A Personal Health Service to Increase Patient Empowerment by Intelligent Use of Electronic Xray-Records

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Abstract

Background: The electronic Xray-Record is the Austrian contribution to the PALANTE project. The Austrian pilot aims to implement a new module into the hospital information system used within the KAGes which includes the summary of the dosage of X-ray examinations in a personal eXray-Record. The main goals are to support the personal health management of the patient and to increase the awareness of patients and physicians for X-ray exposure in healthcare. External access for health professionals and patients will be done via a web portal to provide a comprehensive representation of the X-ray exposure data. Additionally, transparency about radiation doses applied in the context of radiological examinations is provided. **Objectives:** This paper gives a brief description of the web access to radiology data. In particular, the paper outlines the online representation of exposure doses caused by radiology examinations and identifies the challenges. **Methods:** In the analysis, the national regulatory frameworks and standards were considered. Literature research and expert discussions were done to figure out the risks of the radiation exposure in the low-dose range. **Results:** Possibilities for data extraction and data representation were worked out. The architecture of the eXray-Record was designed with consideration of important standards. **Conclusion:** Access to personal health information empowers patients and increases the control over matters concerning their health. Shared decision making would become possible through intelligent use of the eXray-Record and a bi-directional patient-caregiver communication.

Keywords

eHealth, patient empowerment, radiology, X-ray exposure, personal health record, electronic Xray-Record, web portal, web access

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EJBI 2012; 8(4):44–49

1 Background

Patient empowerment [1] is the situation where a patient plays an active part in his/her disease management. Patient empowerment integrates multiple concepts that allow a patient to effectively self-manage his/her disease. In the context of an aging population and an increasing number of chronic patients, it is considered a key tool to reduce healthcare costs and improve both quality and efficiency of the health delivery process [2]. Information and Communication Technology (ICT) applications already help to empower patients. However, there is still considerable potential to develop this concept much further.

Generally, pilots and projects dealing with patient empowerment each address a single element or mechanism of the whole concept. The approach in the PALANTE (PAtient Leading and mANaging their healThcare through EHealth) [3] project is to maximize the potential of ICT technologies by validating at a large scale a significant number of pilots so that all the mechanisms involved in patient empowerment are addressed. Thus the project approach considers the implementation of seven new pilots and the evaluation of two additional ongoing pilots. Globally, the project mobilizes twenty-one partners in ten different countries and 69.550 new users. The project therefore responds to the main challenges that European health systems are currently facing: demographic changes, demand for access to health relevant information, quality of care, and an increasing number of chronic patients.

1.1 Electronic Xray-Record

The Austrian contribution to the PALANTE project is to analyze, implement and evaluate one of the seven pilot implementations, the electronic Xray-Record (eXray-Record). The Styrian Hospital Holding (KAGes[1]) will implement the eXray-Record in 19 hospitals with 270.811 inpatients and 928.015 outpatients per year[2]. Currently, exposure data is not available in the Hospital Information System (HIS), neither electronically nor on paper and even less in a cumulative way. Therefore the X-ray exposure data is not accessible for health professionals and patients. In addition, it is difficult to keep track of all radiology examinations for both health professionals and their patients.

The eXray-Module to be piloted within the PALANTE project will summarize X-ray exposure data for every patient's life time in a personal eXray-Record. The information about the X-ray doses coming from radiology examinations can support decisions about further X-ray examinations.

Besides the knowledge about the cumulative doses of X-ray examinations an economic benefit is expected, because currently very similar or even the same X-ray examinations are often done twice, usually in an inpatient and an outpatient setting. Considering the information available from the eXray-Record the patient as well as the doctors will be aware of this exposure and may reduce the number of X-ray examinations, respectively avoid redundant X-ray examinations. The information stored in the eXray-Record will empower the patients in their personal health management. Furthermore, clinicians and referring physicians are interested in a high quality documentation of radiology examinations and also consider actuality, clarity, and completeness to be very important [5].

It is not an objective of the eXray-Record itself to derive recommendations on further radiological investigation opportunities. The medical assessment based on the data that the eXray-Record provides will remain within the responsibility of the physicians.

