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# Reliable Personal Health Records

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**Abstract.** A number of applications based on personal health records (PHRs) are emerging in the field of health care and wellness. PHRs empower patients by giving them control over their health data. Health data for PHRs can be supplied by patients, wellness providers and health care providers. Health care providers may use the PHRs to provide medical care. Unfortunately, the quality of the health data in PHRs cannot be guaranteed in all cases. For example, consider cases where non-professionals such as patients and wellness providers supply data. To address this problem, we present in this paper a system that provides health care professionals with an indication of the quality of health data in a PHR. This indication is based on the reputation of the supplier and on metadata provided by measurement devices. The proposed reputation system mimics the way in which trust in health data and their suppliers is built in the real world. The system introduces minimal overhead for health care providers and patients.

**Keywords.** Quality management, EPR-CPR-EMR, telehealth, security

## Introduction

For years, patient information has been maintained in paper-based records. Paper-based systems bring many disadvantages [1]. They have to be carried or faxed from one place to another, resulting in lack of availability of the records. Furthermore, illegible handwriting in paper-based records may lead to loss or misunderstanding of important health data [2]. Because of these disadvantages, paper-based systems are being replaced by electronic health record (EHR) systems. These EHRs are maintained by health care providers. Next to these EHR systems, personal health record (PHR) systems are developed [3,4,5]. The PHR is a health record maintained by the patient instead of the health care provider. PHRs empower patients by providing them control over their health data. The patient can manage and share his health data in his PHR at his own discretion. After sharing, the health data in the PHR can be used by health care providers and wellness providers to improve the patient's health.

Health care providers are most often the only parties providing health data for EHRs. However, health care providers are not the only parties that can provide health data for the patient's well-being. Patients (as well as people that are not ill, but are concerned about their health) may want to collect health data for their health records. Think for example of weight, heart rate and blood pressure information collected by the patient. Furthermore, as wellness providers such as fitness clubs and weight control clubs are professionalizing, they may want to use and provide relevant health data for

the patient's health record (see [4] as an example). This data is valuable information that can help a health care provider when treating the patient. The need of health care providers to use PHR data has been recognized by several standardization organizations that are already developing standards to enable exchange of information between EHRs and PHRs (e.g. IHE XPHR [6] and Continua xHR interface [7]).

For health data in a PHR, it is unknown how accurate and trustworthy this data is. This is because health data in a PHR is different from health data in an EHR. Health data in an EHR is always supplied (or at least reviewed) by a professional and may therefore be considered accurate and trustworthy. In contrast, health data in a PHR can be supplied by professionals as well as non-professionals. To be able to use the health data in a PHR, health care providers need to know whether this data is trustworthy and accurate.

The problem of assessing the reliability of websites is related to the problem of assessing the quality of PHR data. Assessing reliability of websites is done by measuring characteristics as completeness, accuracy and consistency. However, as measuring the quality of the measurement process for health data is very complicated we need a more general measurement for quality.

In this paper we propose Hedaquin, a system that provides a quality indication on health data in personal health records. This quality indication is based on the reputation of the supplier of the health data and on metadata provided by medical devices.

## 1. Approach

In order to have an indication of the quality of health data in a PHR, we design a reputation system that mimics the way in which trust in health data and their suppliers is built in the real world. To determine the quality of health data, the reputation of the supplier is used as a quality indication. In our approach, to determine the reputation we consider the following factors:

**Credentials of the supplier**: persons who have successfully completed a course of study are issued a diploma or certificate for that. Similarly, a credential may serve as a proof of quality or competence for a certain task. Diplomas, certificates and credentials are supplied by a trusted authority that is entitled to do so. For example, a person that has an academic degree in medicine has successfully completed a medical school. Therefore, the person can be expected to provide high quality health data.

**The quality of previously supplied data**: in case a non-professional supplies health data, a health care provider can state a judgment (i.e. give a rating) about the quality of the health data. The health care provider can do this if he observed the measurement process or if he verified the health data. The rating is later used in calculating the supplier's reputation.

**Metadata**: aside from the reputation, valuable information about the quality of health data can be supplied by medical devices. Medical devices can provide two types of metadata (information about the data supplied by the device). The first type of metadata is metadata on how the person uses the device (e.g. whether the device was used in a proper way). This type of metadata can be used to determine a rating that can be used in reputation calculation. The second type of metadata is metadata concerning the device itself (e.g. device model or calibration data). This type of metadata can be used to determine a quality indication of the data, but it does not influence the reputation of a supplier.

