

Improving EHR and Patient Empowerment based on Dynamic Knowledge Assets

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Abstract: Patients like to keep track of their health related issues and Personal Health Records can be useful for managing their health related information. On the other hand, Electronic Health Records also offer medical professionals an insight into the medical profile of the patient, based on examinations, results or treatments. This work proposes the enrichment of these records with data from Personal Health Records as well as data from a patient care social network. For supporting this conceptual approach and sustaining long-term healthcare, Dynamic Knowledge Asset Management is considered. Tracking data and process changes is made possible.

Keywords: Personal Health Record, Electronic Health Record, Social Networking, Process Mining, Dynamic Knowledge Asset Management

1 Introduction

“Recently, the social-networking revolution came to the healthcare industry via online social networks that enable information sharing, collaboration and communication in the area of personal healthcare data” [Do10], in [SLI12]. With this definition Sahama et al. [SLI12] give an indication of the way where healthcare and especially the distribution of healthcare information is heading in the future. The approach of enabling social networks to exchange information between doctors and patients furthers the already established concept of Electronic Health Records (EHRs), which summarize patient information and e.g. examination results in one record. While EHRs are an established concept, in reality patients often need to bring certain information or test results from one healthcare institution manually to another doctor, who might do a follow up examination. In this context the given paper addresses two central questions:

- “How is it possible to establish an EHR which is enriched with data from a Personal Health Record (PHR) and data from social network communication between patients, caregivers and doctors contributing to a better understanding of the patients background for the doctor?” and

- “How is it possible to handle changes in the enriched EHR record in a dynamic way, thus enabling a doctor to always have up-to-date data, while treating the patient and at the same time improving the quality of the process and the empowerment of the patient?”

The following chapters give answers to these questions: The second chapter introduces social networking in healthcare and EHR data management. In the third chapter the connection between EHR and PHR is highlighted, as well as using data from social network communication with highlighting the aspects of interoperability in EHR. Additionally the connection and interaction to Dynamic Knowledge Asset Management (DKAM) and process mining is established. A conceptual model is introduced and the next steps for implementation in a medical environment are explained. The last chapter concludes and summarizes the work.

2 Social Networking and EHR Data Management

In the last years, manufacturers discovered the health sector as a big market for new and advanced products and services, aiming for the improvement of patient treatment, observation and collaboration. In addition to “hardware” products, services for ambient assisted living, care at home or services in social media¹ increased significantly. The patient’s role changed from being informed to being actively involved in all stages from diagnosis to treatment. In the literature the products and services of this development are titled with various names and categories like Health 2.0, Medicine 2.0, both in reference to the Web 2.0 or eHealth for electronic Health. For each technology different definitions are available e.g. in [Ey08, VDB10, Wi10]. Bos et al. [Bos08] defines Health 2.0 in their work about Patient 2.0 Empowerment as “the combination of health data and health information with (patient) experience through the use of ICT, enabling the citizen to become an active and responsible partner in his/her own health and care pathway”. The title of the source shows the new role a patient has in healthcare. While in former days the practitioner was the one who held all the knowledge about the diagnosis and treatment of a patient, today it is expected that patients use ICT services to gain information and knowledge about what is happening to them. Hughes et al. define Medicine 2.0 as “the use of a specific set of Web tools (blogs, Podcasts, tagging, search, wikis, etc.) by actors in health care including doctors, patients, and scientists, using principles of open source and generation of content by users, and the power of networks in order to personalize health care, collaborate, and promote health education” and focus more on the technical point of view [HJW08]. Eysenbach [Ey08] sees a strong correlation between Medicine 2.0 and PHR 2.0, whereas PHR 2.0 “not only allows patients to access their electronic health record, but to share parts of it with other people, building communities around certain health topics and issues” [Ey08]. Tang et al. [Tan06] already concluded before that PHRs “help individuals take a more active role in their own health” as patients enter the data themselves and manage the level of details. Since this time, the mobile apps

