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Empowerment of patients and communication with health care professionals through an electronic health record

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Summary *Objective:* The aim of this project was to design and develop a personal electronic health record (EHR) in order to support patient empowerment and additionally to enhance their communication and information exchange with health professionals through this EHR. *Method:* The functionality of a personal Electronic Healthcare Record (EHR) may vary from a simple web-based interface for interactive data entry and data review up to a much more powerful system additionally supporting electronic data/document communication between clinical information systems of primary care practitioners or hospitals and even reminder based support for the empowered citizen, to actively take care of his health, based on relevant disease management programs. It is one means to support patient empowerment, additionally supported by tools for building a patient community. Since storage and communication of data in an EHR comprises sensible personal health data, each of those functions needs specific security and access management requirements to be considered and implemented. *Result:* Clinical pilot projects are already done or under development.

1. Introduction

At present the improvement of communication between different institutions of the Public Health Service (e.g. between outpatient and Hospital departments and even between physicians and patients) is the research focus of many projects. Effective and continuous patient-care and management of therapy spread over several institutions need communication relating to patient data between these institutions and sometimes even the integration of such data. As illustrated for example by Kuhn and Giuse [1] the shift of healthcare

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organizations towards integrated care and integrated healthcare networks provides new challenges for the development of health information systems.

Many of the telemedicine systems being currently implemented aim at faster and more extensive communication of patient data across institutional borders. Others extend their focus towards the challenge of really integrating patient data within electronic patient records. Different steps of integration were described by Waegemann [2]. He mentioned at first the *automated medical record*, *computerized medical record* and *electronic medical record* as different stages of automation within one health institution. On top of that *electronic patient records* play their role by extending the record integration across the borders of institutions. The last step, the so called *electronic health record*, further includes the control of a responsible citizen over his or her own medical data including the possibility of reviewing his/her health record over the internet and even adding health data himself.

Examples of projects which try to improve the communication between primary and secondary care as well as among primary care physicians have been reported by Heitmann et al. [3], Hellmann [4] and Moorman et al. [5]. Even though the process of newly defining the doctor–patient-relationship started already a few years ago in the US and the UK (see [6–9]), only few projects yet try to empower the citizen himself by giving him the management control over his own record in the meaning of an *electronic health record* as described above (compare [10]).

Ball and Lillis [11] summarize new possibilities arising through internet technologies under the expression *e-health*, and write:

> "With its capacity for inexpensively retrieving information when, where, and how it is needed, the Internet is already transforming the physician/patient encounters. In fact, the word 'patient' is being slowly replaced, at least implicitly, by 'consumer'. As increasing numbers of healthcare consumers demand a more active role in their own care, the two sides of the power scale are edging towards balance".

Even if this new expression of "*electronic health*" is nothing more than a new catchword, the above cited papers at least underline a new process of thinking, which starts new relationships between doctors and patients. It also points out which role the empowered citizen will play in the future of our health system.

While first evaluation results of patients accessing their personal medical records show their willingness to be empowered by such an access, their wish to really "control" their health records still varies [12–14]. Researchers agree in the conclusion that security features need to be flexible and configurable, based on the needs and expectations of users and the actual functionality provided by the EHR [12].

2. Electronic health record *akteonline.de*

In this context, at Muenster University Hospital we have initiated a project to design and develop an EHR already in the year 2000, which has been called *akteonline.de* [15] (which is an artificial German term meaning "medical record online"). The goals of akteonline.de as an electronic health record are

- to give citizens the possibility to be in charge of their own health record electronically,
- to provide access to this record through the internet independent from place and time,
- to present personalized health information online and
- to serve as a medium for sharing selected areas of health information with caregivers (which in the end can be used as a communication between medical professionals, but under control of the concerned patient).

Users of the healthcare record *akteonline.de* are able to store parts of their medical data on a central server system and maintain it over the Internet at every time. The data input and output is supported by modern web technology with prefabricated and easy to use screen forms. Security during the whole process of data handling plays an important role. The data structure is held flexible so it can be extended by new kinds of documentations. As an additional service health- and wellness information are implemented as well as automatic notifications, e.g. reminder for vaccinations or preventive medical checkups and medical follow-up examinations (Fig. 1).