1.2 Integration into ELGA

The Electronic Health Record (EHR, ELGA) [6] is being implemented step by step in modules in Austria. Core applications of the first implementation phase of ELGA consist of the electronic discharge letter, e-Report laboratory, e-Report radiology and an e-Medication tool. In the future all relevant medical findings and documents will be stored in ELGA. Patients and their physicians will be able to access this data. The relevant data is provided by different health service providers (physicians, hospitals, etc.) and by the patient. In this context, data privacy and security are given highest priority, because ELGA contains medical information which is directly assigned to one distinct person. ELGA is a virtual health record, so its data is stored in several different information systems at the health service providers. For authorized persons all medical findings and documents are provided independently of location and time of the treatment. The data provided has to be relevant and up-to-date and is appropriately pre-processed and displayed for the specific user. Every patient has the right at every stage to refuse the storage of his/her data.

The Austrian Health Commission has decided to use established international standards for information and communication in healthcare. As a result, the following frameworks and standards are used for ELGA [7]:

- IHE Framework [8]
- Health Level 7 – Clinical Document Architecture (HL7 CDA) [9]
- Logical Observation Identifiers Names and Codes (LOINC) [10]
- Digital Imaging and Communications in Medicine (DICOM 3.0 incl. Web Access to DICOM Persisting Objects (WADO) [11]
- Health Level 7 V3 RIM as data model [12]

In a first step, the eXray-Record will only be offered to the patients of KAGes via a web portal. The eXray-Record should comply with relevant international technical standards and ELGA-specifications, so that it could be used to implement a further module of the Austrian health record ELGA. The data will be stored in compliance with the standards proposed for the Austrian electronic health record. The pilot project aims to implement the eXray-Record as an independent module. In this way, it can be integrated in other applications based on compliant international standards.

1.3 Web Access

According to a U.S. study [13] most patients are dissatisfied with the current reporting system in radiology. Referring physicians as well as radiologists are aware of this dissatisfaction of patients and think that patient access to radiology data should be provided. Researchers figured out that patients wish to have easy access to their personal health information and like to be involved in medical decision making. The representation of the data is expected to

[1]KAGes is a Styrian Hospital Holding, a non-profit organization and the public welfare promoter. Its core task is the construction and operation as well as the management of regional hospitals in the Federal State of Styria [4].

[2]http://www.kages.at/cms/ziel/2326/DE/ (2011)

be understandable, meaningful and clear. It is generally accepted that such an involvement leads to better clinical outcomes. On the basis of this evidence, it is believed that improved access to radiology information increases both patient satisfaction and clinical outcomes. A system that grants access to personal health data and additionally provides educational information could be expected to increase patients' knowledge and understanding of his/her own state of health. In addition, patients obtain greater autonomy because they take more responsibility for their own health care. A study of the American College of Radiology [14] outlines that patient access to radiology data provides the opportunity to develop better relationship between patient and radiologist.

Although there is reason to believe that the clinical outcomes could be improved, physicians are concerned that online access to radiology data could potentially increase patient anxiety. Furthermore, radiologists and referring physicians worry about patients' ability to understand the complex context of radiology data [13].

2 Objectives

This paper aims to endorse the necessity of an electronic Xray-Record and can be seen as a summary of recommendations for the implementation including issues and resulting advantages. Therefore we have to investigate national regulatory frameworks and standards to guarantee the feasibility of the eXray-Record project. As a result, we want to provide a list of relevant laws which have to be considered during the analysis and implementation phase.

In order to provide web access for patients and external physicians to radiology information, we have to examine possibilities of how to grant secure access to sensitive data. Additionally, we need to investigate the various possibilities of radiology data extraction and the process of transferring the measurement data into the record.