¹ „Social Media [...] refers to activities that integrate technology, telecommunications and social interaction, and the construction of words, pictures, videos and audio.” [He10], [EE10], the definition is originally from wikipedia, but has been reused and adapted in several other (web) sources

market (2012 there were around 40.000 available mobile health applications [Wes12]) encouraged this development significantly. Only a short search via any internet search engine throws out lots of apps from tracking a patients fitness, recording of former diseases, reminding him about his medication, heart rate measurement with the help of a smartphone, eye examinations and of course dieting apps for a healthier nutrition (to name only a few categories). Due to the character of certain types of apps, especially apps which build on the patients motivation (e.g. dieting or fitness), they allow for the interaction with other users or direct sharing of a new high score via social media services. A recent commercial study by eClinicalworks with healthcare professionals in the USA indicated that 93% of the 649 physicians found connecting a health app to EHRs is valuable, especially for appointment management and medication reminders [Ka13]. While the mobile apps market is booming, Google decided to shut down its web based health application “Google Health” in 2012 due to lack of growing into a widespread application, which is also used by both patients and professionals [GB11]. The competitors of Microsoft with their HealthVault [MHV13] or World Medical Card [WMC13] on the other hand offer support for apps, the connection to APIs or social media, as e.g. the HealthVault allows to login via the users Facebook authentication.

While already indicated in the paragraph before, the role of social media and mobile access to healthcare services have increased significantly, this section focuses specifically on social media applications and support in healthcare. While in the context of IT, industry and business in general, the use of social media services focuses mainly on marketing via social media and is initiated by the companies, the usage of social media in healthcare happens on a more personal and private level. Loh et. al. define this impact with the words “Greater social media use by patients, physicians, health care institutions, industry, and public health may result in significant positive and negative impacts both for individual patient care and at a population health level”. [Loh12] This way all mentioned stakeholders are able to initiate a topic for discussion in social media channels, although patients might hesitate to ask questions in case of a personal or related illness because of being ashamed, while at the same time hoping for support. For a healthcare professional the usage of social media is in no way more easy, as they may have the urge to give support to people, but due to ethical issues are not allowed to talk about related cases or patients they are treating at their place of work. Another remaining question is, why professionals should shoulder the extra work of communicating with a patient via social media. Lau et al. answers as follows: “Because [...] knowledge sharing, learning, social interaction, and the production of collective intelligence are important for them to improve their skills and deliver a higher quality of medical service. Since Web 2.0 tools provide a platform to connect all these professionals together for knowledge sharing, learning, social interaction, and the production of collective intelligence, health policy makers can extend the use of Web 2.0 tools to these professionals.” [La11]. While their definition is more focused on the application for the interaction between professionals, the same applies for a better understanding between practitioners and patients.

3 EHR and Dynamic Knowledge Asset Management

3.1 EHR enriched by social networks data

After giving a basic overview about healthcare and social media, this section focuses on creating an EHR that is enriched with data from PHR and social media, specifically from social networks communication, thus integrating dynamic knowledge assets into the EHR too. Enriching an EHR with PHR data and social media data offers a more profound basis for medical decision making. A use case about diabetes will be introduced later in this chapter.

Based on the definition of HIMSS², EHRs have “the ability to generate a complete record of a clinical patient encounter - as well as supporting other care-related activities directly or indirectly via interface - including evidence-based decision support, quality management, and outcomes reporting.” [HIMSS] The content of EHRs consist of administrative and medical or clinical data [HIMSS]. This content should be comprehensive and expressive, addressing all aspects of the healthcare process for all related disciplines and authorities. There should be no restrictions on the type of data that can be entered into the EHR [KS09]. The clinical data include e.g. the medical history, physical examinations, clinical orders, pathology reports, consultations, operative data, monitoring data, observations etc. of a patient. Ideally, the EHR includes all available patient data, irrespective of its source and provides medical professionals with meaningful views on these data [NSK11].