3. Contents

In contrast to many other EHR developments, which limit their current functionalities to a pass-

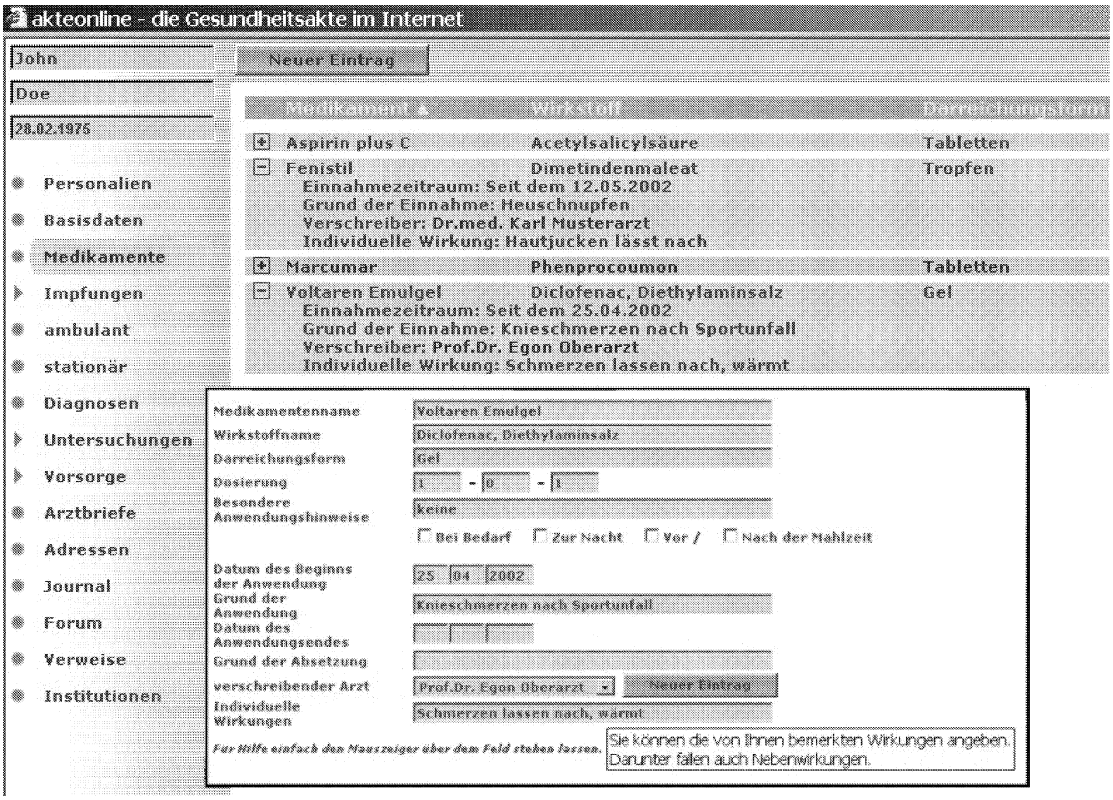

Fig. 1 Montage of two screenshot parts for in- and output of medication data as example for the web interface. The navigation menu is shown in Fig. 2 in English. The right side of the screenshot in the background shows information on various medications like brand name, active substance or instructions for drug application. The screenshot in the foreground shows the form with which the user is able to enter these details.

word protected interactive patient access to their EHR via the Internet [14], the concept of *akteonline.de* considers a much wider approach.

The contents relating to a patient's medical data comprises **personal data**, **general medical data** (e.g. with passport function in case of a chronic disease like Diabetes or special condition like taking anti-coagulation medicine), **medications** (e.g. with stopped medications and reasons for break off), **outpatient data** (e.g. tests, diagnoses, therapies and contact information for every visit to primary physicians or outpatient clinics), **hospital data**, **address lists**, **laboratory reports** (e.g. with reason, place, time and specification of the examination), **vaccinations** (e.g. with automatic notification, consultation for journeys and vaccination calendar), **preventive checkups** and a **personal health journal**. The non-personal data contents comprises **general medical information** and a **forum** (anonymous message board, e.g. with function similar to self-help-groups).

Data which may be derived from other clinical information is automatically calculated. All tabular presentations of medical records subsets can be sorted by time, data type or diagnoses. Many data elements are linked to pop-up windows with more associated information from inside and outside of the record. Data items, which have been invalidated are filed together with the reason for invalidation and can be quickly presented on request. Entering data into the different parts of the health record is mandatory. The user himself decides to which amount he wants to fill his record and which contents are important to him. An example is shown at http://www.akteonline.com.

In accordance with those functionalities, security and access control functions have also been developed on different levels [16].

4. Security

The aspects of security are manifold. Among the technical protections of hard- and software not only the kind of storage and transport of data, but also the internal structures, which allow users to give different levels of authorization to their providers or caring relatives, must be considered.

