists already have evaluated the value of an empowered patient with access to his own medical data [2], [3]. Cimino and colleges for example reported a study, where patients and their caring physicians are concluding, that their communication and the compliance of the patient have been improved [4]. On the other hand, Kim and Johnson tested the functionality of eleven American EHRs and came to the conclusion that all of these only offered very limited functionality [12].

In comparison the akteonline.de EHR makes a difference because it does include additional value for the patient and the healthcare professional. The additional patient information materials within akteonline.de are helpful for the patient and for the HCPs dealing with rare diseases. The integration of such a system into the clinical workflow is an essential prerequisite for its use. Only then such a system is accepted and grows the potential to change the role of the patient.

An EHR with enhanced functionality such as akteonline.de will play a growing role for patient education and maybe even influence outcome: Goldsmith et al. cite for an EHR "which demonstrated that web based education used by patients at a time that was most convenient and relevant to them would in fact improve their clinical outcomes. Clinicians [...] agreed that educational support for patients was a major benefit of an Internet based support system" [17].

The work of HCPs may also be influenced positively. In a review from Treweek et al., computer generated patient information had shown such positive effects [18]. For clinical trials and therapy optimising studies with the subject of rare diseases or within disease management programs, the EHR can be a valuable resource for patient entered data.

Conclusions

An EHR offering an access management system is not only of value for chronically ill patients. Through improve of communication, it also can save money. The first evaluation results show a positive attitude of the patients towards their own EHR. Now it is time to evaluate the at-
titude of the HCPs towards the EHR and the patient's use of it. Also the tool has to be presented and brought into action within health networks, networks of rare diseases and other fields. The CDA showed itself as a suitable tool for structuring and communicating medical information between different IT-systems.

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