Managing this data effectively is a very challenging task because of the large amounts of data for every person, including different types of data like texts, statistics, images or a combination of all three. The use of EHRs offers significant benefits in healthcare. Direct access to patient history, lab tests and imaging from the point of care eliminates the delay required for the medical attendants to dispatch and retrieve physical records from distant physical locations. Therefore a dynamic way of handling this knowledge is necessary. Regarding these reasons an approach is needed, that has the means to help understanding the relations of different data acquired in the enriched EHR, while giving the right information in the right time to the right person, especially in connection to the mentioned social network. Based on the user role, different views have to be available as well as requirements for different knowledge assets (e.g. organizational, personal, structural, ...). Next to the EHR, a similar concept of PHR has been defined as “an electronic, universally available, lifelong resource of health information maintained and owned by an individual. PHR is different from an EHR system which is maintained by a healthcare provider organization”. [GGN07] This means, “the PHR [...] is separate from, and does not replace, the legal record of any provider.” [EHR07]. The proposed approach now enriches EHRs with the data from PHRs managed by patients and social data, like conversation or communication between patient and doctor e.g. about medication issues or side effects. This relation is illustrated in Figure 1.

² Health Information Management System Society

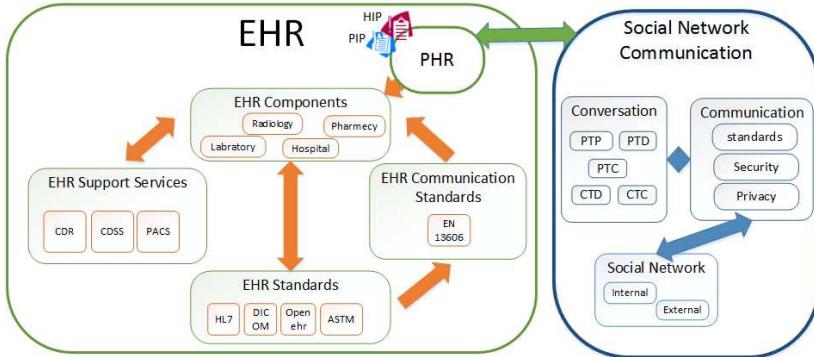


Figure 1. EHR Data Management

For the application or usage of a social network, a user requires a personal profile. He may add more health related information to this profile, thus enriching his PHR. Health information profile stores “users’ health information like specific wellness, conditions, medicines, and allergies. However, factors, such as lifestyle, interests, exercise, interpersonal support, work environment, and job risk, could also be used to give a better understanding of a user’s health background” [SLI12] and they may be stored in connection to the personal information profile. In this paper, these health related information and personal information about the user (in this case a patient or caregiver) will be called HIP (health information profile) and PIP (personal information profile) respectively. The mentioned social network may be a hospital internal social network or a network established via a health collaboration between different institutions (in the following both types are declared as an Internal Social Network (In-SN)). Additionally public social media services like Facebook, Twitter, or others are part of the modern hospital as well. While patients might also use these in their free time, their willingness to share medical information via these mediums is estimated as slim. Using multiple profile management [SLI12], personal profile information from different social media services could enrich the PIP of the In-SN. HIP and PIP include the main information about patients and they are created by patients directly for the PHR or with the help of Social Network Analysis (SNA). The practitioner can access to the EHR system as well as to the In-SN, like patient and caregiver, thus allowing a direct exchange between the most important stakeholders during the treatment of a patient. When establishing such a network the access for the patient should be voluntary, meaning he doesn’t have to use this medium to communicate with his assigned practitioner, while it should be mandatory for all practitioners of the hospital to participate in this network, as otherwise the service is not consistent and doesn’t reach the goal of transparency in the treatment process. The In-SN may conduct communication in the form of:

- Patient-to-Patient (PTP)
- Patient-to-Doctor (PTD)
- Caregiver-to-Caregiver (CTC)
- Caregiver-to-Doctor (CTD) and
- Patient-to-Caregiver (PTC)

This can be done in one hospital or a hospital collaboration, which would probably offer more interaction, but require more openness from the hospitals. Especially the PTD and CTD communication have to be handled in a secure and private manner, meaning that issues between doctor and patient or (e.g. in the case of patients with dementia) between caregiver and doctor have to be between them and not visible to other members of the network. If the patient and his caregivers want to communicate with the doctor or a doctor wants to add another expert to the conversation, both will have to register as communication points, so it is always visible who is part of the conversation. Ideally the practitioner who is assigned to the patient in “real live” will also be the one communicating with the patient or his or her caregiver via the In-SN. This requires a logic for assigning the patient to a specific doctor, a role and rights concept, as well as a flexibility in adding more experts or caregivers into a conversation. To make the previous communication between practitioner and patient visible e.g. for a new assigned doctor, the conversation is stored and archived as attachment to the EHR in form of a protocol. For this approach to work in practice, matching terms of service need to be established and agreed upon by patient (and caregiver). These terms of service benefit the practitioner, as he is able to show a documented conversation with the patient/caregiver, should there be troubles from the treatment. They also indicate the difficulties of a patient network in comparison to a public network.