First of all, on the basic technical level, *akteonline.de* has been split into two different logical

databases which can be established on separated hardware platforms. The first database contains patient identification and demographic data (name, address, etc.) and links it to an internally generated patient ID, but no sensible clinical information. The second contains the actual clinical information, indexed by the patient ID but without any personal data. Not allowed network access to both databases is prevented by a two-level firewall architecture. For the transport of data over the internet SSL-encryption is applied.

5. Access management

5.1. Deputy

The management of the record can be assigned to another user (e.g. a relative) without giving the own personal password away and loosing control or the overall view who made which changes. All activities of the deputy—exactly like anybody else's—are logged and electronically signed, so the owner of the record can understand all the changes of his data. The deputy function makes it a lot easier to integrate minors or seniors, who are not able to use or who are not used to the Internet (Fig. 3).

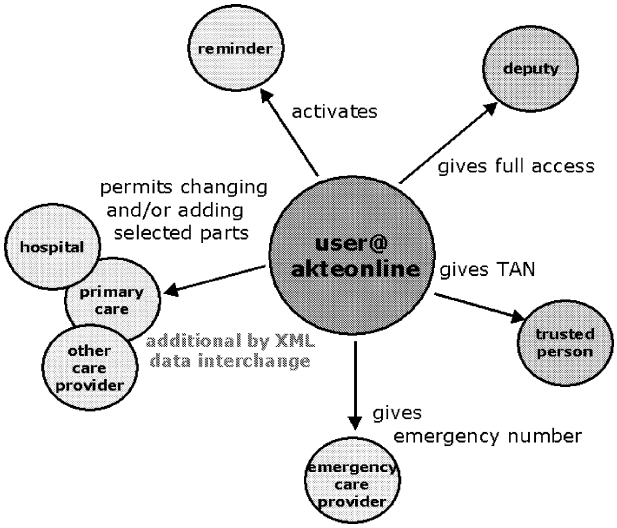

Fig. 3 Overview over the access management.

5.2. One-time access

Reading rights for selected parts of the own or deputy managed records can be granted to each person or institution with access to the internet. For this purpose a collection of identification numbers, similar to the online banking transaction numbers (TAN), may be generated and can be associated with specific access rights. Those iden-

