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Empowerment of Patients over their Personal Health Record Implies Sharing Responsibility with the Physician

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Abstract: Through this article, we point out the unavoidable empowerment of patients with regard to their personal health record and propose the mixed management of patients' medical records. This mixed management implies sharing responsibilities between the patient and the Medical Practitioner (MP) by making patients responsible for the validation of their administrative information, and MPs responsible for the validation of their patients' medical information. We propose a solution to gather and update patients' administrative and medical data in order to reconstitute patients' medical histories accurately. This method is based on two processes. The aim of the first process is to provide patients administrative data, in order to know where and when they received care (name of the health structure or health practitioner, type of care: outpatient or inpatient). The aim of the second process is to provide patients' medical information and to validate it under the responsibility of the MP with the help of patients if needed. During these two processes, the patients' privacy will be ensured through cryptographic hash functions like the Secure Hash Algorithm, which allows the pseudonymization of patients' identities. The Medical Record Search Engine we propose will be able to retrieve and to provide upon a request formulated by the MP all the available information concerning a patient who has received care in different health structures without divulging the patient's true identity. Associated with strong traceability of all access, modifications or deletions, our method can lead to improved efficiency of personal medical record management while reinforcing the empowerment of patients over their medical records.

Keywords: medical record, patient identifier, direct access, data security, privacy, E-health

Introduction

The concept of empowerment can be defined as a “social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own

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problems, and mobilize necessary resources to take control of their own lives.” [1]. In the health care context, patient empowerment means promoting autonomous self-regulation so that the individual’s potential for health and wellness is maximized. Patient empowerment begins with information and education and includes seeking out information about one’s own illness or condition, and actively participating in treatment decisions [2]. It points out the passage from an old model of care based on patients’ “compliance” with a health care professional’s “directives” to a new paradigm based on patients’ “adherence” to health care professional’s “recommendations”, through, among other things, active participation of the patient in the management of his personal medical records. That means also to move from the traditional patient’s medical record managed by health professionals and used under their supervision and authority to a Patient Controlled Health Record (PCHR) [3]. As described by L. Rostad [4] a PCHR contains data from multiple care sites, and the patient is in complete control of the information. According to a previous study conducted by SE Ross [5] and to the results of clinical trials, the main benefit of the giving patients direct access to their medical records is the improved communication between the doctor and the patient. Other benefits concerning only modest improvements in adherence, patient education, and patient empowerment were found in certain randomized controlled clinical trials, but not in all. However this lack of efficacy could result from the fact that patients had only *access* to their medical records, which maintains them in a passive situation; access alone is insufficient as a real active patient *control* over their personal health records is needed. By empowering him of his personal health information, we may expect that patient will become a real key manager of his own health, beside the Medical Practitioner (MP). But at the same time, responsibility must be shared according to the knowledge of each actor. In this case, management concerns mostly relate to validation (or cancellation) of the information, and any information must be assessed before it can be deemed true or false. Thus, the role of patients is to verify and/or modify their administrative data, while the MP will verify and/or modify purely medical information. However, we aim to underline the strong link between these two kinds of data and demonstrate their interdependence in terms of quality. The main objective of this paper is to propose a new method to reconstitute, update and provide the correct administrative and medical data for patients through the mixed management of their medical records. This will empower patients with regard to the management of their health data by increasing their responsibility [1, 2], and by increasing the accountability of MPs concerning the medical data. We propose to correct and update patients’ health information or data, with their help, so as to reconstitute their medical histories efficiently with no or only a slight increase in MPs’ workload and with the highest level of accuracy.

1. Methods

Patients are the best able to validate not only their first and second names as well as their date of birth, but also the health structures they visited and the dates of their visits. MPs are best able to validate medical data as defined below. This means that patients and MPs together should be responsible for the reconstitution and the update of patients’ medical histories (administrative and medical information) of the patient. The division of responsibilities between doctors and patients is very time consuming for decision making [6-12], but has not been extensively investigated regarding the