On the other hand, the PTP, PTC or CTC communication content are totally independent from the EHR and the conversations are not to be stored in connection to the EHR. This allows patients to freely connect to others in a similar situation without the conversation being visible to the practitioner. The design of the network has to show clearly which parts of conversation are visible to all members in the network, and which are just visible for the PTD, CTD or a private 1:1 communication between two patients or caregivers. A difficulty in this context is the asynchronous way of communication, as a practitioner might not give a reply to a question on the same day, while the patient already asked a new question or send a reply to his own message. Additionally the practitioner has to be able to find and restructure a conversation in the EHR at a later point in time. Therefore the conversations need some type of metadata, giving a practitioner the possibility to search for certain information more easily. Furthermore for the creation of PIP and HIP patient rights and communication standards have to be considered.

After talking about the technical issues of such a form of communication, another difficulty will be the participation of medical staff, while having a busy day in hospital. Therefore the medical institution will have to promote a process change for their employees, thus giving them e.g. a fixed time per week for this “remote” consultation and patient service. On the other hand they will receive EHR enriched data, allowing for a better decision making e.g. during diagnosis or further treatment of a patient.

3.2 EHR Interoperability and Dynamic Knowledge Assets

Patients are able to participate in social media to manage their data and to discover and find other patients who share similar disorders or symptoms and to discover relevant clinical trials by leveraging shared patient data [Roi12]. Concepts and products how to

design an infrastructure for that kind of solution, as well as integrating practitioners into the conversation are for example offered by TelemedicineIM. [TIM13] In order to realize the benefits from the increased availability of information and communication, and in particular the possibility of sharing information across all the many organisations and actors as stakeholders that exist in EHR, the role of interoperability [VKD12] is important. By definition of [EHR07], “Interoperability is about continuous change management, implying that successfully establishing and maintaining eHealth interoperability is a long-term endeavour ...” Furthermore the source [EHR07] highlights that EHR interoperability needs to interpret “patient and other health information knowledge” independent of the source and that the eHealth interoperability is divided into different levels. Real interoperation means “using the interoperability features - exchange and share information and knowledge with other actors in the system for the purposes of collaboration, thus changing working practices and roles, multi-disciplinary teams, etc.” [EHR07].

The integration of knowledge management activities into knowledge-intensive business processes on the one hand leads to controlled knowledge flows among knowledge professionals and stakeholders, on the other hand knowledge management potentially improves the utilization of knowledge assets [NAF13]. Knowledge assets are classified on the distinction between stakeholders resources and structural resources. Structural knowledge assets are e.g. standards, best practices, patents, methods or intellectual property, while stakeholder knowledge assets are e.g. capabilities and relations, experiences, skills, creativity and innovation [CS04]. In this context “DKAM, enables the entire procedures and processes considering the dynamics of organizational or systematical knowledge assets through change management, to support each of the states and guarantee a successful approach to the change.” [NAF13] Stakeholders provide value dimensions with respect to the change plans. Therefore knowledge management teams are able to identify knowledge assets and influential factors on changes (i.e. update, create, reuse) of knowledge assets within the change states. Furthermore they are able to identify knowledge assets with respect to the process objectives and project procedures. “Knowledge assets are the completing pieces of the “technical” and “people” puzzle”, bridging the “gap between the technical side and people side”, while considering different factors like performance objectives and indicators [NAF13].