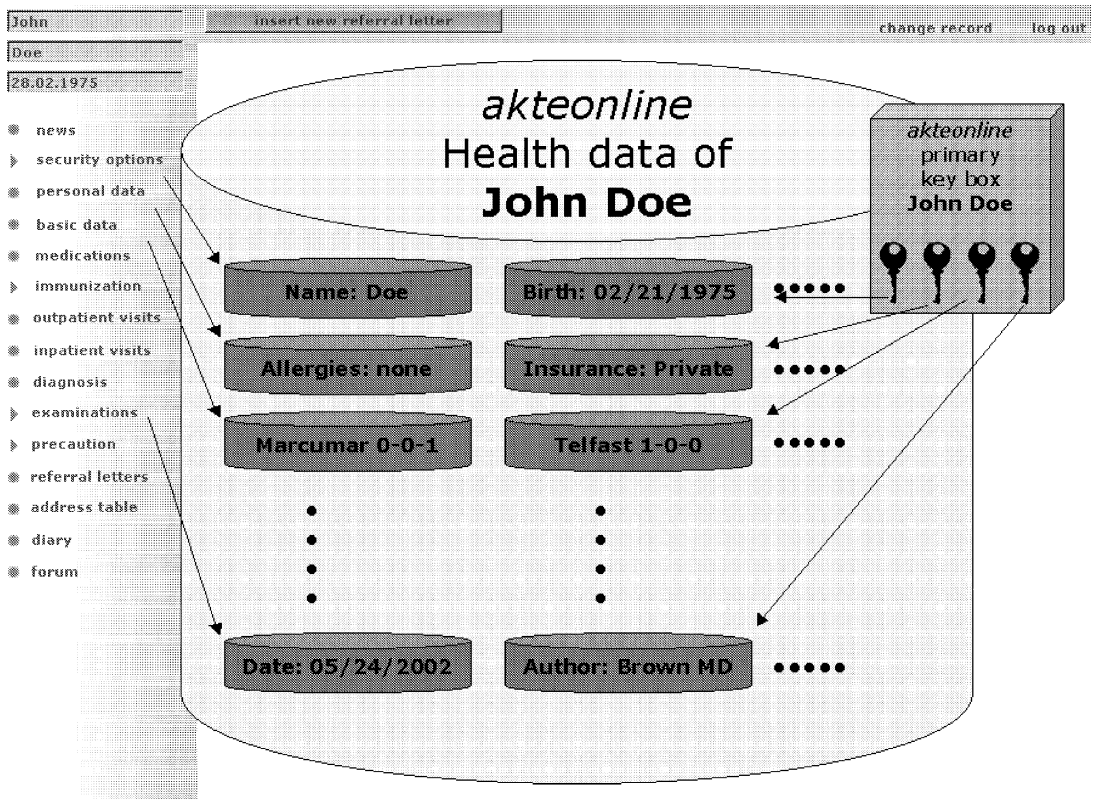

Fig. 2 Principle of key boxes within the security system.

tification numbers will, in combination with the username, allow a one-time access according to the predefined access scheme.

5.3. HCPs

Because healthcare providers can have an own login for *akteonline.de*, a user is able to select his healthcare provider and give him special authorizations for parts of his EHR. The access can be of reading or writing but not of overwriting nature. Data added by a healthcare provider is internally signed and cannot be changed by the user, yet he can delete them. Furthermore the assignment of access may also be granted for healthcare provider roles (e.g. pediatrician). This simplifies the procedure for the user to assign new and/or change healthcare providers, because the whole process may be pursued by simply adding a particular healthcare provider (e.g. physician) to a predefined role. In *akteonline.de* several medically useful roles are predetermined, which are meant as helpful suggestions and not as obligations.

Healthcare providers are able to access the EHR of a patient not only through the Web interface. Additionally electronic communication interfaces between the information system of a healthcare provider (e.g. a hospital information system, HIS) and the EHR have been realized. Standardized data interchange structures for these access channels were defined based on the Clinical Document Architecture (CDA) [17,18]. The tool applied to structure the information is the extended mark-up language (XML). Such an electronic communication can be performed totally transparent for the healthcare provider.

5.4. Emergency

If a patient wishes to provide read access to an ''emergency subset'' of his EHR, he can enable and define this within his record. For this purpose a default setting for the contents of the emergency subset (contact information and information about allergies, confirmed diseases and the list of actual medications) is provided, which may, however, be adjusted by the patient to his personal wishes. When this feature is enabled, an emergency TAN is created. The combination of web address, username and this emergency TAN printed on a small wallet card can be taken along by the patient and used by any other person in cases of an emergency for this patient.

5.5. System

Because data security is a major issue in implementing an EHR, the users' clinical data are encrypted in such a way, that under normal conditions neither the system itself nor a system administrator has any access—not even a reading one—to the decrypted health records (Fig. 2).

For the implementation of automated reminder functions, however, which shall be applied to support disease management programs especially for patients with chronic diseases, access authorization needs to be granted by the user at least to those data items of his EHR which are part of the reminder logic. Since the activation of reminder modules is optional, the process of activating any reminder module is linked with an additional dialogue, explaining to the user which data items are required within this module and asking him to grant read access to those data for the respective system processes themselves.

6. Clinical implementations

Akteonline.de is currently applied within three clinical projects at Muenster University Hospital.

6.1. Obstetrics

''Patients'' of the obstetric department are able to send a digital photo of a newborn and its parents by email to relatives and friends. The midwife can also document the findings of the U1-examination, the first of ten usual preventive checkups for children in Germany, and save it into *akteonline.de*. That is the foundation for the electronic healthcare record, accompanying a human ''from cradle to grave'' [19]. Within *akteonline.de* an event monitoring mechanism has been implemented which supports the definition of small rules, which can automatically trigger reminder messages to the *akteonline.de*-user via email. Usage of this reminder system is voluntary and may be selectively activated by the user himself. In the framework of our project in the gynecology clinic parents may choose to keep the picture of the newborn and the documentation data of the U1-examination as first items within their child's personal electronic health record and activate a rule set, which reminds them in time to make appointments with their pediatrician for the next U-examination. Furthermore patient information on those U-examinations as well as on childhood vaccination programs which are traditionally given to parents by

