Home-centered Health-enabling Technologies and Regional Health Information Systems

An Integration Approach Based on International Standards

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Summary

Introduction: This article is part of the Focus Theme of Methods of Information in Medicine on “Using Data from Ambient Assisted Living and Smart Homes in Electronic Health Records”.

Objectives: In this paper, we present a prototype of a Home-Centered Health-Enabling Technology (HET-HC), which is able to capture, store, merge and process data from various sensor systems at people’s home. In addition, we present an architecture designed to integrate HET-HC into an exemplary regional Health Information System (rHIS).

Methods: rHIS are traditionally document-based to fit to the needs in a clinical context. However, HET-HC are producing continuous data streams for which documents might be an inappropriate representation. Therefore, the HET-HC could register placeholder-documents at rHIS. These placeholder-documents are assembled upon user-authenticated request by the HET-HC and are always up-to-date. Moreover, it is not trivial to find a clinical coding system for continuous sensor data and to make the data machine-readable in order to enhance the interoperability of such systems. Therefore, we propose the use of SNOCAP-HET, which is a nomenclature to describe the context of sensor-based measurements in health-enabling technologies.

Results: We present an architectural approach to integrate HET-HC into rHIS. Our solution is the centralized registration of placeholder-documents with rHIS and the decentralized data storage at people’s home.

Conclusions: We concluded that the presented architecture of integrating HET-HC into rHIS might fit well to the traditional approach of document-based data storage. Data security and privacy issues are also duly considered.

1. Introduction

Health-Enabling Technologies (HET) are an emerging field in research and development. HET aim to support our lives with sensor-based technologies in health prevention, diagnosis, therapy, and rehabilitation [1, 2]. These systems can be located at hospitals, at doctors’ practices or even at people’s home [3]. The latter ones are called Home-Centered HET (HET-HC) and form a class of systems, which are able to continuously collect sensor and other data at home, e.g. data related to physical activity [4], blood glucose [5] or blood pressure [6]. HET-HC are extracting information from stored data and interpret these information using medical knowledge. The scope of HET-HC includes, but is not limited to persons with diseases, who can be monitored in-home using sensors (e.g. monitoring congestive heart failure using a body scale), persons with disabilities, who want to live self-determined and self-sufficient in their own home, and active persons, who want to monitor their activity during sport. There is a wide range of scenarios and medical conditions that can be covered and the choice of the sensor or the set of sensors used depends on the concrete application and the demand of the owner of the system (OoS). Scenarios could be to measure physical activity, to support training of specific muscle groups for rehabilitation, or even to detect emergency situations, e.g. falls. Usually, cheap hardware...
platforms (e.g. Raspberry Pi®, The Raspberry Pi Foundation, UK), which can be used as base station, have enough resources for most applications of HET-HC. Especially, the Internet of Things and mobile health in terms of apps, or wearable sensors can be used to gather data about the OoS and transmit those using protocols like µDTN (Delay Tolerant Network) to the base station. HET-HC are typically able to provide feedback. This feedback can contain information about the health status or it can be an alarm in case of emergency. Alarms are triggered to automatically call for help using suitable communication channels, e.g. by text messages, by phone with prepared messages, or by text-to-speech engines. For these scenarios data are gathered at the OoS’s home and communication is only needed in case of emergency or on demand. Thereby, the best and safest place for sensitive sensor data is the OoS’s home. Collected health information might be also of interest for physicians, but the heterogeneity of HET-HC makes it difficult to access stored data and to adequately transfer information to the requesting physician in a suitable format. To facilitate the use of the data about the OoS’s health state beyond the borders of his or her home environment, it is necessary to enable access to these data. Usually, a patient is consulting more than one physician and sometimes the need to access the data is not known in advance (e.g. during a vacation). But direct proactive communication to one or more physicians is not a satisfactory solution. By consulting different physicians, the patient builds his own informal health care network. This network often changes over time and has an unpredictable structure. Because of the informal ad-hoc character, this information system cannot be managed in a classical way. The ideal architecture would not only allow arbitrary access to any information gathered at home by any physician at any time. It would also support the information exchange between any two participants in the healthcare network randomly build by the patient. There are different ways to store the data of patients in such a Health Information System (HIS). Beside decentralized storage at home, centralized or federated models can be realized. Of course, patient’s privacy has the highest priority. Therefore, access authorization by the patient plays an important role. Given an infrastructure, which provides a secure and standardized way of communicating data, physicians and other Health Care Providers (HCP) could access patients’ existing data. This would be advantageous for all parties. A possible solution is to integrate HET-HC into regional Health Information Systems (rHIS). These systems are standards-based in order to allow for trans-institutional communication and data exchange [7]. Combining HET-HC and rHIS will result in sensor-enhanced rHIS [8].