Another main question of concern is how to represent the figures of X-ray dose (milli-sievert) in a way to make them understandable for both patients and physicians. This could be achieved by putting them in relation to other measures like high mountain walks or Trans-Atlantic flights. However, the difficulty about relating dose to other measures is that these may be perceived as too harmless or too harmful. Relating dose to complications like cancer risk is problematic as well, because there is evidence on X-rays causing complications like cancer but not on the precise relation between the dose and the resulting complication. UNSCEAR states that "there is strong epidemiological evidence that exposure of humans to radiation at moderate and high levels can lead to excess incidence of solid tumours in many body organs and of leukaemia. There is also growing information on the cellular/molecular mechanisms through which these cancers can arise. [...] any increase in cancer incidence thought to be caused by low-dose radiation exposures is modest by comparison." [15]

Currently there are no rules on how to represent the X-ray doses to clinicians, not even in the clinical world. The challenge is thus making patients aware of the risk of radiology. However, no clear specification of the risk can be given.

3 Methods

In order to achieve an electronic record for X-rays the main stakeholders of the pilot were identified. For the pilot project, the KAGes officiates as the owner, provider and maintainer. KAGes provides experience in construction, operation and management of regional hospitals and is the end user and thus the validator of the pilot. The GFST (Gesundheitsfond Steiermark) [16] acts as the regional healthcare provider and is responsible for planning, managing and controlling the Styrian health service. The initiator of the project is the FH JOANNEUM University of Applied Sciences which provides the experts for examination and treatment methods in radiology, medical computer science, process management, health economics and public health.

We investigated the national regulatory frameworks and standards for the development of an eXray-Record. Our analysis was limited to laws and regulations in healthcare and technology, with special consideration of data privacy.

The basis for the development of the eXray-Record is a requirement analysis. Requirements were identified through an analysis of the scientific background and the creation of a questionnaire. We were able to involve a range of medical professionals such as physicians, radiology technicians, medical physicists as well as patients into the requirement analysis process.

4 Results

4.1 Regulatory Framework

The regulatory framework includes the data privacy act (Datenschutzgesetz [17]), a law which defines additional data security rules for electronic transactions with health data (Gesundheitstelematikgesetz [18]), a central law to protect people and environment from harm due to ionizing radiation (Strahlenschutzgesetz [19]), an act about the regulation of measures for the protection of persons against ionizing radiation in the field of medicine (Med. Strahlenschutzverordnung [20]), the Austrian Physicians Law (Ärztegesetz [21]), a law for medical-technical professions like e.g. physiotherapists, speech therapists and radiology technologist (MTD-Gesetz [22]) and regulations for the education of medical-technical professions including radiology technologists (FH-MTD-Ausbildungsverordnung).

4.2 Data Extraction

The X-ray exposure data of the specific examinations of patients is the foundation for the core functionalities in the eXray-Record. Different ways of documenting the X-ray exposure data will be necessary, depending on the type of X-ray unit and manufacturer:

- Transfer via DICOM/MPPS interface from the X-ray unit to the eXray-Record (mainly for CT and fluoroscopy)
- Documentation by manual reading of the data from the X-ray unit and entering it manually in the HIS (mainly for CT and fluoroscopy)
- Documentation in RIS (Radiology Information System) supported by default values which are automatically preallocated depending on the weight and sex of the patient and the radiological procedure (mainly for conventional X-rays and mammography)
- Automatic determination of the required data from the header-data of the PACS images (mainly for conventional X-rays and mammography). This process is triggered after a new picture of a radiology examination has been stored into the PACS.

In every case the X-ray units only provide the physical parameters of the examination like dose area product, dose area product rate or tube current. From these physical parameters, the eXray-Record has to calculate the effective dose by using conversion factors.

4.3 Data Representation

Since the discovery of radiotherapy the use of radiology procedures have globally increased. There are a number of current trends in medical use of ionizing radiation, which offers tremendous benefits to the humans. The rapid increase of new technology for medical exposure and the corresponding speed of clinical introduction of this technology show a major trend, but the associated radiation exposure poses a high risk for patients. In particular the increased usage of computed tomography (CT) scanners causes about 42% of the total collective effective dose arising from medical diagnostic radiology [23].