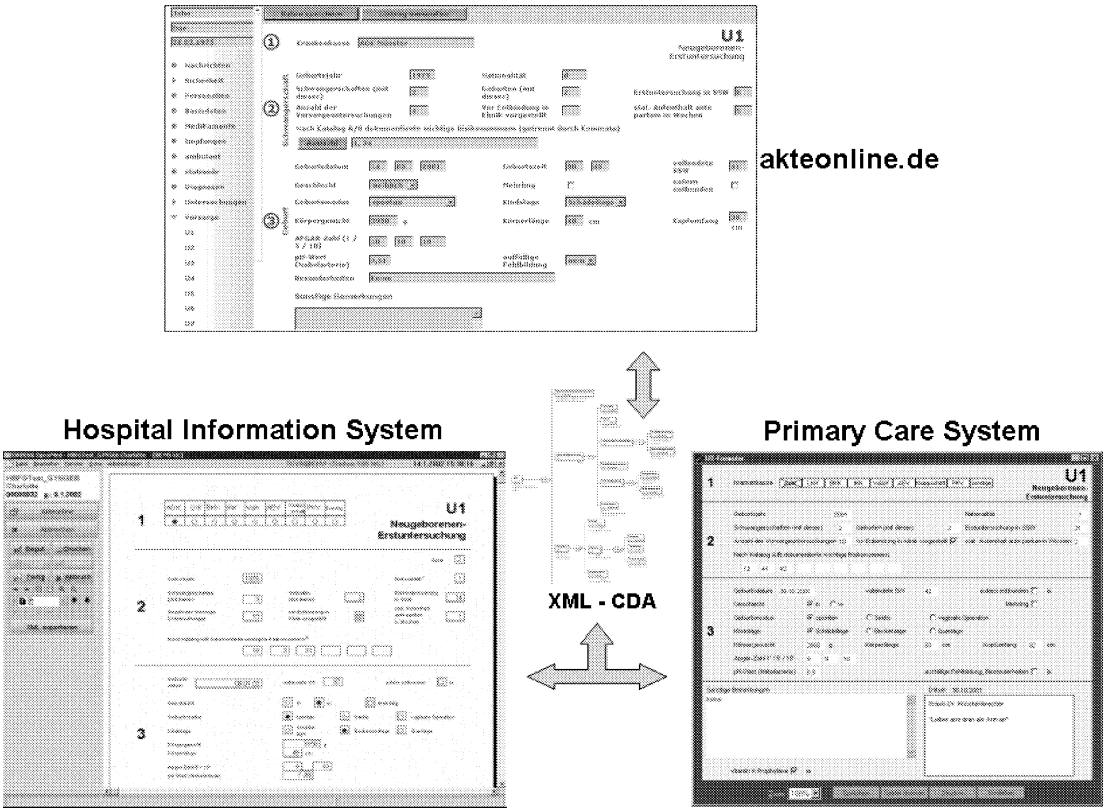

Fig. 4 Principle of data exchange between different systems.

their pediatrician on paper is available directly within *akteonline.de* (Fig. 4).

In Germany currently different communication standards are applied in the various areas of healthcare (HL7 within hospitals, xDT within the general practitioner's information systems), thus establishing large barriers for a cross-institutional data exchange between a HIS and a GP system. In some more recent projects (e.g. Sciphox [3]) the XML-based clinical documentation standard (CDA) [17,18] has been applied in order to integrate those two areas. Because of this much more open and visionary approach we have also applied the CDA for the *akteonline.de* ex- and import interfaces to HIS and GP systems (Fig. 4).

Based on standardized XML-schemes communication mechanisms for the ex- and import of health record subsets have been established. As a demonstrator for this data exchange, an U1-documentation form has been developed within the framework of the HIS at Muenster University Hospital. From this U1-documentation an automatic export file in XML-format can be created and transparently uploaded to *akteonline.de*, when parents have given their authorization. In a follow-up visit with a pediatrician the parents may allow him access to those data via the WEB-Interface, but may additionally allow the download and transfer of the U1-data into the primary care physician's own information system. The pediatrician furthermore may then document the U2-data within his primary care information system and again activate the automatic upload of this data into the child's health record within *akteonline.de*. The latter interface has been realized for one commercially available German primary care system. The structure of the health record items, which are communicated with those mechanisms has been based on the CDA-definitions in order to be consistent to current standardization activities. Besides those syntactical interfaces, however, there still exist many semantical data interchange problems. Those can currently only be solved by proprietary bidirectional mappings between two systems as performed in our above described pilot development. For the future, we hope that the enhancements of the CDA, to structure clinical documents on more detailed levels and the progress in HL7 (RIM) will provide a better means to overcome those barriers. For the mapping of terminologies we currently restrict our data to internationally standardized classification systems (e.g. ICD-10) or apply the UMLS for respective mapping purposes.