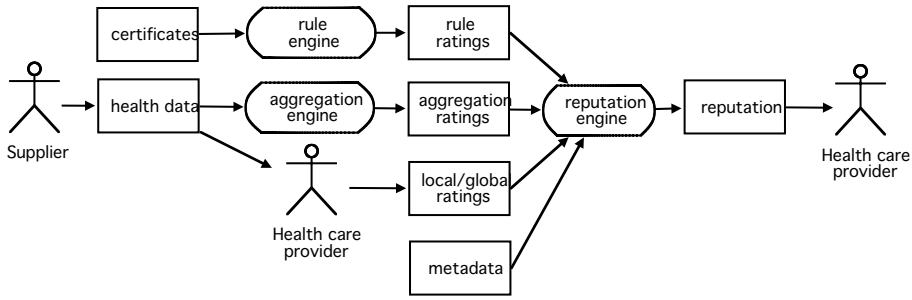


**Figure 1.** Hedaquin architecture

## 2. System Design

Figure 1 depicts the architecture of Hedaquin. The reputation engine takes ratings (local, global, aggregation and rule ratings) as input and calculates a reputation for a health data supplier, based on these ratings. Each rating is accompanied by a certainty level. The reputation engine is constructed in such a way that ratings with low certainty are given less weight than ratings with high certainty.

A reputation is a judgment on a supplier based on his past behavior. To represent a reputation, we use Jøsang's belief model [8]. We model a reputation as an opinion of a health care provider about a health data supplier. An opinion is a tuple *(b,d,u)* where *b* represents the belief in a statement, *d* represents the disbelief in a statement and *u* represents the uncertainty of a statement. An example of such a statement can be 'The person supplies high quality health data'. The reputation of the supplier, as calculated by the reputation engine, is used by the health care provider as a quality indication on the health data.

The aggregation engine calculates ratings based on the comparison of measurements and the rule engine creates ratings based on certificates of the supplier.

### *2.1. The Reputation Engine*

The reputation engine calculates the reputation of a supplier of health data using available ratings. Suppose a health care provider calculates the reputation of a health data supplier. We distinguish four kinds of ratings that can be used in the calculation of the reputation:

**Local ratings**: ratings the health care provider himself has given to a certain supplier.

**Global ratings**: ratings that other health care providers have given to a certain supplier. There is a subtle difference between global ratings and local ratings. Because global ratings were not given by the health care provider himself, the certainty associated to these ratings must be decreased when calculating reputation. After all, a health care provider has less trust in other health care providers than in himself.

**Aggregation ratings**: there are some cases in which the quality of health data can be determined by comparing different sets of health data. If this is the case, a rating can be calculated automatically.

**Rule ratings**: a rule rating is based on the supplier's possession of certificates issued by independent organizations. Rule ratings are determined by the rule engine.

In order to calculate the reputation, we do not only consider the ratings themselves. We use additional information that is available on the rating and on the health data. This additional information determines the weight that is given to a particular rating. The following additional information is used:

**The certainty of the rating:** a rating with a high certainty should be given more weight than a rating with a low certainty. The certainty is supplied by the health care provider and indicates to which level he is certain about his rating.

**The time of a rating:** as the time between the creation of the health data and the calculation of the reputation part increases, the rating should be given less weight. After all, if a health data supplier performed good (or bad) a very long time ago, there is no guarantee that he will do so now. Wixted suggests that humans forget memories according to a power function [9]. Therefore, a power function should be used to mathematically capture the fact that reputation decays over time.

**The order of the ratings:** health data suppliers may start behaving better (or worse) over time. Therefore, recent ratings should be given more weight than older ratings. The last rating should be given the highest weight, the one before slightly less weight, etc. The weight assignment is done using a similar function as for the time of the rating.

**The similarity in scopes:** a scope relates to the task a health data supplier can perform, e.g. taking blood pressure measurements. If not enough ratings are available for a certain scope, ratings for similar scopes can be used. We use a scope function to assign high weights to ratings for similar scopes and low weights to ratings for dissimilar scopes.

Due to space limitations, the model and supporting formulas are not presented in this paper. We refer the reader to [10] for more technical details.

### *2.2. The Aggregation Engine*

The aggregation engine automatically calculates aggregation ratings that are used to compute reputation. An aggregation rating is computed by comparing measurements from different suppliers with a small time difference. If two health data suppliers (e.g. a doctor and a patient) take the same measurement on the same person and these measurements are similar, then the reputation of both suppliers can be increased. If two suppliers take the same measurement on the same person and the measurements are not similar, then the reputation of both suppliers must be decreased. The amount with which the reputation should be increased or decreased depends on the reputation of the suppliers that take the measurements. Therefore, in the case of a doctor and a patient taking the measurement, the reputation of the patient is much more influenced than the reputation of the doctor.