This paper describes an architecture how an exemplary HET-HC could be integrated in a specific rHIS that is currently in its setup phase. Different issues are mentioned, which have to be considered to achieve this vision. An evaluation of the implementation will follow in future steps.

1.1 Related Work

The integration of HET-HC into rHIS is often done through proprietary protocols or is not sufficiently reported in the literature. In the following, we briefly present realizations of HET-HC, which have a connection to the outside world and transmit data and information to an external HIS.

Vironne et al. developed a HET-HC to identify circadian activity rhythms and behavioral patterns of elderly persons [9]. Infrared motion sensors, temperature sensors and a bed-based vital sign monitor were used in the HET-HC. The HET-HC was able to trigger alerts in case of abnormal situations. Sensor data were transmitted continuously to a personal computer and periodically transferred to a remote and secure database. For the remote database, compliance of Health Insurance Portability and Accountability Act (HIPAA) was ensured through network security techniques. The HIPAA covers a number of aspects, including the regulation of national standards for secure data transmission in the context of health care [10]. However, in their article the authors did not report about the protocols used.

Bourke et al. tested a long-term fall detection system for elderly people [11]. A tri-axial accelerometer was incorporated into a vest and was used to detect falls. A self-developed algorithm was able to generate fall alerts based on the accelerometric data. The fall alerts were forwarded to caregivers through a mobile phone. A total of 115 fall events were detected by the fall sensor system, whereby 532 fall-events were received at the care center. This deviation was due to technical malfunctions.

To improve the quality-of-life of patients with Cardiovascular Implantable Electronic Devices (CIED), a telemonitoring system was implemented [12]. In this telemonitoring system, three standards were used: ISO/IEEE 11073, HL7 v2.x and Integrating the Healthcare Enterprise (IHE) profiles [13, 14]. By using these standards, vendor-independent CIED report data can be delivered to adaptive care planners. The ISO/IEEE 11073 nomenclature can be used with medical, healthcare and wellness devices. However, it may not fit to the demands of all HET-HC applications and scenarios (e.g. power sensors, motion detectors, and various aggregates).

There are also commercial services available. On the one hand, these services are able to store health-related data, e.g. Microsoft HealthVault, but they primarily provide non-structured and non-machine-readable deposition of data. On the other hand, Care Innovation or Tunstall offer scalable HET-HC platforms, but they only support their own sensor products due to the use of proprietary protocols.

These examples make clear that it is necessary to establish reliable, stable and standardized communication infrastructures. A secure and standards-based communication in a sensor-enhanced rHIS infrastructure could enable pervasive healthcare by connecting, collecting and providing machine-readable information anywhere and anytime needed by providers or consumers of healthcare services.

2. Objectives

Aims of our research are

- to present PICS (Personal Intelligent Care System) as a prototypical implementation of a HET-HC and
• to integrate PICS into an exemplary, standards-based rHIS, considering developed requirements.

Data security and privacy issues are highlighted and duly considered.

3. Scenario and Requirements

Based on a rHIS infrastructure, four types of architectural paradigms for information and communication technologies are conceivable: Person-centered, home-centered, telehealth service-centered and health care institution-centered architectures [3]. In the following passage, one concrete scenario is described to outline the practical use and to show possible benefits of the integration of HET-HC into rHIS.

One imaginable scenario might be that a patient with hypertension consults a general practitioner. The general practitioner wants to monitor the blood pressure of the patient for the next couple of weeks in order to control the dosage of the anti-hypertensive treatment. The patient receives a home blood pressure monitoring device, which is able to communicate wirelessly with a base station. The benefit for the general practitioner is to save money and hours of work, because the patient is able to measure on his own. Furthermore, blood pressure measurements at home might also be able to avoid white coat hypertension [15]. Utilizing a sensor-enhanced rHIS, the general practitioner could remotely access blood pressure data from the patient's base station at the next visits with the authorization of the patient. In addition, the general practitioner can refer the patient to a cardiologist, who can access the data from the HET-HC as well as the findings of the general practitioner.