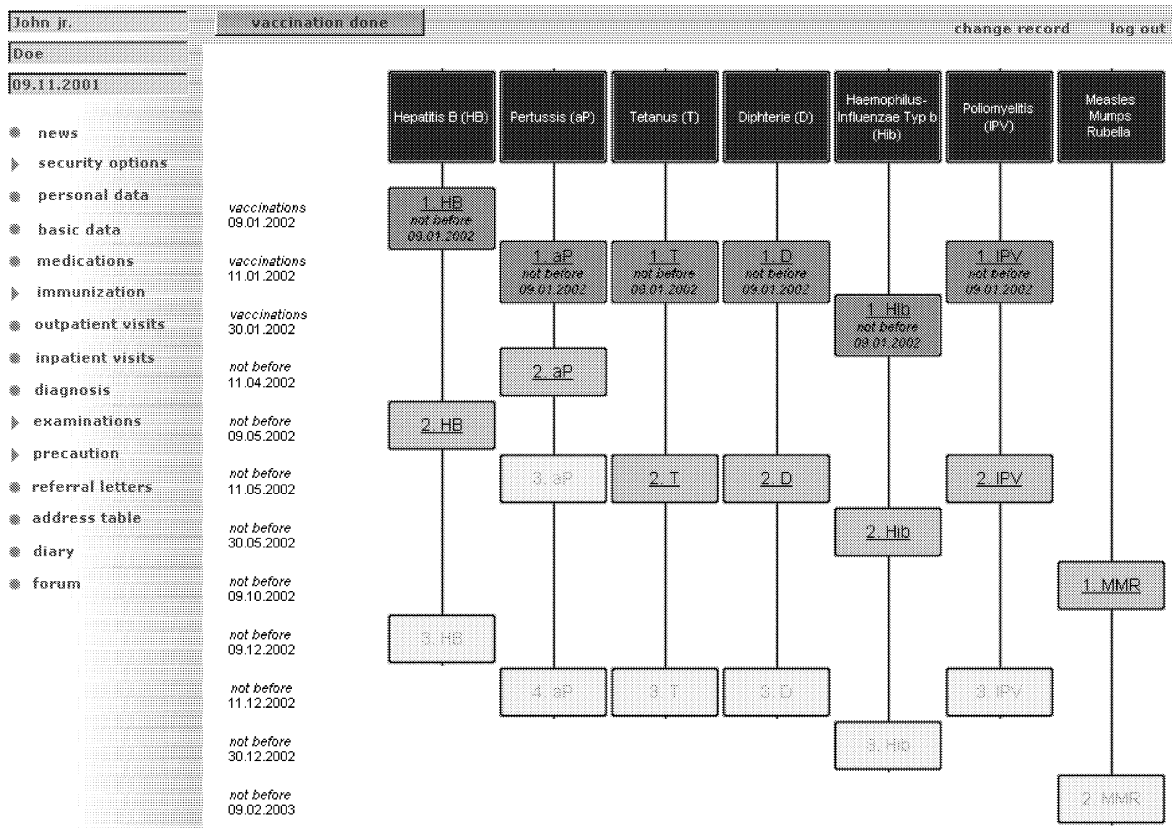

Fig. 5 Screenshot of overview of children's vaccination.

6.2. Gynecology

A second pilot project is set up in the clinic for gynecological oncology. There, next to the standard functions of *akteonline.de*, the findings and referral letters are transmitted as electronic documents (mainly MS-WORD files) via an easy to use web interface into the EHR by the physician or his secretary. These documents can be transformed into several different formats like pdf, doc or txt when requested (Fig. 6).

6.3. Pediatrics

The third pilot project in the department for children's oncology is just about to start. To replace paper documentation done by the parents, the laboratory devices were equipped with an HL7-interface to send HL7-messages to the HIS. These messages are combined by the HIS in documents according to the CDA, which then is send to *akteonline.de* via the internet as a XML structure (Fig. 7).

The HIS of the University Hospital Münster has been extended for the project of the children's oncology in a way, enabling the physicians to send signed documents like the referral letter to akteonline.de. These documents then get automatically transformed to the CDA-standard and sent to the EHR.