management of patients' medical records. The methodology we propose for responsibility sharing between MP and patients relies on two processes: The first process aims to provide patients' administrative data to know where and when patients received care (name of the health structure or health practitioner, type of care: outpatient or inpatient). Patients will be responsible for the validation of this information [3, 4]. The first objective of this validation is to obtain the right information for the right patient at anytime and anywhere and to be sure that the information concerns only the patient, and to avoid providing or considering information from another patient. Secondly, the validation of the information retrieved will constitute the patient's medical history. During this validation process, the MP may confer with the patient. The validation of this administrative information will be under the exclusive responsibility of the patient, with the help of the MP if needed. The main objective of the second process is to provide patients' medical information. The MP will be accountable for the validation of these medical data, with the help of the patient, if needed. For this validation process to be successful and efficient, it will be useful to take into account the help patients are able to provide given their thorough knowledge of their administrative and medical information. In fact, patients who have all their mental faculties know the history of the care they have received better than anybody else. Patients could regularly update administrative and medical data, for example, once or twice a year depending on the national public health strategies with regard to periodic health check-ups. Such checkups may be initiated by national health authorities or employers, like, for example, in the offer of a minimum package of services for employees for the prevention and follow up of transmissible and non transmissible diseases. In both processes these, patients' privacy is a key issue and has to be ensured. Patients' privacy is one of the main concerns in the storing, sharing or transmission of personal medical data and it is comprehensively covered by legal acts like the HIPAA in the United States or Directive 95/46/EC in Europe. Many companies including employers, insurers or banks are very interested in gaining access to such data. Recently, attempts to gain illegal access to such data have been reported in the network. Thus, systems to share medical data through open networks like the Internet need to prevent access to the identity of the patient. Pseudonymization is one of the solutions that have been suggested for this purpose. It provides a trade-off between patients' privacy requirements and society's needs in order to improve health care systems by linking the patient's identity to a pseudonym from which it is not possible to get back to the patient's identity [13]. Cryptographic hash functions like the Secure Hash Algorithm can be used to reach this goal of pseudonymization [14]. However, sharing this pseudonym or code without introducing secrecy in its calculation may lead to specific attacks, in particular when the total number of possible messages that could have been hashed (pre-image) is too small. In this case, the authorized receiver as well as a pirate eavesdropping on the communication could retrieve private information. A pirate, who obtains lists of patients' pseudonyms, by illegal access or simply by listening to the Internet network, may be able to retrieve the real identity of the patients. The solution we have proposed [15] within the framework of a medical record search engine procedure would counter such risks. It relies on two entities: i) the MRSE (Medical Record Search Engine) which sends out one request issued by one MP, and; ii) the aggregator which gathers responses from the health structures that receive requests for information. In the first step of this procedure, our solution encrypts the patient's pseudonym and the secret key to be used for its decryption before sending them through two different channels. If gaining access to private information

becomes more difficult for someone who is spying on the network, such as MRSE intruders, it will be almost as difficult for the MRSE and Aggregator entities involved in information gathering, and which may be tempted to obtain information illegally. Any attackers will face a set of patient pseudonyms without being able to identify those associated with the same patient. In fact, a one-time pseudonym will correspond to each request. This is the main interest of using pseudonyms in our proposal.

1.1 FIRST PROCESS: Reconstitution of a Patient's History

The first step of this process is the pseudonymization of the patient's identity and the generation of several pseudonymous codes. During a consultation between an MP and a patient, the MP enters all the components of that patient's identification such as his first and last names and his date of birth. Of course, the choice of these components will depend on their availability (exhaustiveness) and their quality. To optimize the request concerning the patient's data, several identifiers can be generated, based on the different combinations of first names, last names and date of birth of a patient. This information related to the patient's identity will be rendered anonymous using a robust cryptographic hash function. To improve patient's privacy, the pad used for hash coding is not the same for each request. A specific pad is generated by the first Medical Record Search Engine (MRSE 1) and sent to the MP, after being encrypted with the MP public key. The MP can then hash the patient's identifiers with this pad. As a consequence the MP sends not only one pseudonymous identifier per patient but a list of pseudonymous partial identifiers for each patient. The aim of this first step is then to obtain several pseudonymous codes, but, hopefully, always the same ones for a given individual in order to link all of the information concerning any given patient.