One of the requirements to handle when integrating HET-HC into rHIS is the use of differing data representation paradigms. On the one hand, HIS are typically built to handle documents, which are the classical type of container for medical data and information. On the other hand, HET-HC are continuously capturing and processing data and are generating a continuous data stream. Both paradigms are based on different principles and there is a need to consider this issue when integrating HET-HC into rHIS.

Beside representation paradigms, it is important to make information machine-readable, but existing coding systems (e.g. SNOMED CT, ISO/IEEE 11073) might not be sufficient to encode the huge variety of sensor information and aggregates gathered and produced by HET-HC.

In the following sections we present an existing prototype of a HET-HC and its integration into an exemplary rHIS. Thereby, we focus on data representation, exchange and security, and coding terminologies.

4. PICS Prototype

The Personal Intelligent Care System (PICS) is a realization of HET-HC and primarily aims for capturing, storing, merging and processing data from various sensor systems at people's home in a medical context [16]. PICS also enables to manage simple and complex control functions of home automation systems such as light regulation or stove control. Secondary aim of PICS is to provide an interface to the outside world, which can be used as an interface for data and information access as well as a feedback component. Because of the heterogeneity of existing sensor systems (e.g. home automation systems, home blood pressure measuring devices, body scales, etc.) and utilization of the existing individual communication infrastructure at people's home for data and information access from outside, PICS has a modular structure. PICS is based on an Open Services Gateway initiative (OSGi)-framework, which runs in a Java virtual machine. This framework allows for encapsulating pieces of software into modules (called bundles), which can be installed, removed and updated during runtime. Each bundle provides a number of services and registers these services at an internal centralized service registry. Other bundles can find and use these services. Figure 1 shows an exemplary bundle structure of PICS. Again, this structure is OoS-specific and depends on the presence of sensor systems and the given individual communication infrastructure. In our case, the implementation of PICS covers sensors of a KNX home automation system (i.e. switches, motion detectors, flow sensors, and a bed occupancy sensor), a power consumption measurement device (Current Cost*, Aldershot, Hampshire, UK), and a home blood pressure monitoring device (Omron Healthcare Co., Kyoto, Japan).

PICS interconnects all communication channels. Currently, PICS uses the lightweight MQTT (Message Queue Telemetry Transport) protocol [17] for internal communication. This enables PICS to run in a distributed environment rather than in a single Java virtual machine. Messages can contain a variety of tags, e.g. %fullname, %phone, %date etc., which will be replaced using personal configuration files.

Actions on simple sensor events can be parameterized in a sensor configuration file, e.g. to turn on a light or to trigger a manual alarm via email or text message. The main control bundle is a decision support system based on an Arden syntax compiler and runtime environment (Arden2ByteCode [18]). Arden syntax is a Health Level 7 (HL7) standard for representing medical knowledge for decision support in a manner close to a natural language. Knowledge is encoded in Medical Logic Modules (MLMs). MLMs are able to generate a predefined action based on sensor data, such as to generate an alarm or to feedback information to the OoS [19]. MLMs are used, if more complex processing on sensor data is needed instead of simple events generated by a single sensor. This is the case, especially if more than one sensor is involved in data processing.

For external communication purposes, e.g. to send alarms, HL7 CDA-documents are generated, which include information about the type of alarm and personal information about the OoS. The documents are transmitted to a sink for further processing. This is the connection of PICS to the outside world. In the following, we will describe an example rHIS architecture that can act as document sink and show new applications for PICS, which emerge from this architecture.
5. Integration of HET-HC into sensor-enhanced rHIS

5.1 HET-HC rHIS-Gap

In their proactive nature HET-HC differ from classical medical practice. A lot of data are generated by the everyday continuous use of the system. HIS instead are often built around the artifact 'document'. While this artifact from the pre-digital era fits the procedures of classical medicine, it cannot be seamlessly used to represent continuous data streams. Data stream management systems are solutions to handle and process these kinds of data, but these concepts have not made their way into rHIS, yet [20, 21].