Information about health is widely spread in the internet. In an attempt to enlighten the patient,

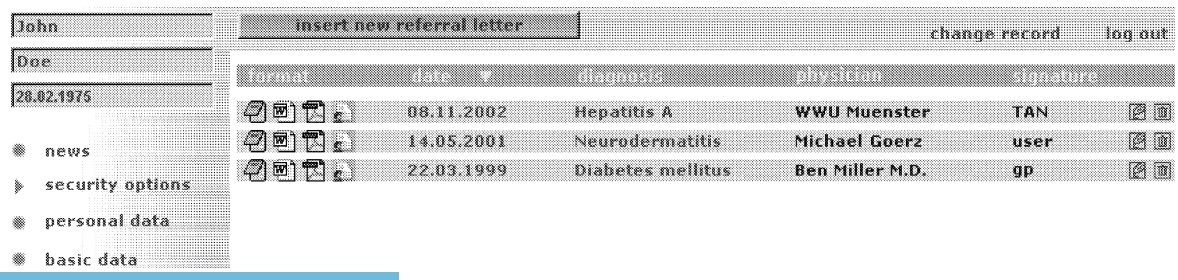

Fig. 6 Screenshot of referral letters listed in akteonline.de.

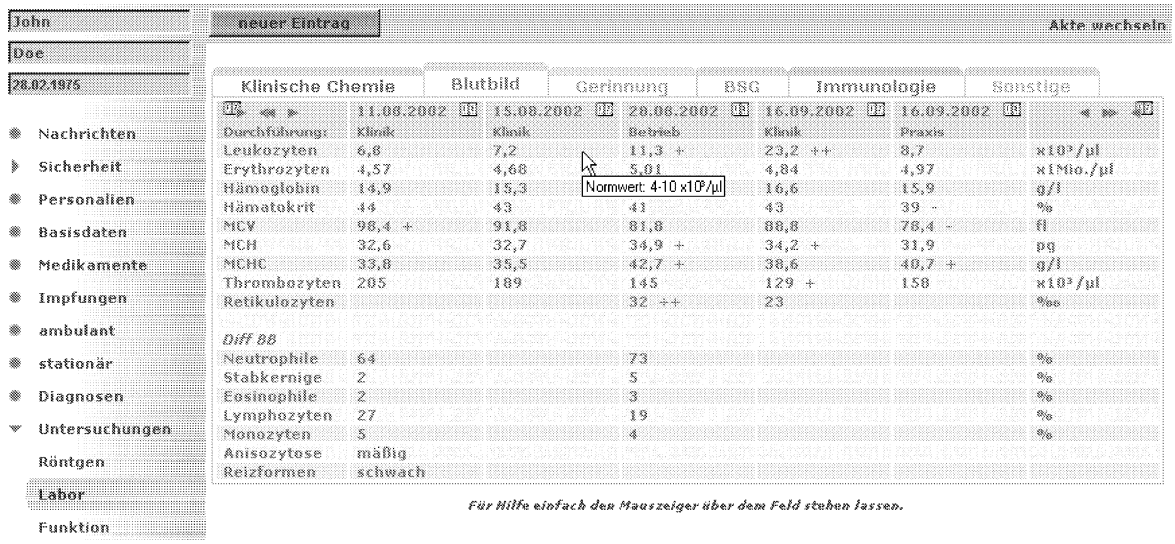

Fig. 7 Screenshot of laboratory data imported from automatical data exchange.

akteonline.de offers an own information database as well as internet links accessible to the patient (Fig. 8). EHR contents like diagnoses or examination results, but also values and the normal value range of single laboratory data items, are linked to further information. This includes decision support when to see a physician personally (Fig. 5), information which food in which stage of the treatment is healthy and which is forbidden, overview of supporting governmental, private or university institutions they can get help from and how they get it. One part of this patient information is a forum in which patients/parents offer opinions and help among each other (Fig. 9).

7. Discussion

The view of the electronic healthcare record *akteonline.de* is patient oriented. It is designed primarily for the direct use of citizens their selves. It currently comprises a basic structure for the documentation of personal health data, patient information for childhood examinations and vaccination programs as well as a clinical pathway monitoring engine which is intended to support preventive care. At the same time it provides possibilities of communicating health record subsets with other health information systems through open interfaces (XML, CDA).

It thus provides a comprehensive and flexible tool for the empowered patient, who wants to maintain his own personal health record. In contrast to other projects known to us, which also provide such electronic health records through the internet, it is designed not only for direct data input by the citizen himself, but additionally for automatic data transfer with other health information systems.