At a second stage, occurs the search for patient's administrative data. The Medical Record Search Engine Procedure [15] is used to provide a patient's administrative data. For one health structure, MRSE 1 encrypts the pad with the public key of this health structure and sends it. Each health structure can then search for administrative information corresponding to these pseudonymous codes (by comparing them with hashed identities of the patients cared for in the structure). All the pseudonymous codes created from the different possible combinations are considered. This administrative information will be sent back to the MP, through the aggregator.

The third step is the validation of a patient's administrative data by the patient. Any patient of sound mind is the only person who can confirm, where, when and for what reasons she/he consulted for health problems. In patients with a mental handicap, MPs will help patients to confirm or not the doubtful administrative information, thanks to their experience with these patients and their diseases. The doubtful administrative information may relate to a long distance between the patient's residence and the health structure supposedly visited, or to the lack of coherence between the type of health care provided by one hospital or clinic and the patient's disease. An automatic check for this coherence can be implemented, not to automatically exclude any information, but to help the MP and the patient to highlight potential errors and correct them if necessary.

At the end of this validation procedure, the list of administrative information (pseudonymous codes, dates and health structures) to be conserved is transmitted to MRSE 2.

1.2 SECOND PROCESS: Access to Relevant Medical Data for Patient Care.

Firstly, patient's medical data are retrieved. The MRSE procedure is used to make available a patient's medical data. Each health structure that has been contacted or selected during the first process can then search for medical information corresponding to the pseudonymous codes and dates it receives. Medical information retrieved in this search will be sent to the MP, through the aggregator.

Secondly, this medical information is validated by the MP, with the close collaboration of the patient, is accountable for the validation of the medical information.

2. Discussion

Some MPs may object to our procedure because they believe it will increase their workload as they will have to read all of the information in order to detect possibly false or missing information. However, the burden is not as heavy as they may think for many reasons. First, this enquiry on the patient's past history will not be necessary for all patients. Secondly, the number of different medical records that MPs will have to summarize for a particular patient will more frequently be one or two (or eventually three) rather than ten or twenty; but that should be verified. Finally, this work has to be done in with the patient collaboration which can speed up this task. An improvement in time efficiency could also be the reduction of gathered data, via a selection tool as implemented in any kind of search engine and based on several criteria such as a time period, a list of hospitals, a kind of ward or pathology. One could also figure that the first process could be done by the patient alone before meeting the MP, subject to his computer skills, but this point has to be assessed, as it regards data security. However, impact of patient behavior on the quality of his health information may happen independently of the management of the medical record, in the daily practice, and the relationship between the patient and the MP is unavoidable based on reciprocal trust. Moreover, more and more health professionals involve patients in discussions and decision-making concerning their health status and future. Considering that this patient empowerment is bound to happen, the question is how we can contribute to this evolution. However, the impact of the collaboration between the patient and the MP to identify potential errors should be evaluated. For some diseases, the understanding of the natural history is fundamental [19]. Obviously, the history taking [20] requires the patient's help. The study about patients' access [5] reported that a substantial proportion of patients can identify factual errors in their records, but concluded that it was difficult to assess the rate of finding clinically important errors. In this procedure, we have to find a balance between the potential improvement in the overall quality of the information resulting from patients' management of data collection from all sources and the risk of altering the accuracy of the data especially since patients will be able to delete information. Naturally, appropriate modifications to our methodology have to be proposed in the case of mental handicap (by calling on trusted third party: next of kin, proxy or legal representative), in case of emergency care (by exceptionally authorization granting even without validation) or even in the case of a patient meeting a new MP (communication between MPs based on the patient's willingness). One other aspect that our paper is not presenting is related to the safety of EPHR. This aspect has been studied in a previous paper [18] where it was demonstrated that strong traceability is required to build trust in EPHR.

3. Conclusion

With our proposal for the administration of health records, for the first time, patients will be involved in the management of their medical records, which gives them more responsibility for their health care. Furthermore, the MP would obtain more reliable information, which would provide a better basis for decision making and lead to more appropriate treatment. Moreover, the sharing of these responsibilities would enhance the doctor/patient relationship and hopefully mutual trust. Finally, it appears that sharing responsibility for the management of medical records between the patient and the MP can help to provide better health care by increasing the efficiency of the management process. However, even if have confidence in MPs and patients, strong traceability would be required to complete this organizational scheme.

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