### *2.3. The Rule Engine*

The rule engine determines rule ratings that can be used by the reputation engine. These rule ratings are determined based on the certificates the supplier for which the reputation is calculated possesses. The rule engine uses a predefined mapping to find the rule ratings associated with a certificate. Examples of certificates are medical diplomas or certificates for completing courses.

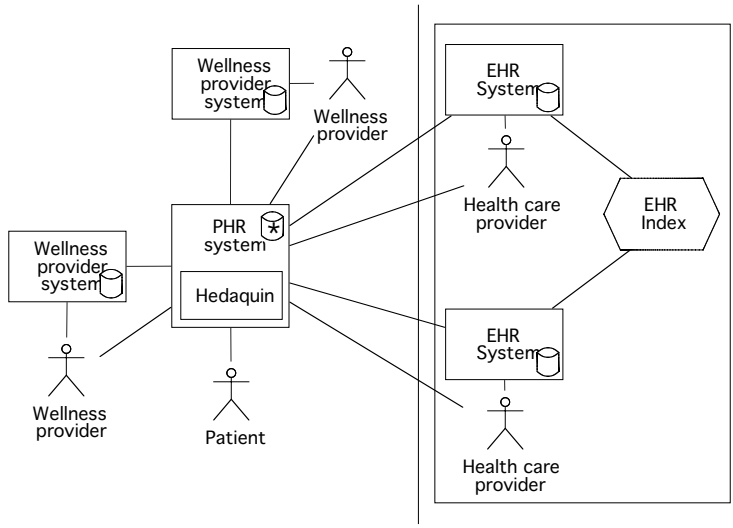


**Figure 2.** Integration of Hedaquin in a PHR system

## 3. Application of Hedaquin in a PHR System

### *3.1. Integrating Hedaquin in a PHR system*

Figure 2 depicts the integration of Hedaquin in a PHR system. A data store indicates presence of health data and a star indicates presence of ratings. In the depicted instance, ratings are stored centrally in the PHR system, which is efficient and secure. The interactions between the patient and the PHR system and between the wellness provider and the PHR system are adapted such that the health data that is sent to the PHR system by these suppliers can be accompanied by metadata. For the health care provider the interactions with the PHR system are adapted such that they can obtain reputations and supply ratings. Hedaquin can be integrated in PHR standards, such as the XPHR integration profile of the IHE framework [6], by embedding the reputations and ratings in the messages.

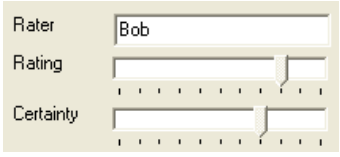


**Figure 3**. Sliders for entering ratings

**Figure 4.** Representation of a reputation

### *3.2. Integration in Clinical Client Software*

While entering numerical values is an easy and convenient way to provide ratings, health care providers may prefer a graphical method for entering ratings. A simple solution is providing the ratings by means of sliders (Figure 3). The value of the ratings is entered by sliding to the right (for a high rating) and to the left (for a low rating). The slider for entering the certainty of the rating can be used in a similar way.

Recall that a reputation is represented by an opinion of the form *(b,d,u)*. The advantage of using an opinion is that opinions are normalized (i.e. $b+d+u=1$) Therefore, we can represent an opinion by a bar where the values of $b,d$ and $u$ determine the look of the bar. The belief $b$ determines the size of the green part of the bar, the disbelief $d$ determines the size of the red part of the bar and the uncertainty $u$ determines the white part of the bar (Figure 4). By visualizing the reputation instead of showing numerical values, the quality indication is much faster and easier to comprehend.

## 4. Conclusion

In this paper, we proposed to use a reputation system and metadata provided by measurement devices to give a quality indication for health data in personal health records. Therefore, health care providers can use health data supplied by non-professionals, such as patients and wellness providers, in a much safer way. This also results in reduced costs and higher quality of health care.

The purpose of a reputation system is to build trust in online environments and to provide an incentive for good behavior. Therefore, using a reputation system to make a quality indication of health data is a natural choice. It also mirrors real practice, in which a health care provider builds trust in patients and the health data they supply.

All in all, Hedaquin gives health care providers the opportunity to make an informed decision on the quality of health data that is supplied by patients and wellness providers. For patients and wellness providers there is no overhead in using the system.

Future research will concentrate on testing the concept in a medical setting and on the use of metadata to determine health data quality and ratings for health data quality.

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