Based on research of Rebuge and Ferreira, healthcare processes in general are recognized to have the characteristics of dynamic process changes, dependencies due to complexity in medical decisions and amounts of data, multi-disciplinarity inside the healthcare network, ad-hoc decisions and individual processes, as well as log data management, which make them challenging for applying process mining [RF12]. The last aspect of log data management is especially interesting, as the availability and quality of data is the key to be able to apply process mining techniques. “The idea of process mining is to discover, monitor and improve real processes (i.e., not assumed processes) by extracting knowledge from event logs readily available in today’s (information) systems” [vdA11] According to the authors process mining focuses the process perspective, the organizational perspective and the case perspective [vdA11]. Caron et al. believe that process mining “addresses the problem that most organizations, and their stakeholders, have very limited information about what is actually happening in

the business processes” [CVB13]. Applying process mining techniques in healthcare has been highlighted by the Process Mining Manifesto [PMM09], which has been created by a group of more than 75 people involving more than 50 organizations. Today’s healthcare has gained complexity thus medical procedures and processes are changing continually. Healthcare processes are less structured due to expertise, intuition and creativity, but at the same time there are huge opportunities and improvement potentials (“Spaghetti process improvement”) to learn and interconnect with other users [vda11]. Mans et al. defined healthcare processes as diverse in a wide range of offerings, distributed, with involvement of multiple staff and departments and leading to different treatments, even if the diagnosis is similar [Man10]. Using DKAM leads us to the implementation of changes and also to sustain long-term healthcare advantages.

In the proposed concept the knowledge assets are the knowledge elements contained in the EHR and PHR of a patient. Due to examination or laboratory results being added, medications being changed or starting new therapies, they are continuously expanding, thus changing. The processes for the practitioner again are changing as mentioned in the section above in reference to [RF12]. Utilizing In-SN by a practitioner is only possible when this dynamic expansion of knowledge assets in the patient file is transparent, as otherwise he won’t be able to support the patient via the social network or to answer specific questions e.g. regarding the latest examination results. A dynamic EHR based on dynamic knowledge assets is illustrated in Figure 2.

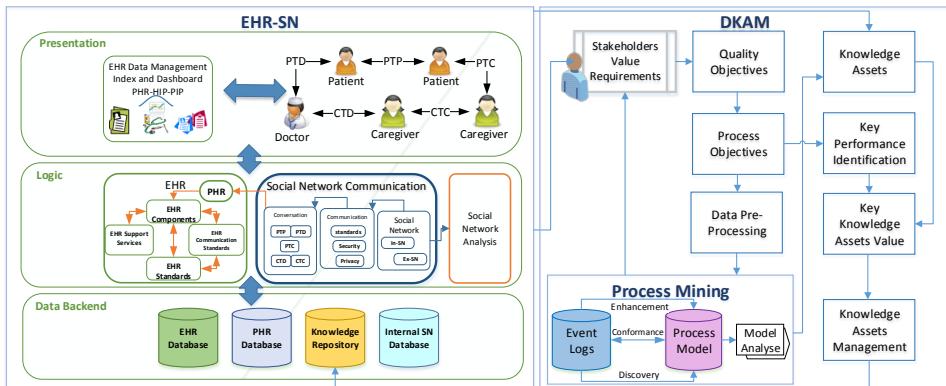


Figure 2. Conceptual Model

In the left side, an interoperable EHR model using In-SN is depicted. It is based on the three layer architecture.

- Participants in the network are medical staff, patients and caregivers. The presentation layer contains different views, as the different participants require different knowledge assets. The doctor focuses on the enriched EHR and his communication inside the network, while the patient adds information to his PHR including HIP and PIP.
- The logic layer visualizes the aforementioned and explained enrichment of EHRs with PHRs, social network communication as well as data from social network analysis (if available).

- The data backend consists of different databases (EHR, PHR, internal social network, additional knowledge assets) which are brought together via the logic layer.