The eXray-Record provides an accurate summary of doses for physicians and radiologist to make them aware of the amount of radiology examinations. To still the fears of radiologist and referring physicians about clear data representation for patients the web portal offers meaningful comparisons of radiation doses. Cumulative or other radiology doses, which are shown in milli-sievert (mSv), are presented in a clear, understandable way and the radiology exposure data is explained on the basis of comparable examples. Figure 1 provides comparisons between doses from radiology examinations and the natural radiation exposure. In Austria the effective dose of natural radiation exposure amounts to 2,5 mSv per year which is equivalent to 0,007 mSv per day [24]. The various examination procedures are normalized by comparing it to a common thorax radiology exposure. Such comparisons support patients to become aware of the risks of radiology. However, a clearer specification of the risk is not possible.

Examination Procedure	Effective Dose (mSv)	Equal to n pa-Thorax-Xray	Equal to Natural Radiation Exposure in Austria
Thorax pa	0,02	1	~ 3 days
Skull 2 planes	0,07	~ 3,5	~ 1 week
Abdomen ap	1	~ 50	~ 5 months
CT skull	2,3	~ 115	~ 1 year
CT thorax	8	~ 400	~ 3 year
CT abdomen	10	~ 500	~ 4 year

Figure 1: Typical effective doses, based on VBDO [24]

4.4 Architecture

Figure 2 shows the framework of the eXray-Record. Every X-ray examination in a patient life is stored in the personal eXray-Record. Physicians within the KAGes are able to access the eXray-Record through the hospital information system. External physicians and the patient can access the data through a web portal. Based on this data they are able to make an informed shared decision about future X-ray examinations. The collected data of radiology examinations is stored in the Clinical Document Architecture (CDA) format. The standard used is based on the latest implementation guidelines for CDA reports of imaging diagnostic in Austrian healthcare [9]. The usage of the standard provides a harmonized, structured and standardized way to transfer medical documents from health services to patients.

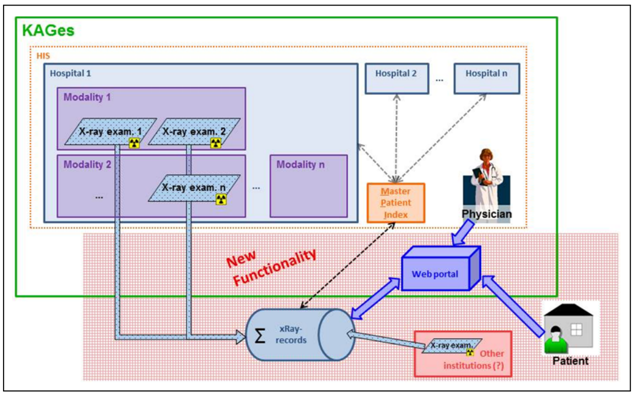

Figure 2: eXray-record architecture

5 Conclusion

Promoting the deployment of new information and communication technologies in the health care system is the explicit aim of a series of international and national strategies in Austria, the majority of which are related to the Europe initiatives and the eHealth action plan of the European Union. Austria is participating in the European PALANTE project to maximize the potential of ICT technologies and to achieve patient empowerment.

It is widely accepted that the access to their own health information empowers patients and increases their control over matters concerning their own health. However, access to personal health records is just the first step in the process of patient empowerment. The ultimate goal is the evolution into a system where bi-directional patient-caregiver communication is possible and shared decisions can be made within disease management.

The development of the eXray-Record was initiated first of all to summarize the X-ray exposure data for every patient's life span in a personal record. An additional goal is to make the X-ray exposure data available for patients and health professionals. The eXray-Record provides doctors with additional information to decide about further X-ray examinations which help to minimize the total X-ray exposure of a patient. The online representation of the eXray-Record for patients and external physicians is a crucial point.

Online access to sensitive data is always assumed to be critical, because high security standards have to be ensured. Therefore a smartcard and SIM card based approach is a possible way to ensure secure access to the eXray-Record [25].

In the end, the implementation of an electronic Xray-Record can be seen as another step towards patient centered integrated care and patient empowerment. It is highly expected that this project will generate economic, medical and social benefit for patients, physicians and ultimately the healthcare system.

6 Acknowledgements

This project has received funding from the European Union's ICT Policy Support Programme as part of the Competitiveness and Innovation Framework Programme under GA n^o 297260.

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