When *akteonline.de* is actively used by a citizen as a personal electronic health record it may contribute to avoiding double or unnecessary tests,

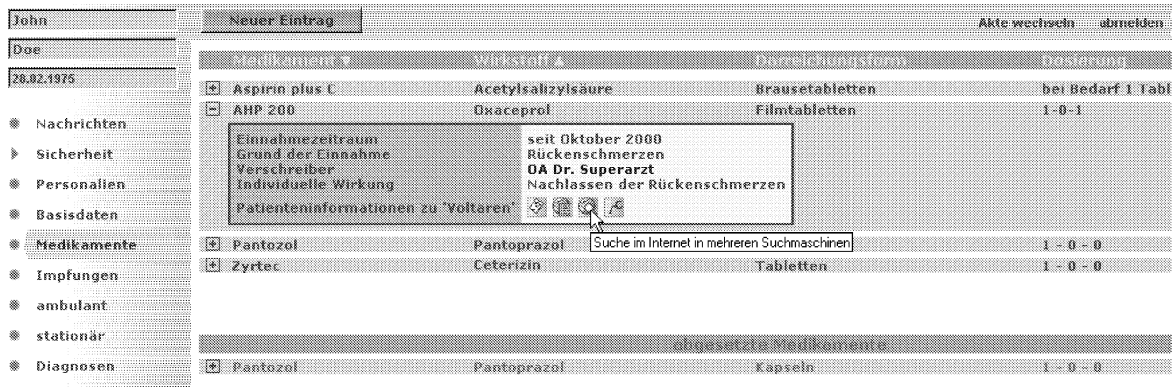

Fig. 8 Screenshot as example for patient empowerment through various information resources.

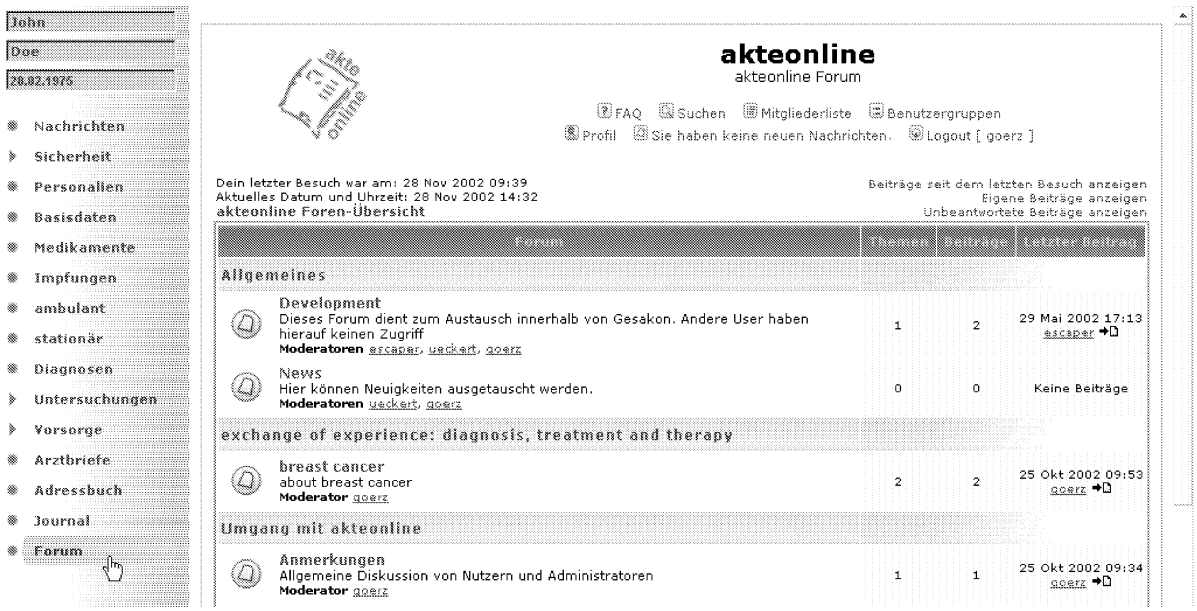

Fig. 9 Screenshot of forum with opinions and help among patients.

providing better comparison with existing data from earlier examinations, reducing the number of ineffective treatments, increasing patient's compliance with clinical care processes, reducing length of stay within hospitals and providing a lifelong health record across institutional boundaries. In a review done by Treweek et al., computer generated patient education materials have also shown a positive effect on the professional practice [20]. "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" [21]. Many researchers have reported the value for empowered patients to have access to their own patient information over the Internet [12–14,22]. Cimino and colleagues for example reported from a study in which both, patients and their caring physicians, believed that access to their personal health records enhanced the patient's understanding of their conditions and improved their communication with their physicians [23]. That is what we also believe and want to prove in routine use.

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