On the right side of the layer architecture the DKAM workflow is illustrated. This workflow builds an extension of the logic layer for assessing the knowledge assets. All assets are classified on the distinction between stakeholders resources and structural resources. **Quality and process objectives** are identified from **stakeholders value requirements**. The main stakeholders are the practitioners, who determine the requirements and the associated priorities. With respect to these objectives, **data pre-processing** extracts **event logs** which are related to EHR data elements. **EHR event logs** are records of named activities that are created by using EHR. Cases are made of events that are usually represented by time stamps. Event logs are an input for process mining. For processing it is recommended to create a process map or process model from the event data. [We12]

Today, “EHR process mining can discover, monitor and improve evidence-based processes (not assumed processes) by extracting knowledge from event logs available in (or “generateable” from) today’s EHRs.” [We12]. Process mining can discover information, make comparisons for conformation and enhance processes [vdA11]. The **model analyses** are the output of mining EHR processes that may lead to EHR process improvements. With respect to the different perspectives of process mining, event logs can derive relations between performers of activities [vdAR05]. Mining these relations using metrics based on cases, activities and special events leads us to generate sociograms that can be used in SNA software as an input. Related Key Performance Indicators (**KPIs**) are identified according to process objectives. Furthermore important KPI factors are specified with the use of process mining and comparison between KPIs. A matrix of knowledge assets and performance objectives is used to find the **knowledge assets value**³.

Afterwards knowledge assets are valued depending on the level of performance objectives achieved compared to predefined performance objectives. Key competence is created by performance measurement and with these EHR competences **knowledge assets are measured** and **managed**. By research of Malhotra, different knowledge assets measurement models exist and they are compared and analyzed with indicators. Knowledge Management activities, process improvement, stakeholder relationships and satisfaction lead to create objective indicators [Ma03].

After introducing the concept in a theoretic way, a use case of diabetes patients will be used for highlighting the practical benefits of the concept: The participants in this use case are the patient himself as well as one or more practitioners. The EHR contains all information about tests, medication and visits in the clinic. The patient is now able to keep the PHR like a diary and monitor his condition, medication and possible side effects. Additionally he is able to communicate remote with the practitioner about questions related to his illness. All aforementioned actions are activities, which are

³ Knowledge assets are listed in rows, classified in accordance with the knowledge assets map, and the specific defined performance objectives are listed in columns [CS04]

logged in the EHR event log, which will lead to a dynamic update of the knowledge assets in the EHR. Based on these event log information, a new model is derived, which shows the differences between an “a priori model” and a “real treatment process model” (like medical errors) to enrich the a-priori model. If the practitioner for example prescribed a more balanced medication (objective) and the blood sugar level development improves (medical performance indicator), then this objective is a structured knowledge asset in the PHR of the patient, which again could be valued. The dynamic interaction of various knowledge assets could provide a sustainable competitive advantage [CS04].

Considering effective self-care tools for at home, the proposed concept is also able to empower patients who suffer from diseases which need long term care to e.g. lower care expanses. Regarding EHR data and dynamic knowledge discovery from event logs, there are a lot of events that are related to EHR knowledge assets. Enriched EHR data application process mining might then lead to dynamic interaction of all stakeholders’ knowledge. The aforementioned process may also be applied for improving the performance and processes inside the hospital and during the treatment process in general.

After detailing the concept, the question about its applicability remains. Basis for implementing the concept in a real medical environment are not only technical changes regarding the management of the EHRs, but also process changes for the institution, practitioner and patient. Therefore the next step will be the prototypical implementation of the concept with medical institutions of different sizes. As it won’t be possible to integrate the prototype directly inside a real-time environment a test with a limited number of test candidates is aspired.

4 Conclusion

The paper discussed a concept for enriching an EHR with data from PHRs and social media communication. For handling these different data sources DKAM is proposed, as it offers the handling of knowledge objectives and events. It also bridges the gap to process mining. The changed role of a patient in today’s healthcare environment and his use of ICT technologies has been discussed. Consequently, the authors focused on the integration of a social network for patient care, which would allow a direct communication between practitioner, patient and caregiver. This enables a doctor to always have up-to-date data, while treating the patient and at the same time improves the quality of the healthcare processes and the collaboration between doctor and patient. It also offers a better overview of the status of a patient to doctors with a more comprehensive personal health summery. Discovering dynamic knowledge from these systems and using process mining to mine the complex healthcare processes could be the main results of this approach which still stands on a conceptual level. The next steps for proving and evaluating the proposed concept would be the establishment of a prototype and running tests with experts and patients alike. Additionally the necessary process and workflow changes for a medical environment will be analysed from a process, change and knowledge management point of view.

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