One common approach to bridge this gap is to slice the data stream in predefined time intervals. The resulting segments are artifacts that can be represented by a document and aggregations of these documents can result into further documents. While these documents can easily be handled by classical HIS, the generated artifacts are not necessarily the best form of representation. For example, it might be an approach to dissect streams on a daily basis. Often midnight is used as the point in time to end one document and to start the next. This approach might be useful if one is interested in daily activities, but e.g. nocturnal sleep is scattered over two documents, which makes an automated sleep analysis unnecessarily more complex.

The World Wide Web is an architecture that is based on documents as well. Classically, a document has been stored on a web server and the server delivered the document to clients upon request. Nowadays, most of the web sites are of dynamic nature. Information is stored in databases and assembled to a document by the server upon request by the client. In some situations the information of multiple servers is assembled by the client to the finally rendered document. The latter approach is interesting in the focus of integration of HET-HC into document-based rHIS and is already used in productive rHIS applications [22].

5.2 Lower Saxony Bank of Health

Facilitating data transfer is a major problem in health care. One recent approach is to detach medical data from the HCP and establish a neutral third party providing a service to access these data in documents. This approach is called health record banking and was first suggested by Dodd [23]. One instance of a provider centered, consumer controlled, decentralized health record bank is the 'Lower Saxony Bank of Health' (LSBH [24]). It aims to provide a neutral third party information broker for medical data, based on the Cross-Enterprise Document Sharing (XDS) and Cross-Enterprise Document Reliable Interchange (XDR) communication profiles defined by the IHE in the Lower Saxonian region of
Germany. A legal informed consent provided, data can be registered and accessed by HCP building a lifelong electronic patient record.

The architectural design combined with the integration profiles used leads to format independency. Medical data, aggregated by a HET-HC, can be expressed as encapsulated CDA, providing required metadata for post processing. The information encapsulated can be of any format, as long as the receiving HCP can handle it.

5.3 Document Registration

The decentralized approach implies that data are not being stored centrally by the LSBH, but only the links to the registered data. Accessing a link registered by a HET-HC (and in this particular case by PICS) can invoke the OoS's PICS instance to deliver the requested document. To realize dynamic generation of documents, PICS can register a kind of placeholder-document at the LSBH and the corresponding document is generated on demand by PICS, if an authorized party tries to access it. In this approach, no documents are generated without necessity and the system could allow the receiving party for controlling the information granularity without storage overhead. Furthermore, this has the advantage that requested documents are always up-to-date.

The registered documents could represent the whole spectrum of possible analyses of each module of PICS. In case of an accelerometer module, analyses might cover an activity score (e.g. calories burnt), a gait pattern assessment, or a sleep monitor. In addition, this module could register the raw accelerometer data at the LSBH and the requesting HCP can send the anonymized data to an external commercial service provider in order to get more specialized analyses. It would also be possible to create a module that combines data of several sensors and analyzes these fused data, but this depends on the individual installation.

5.4 SNOCAP-HET

The structured part of HL7 CDA relies on coding systems and every single piece of information needs to be coded. Typical coding systems in the clinical context are LOINC and SNOMED CT. In view of continuous sensor data streams or aggregates, these systems may currently not be suited to cope with such data. Especially, codes for accelerometers, motion detectors, or power sensors may be missing. An alternative approach could be the use of ISO/IEEE 11073. This standard covers the coding and realtime transmission of sensor data streams [26], but it might not be suited to manage the huge variety of data and aggregates gathered by HET-HC in its current form. But since CDA allows for using any nomenclature or classification system as coding system, the Systematic Nomenclature for Contexts, Analysis methods and Problems in HET (SNOCAP-HET) might serve as a suitable alternative [25]. As an index for describing the context of a certain measurement, SNOCAP-HET is an open monohierarchical nomenclature with the three axes “contexts” (C), “problems” (P) and “analyses” (A). The aim of SNOCAP-HET is to describe any possible scenario consisting of a context (specified by the objects to be measured, their initial frame of reference and the data sources), a healthcare-related question and a preferably complete list of analysis methods suitable for HET.

5.5 Data Security

Data generated by HET-HC may contain medical (e.g. blood pressure, weight, blood sugar, gait parameters, etc.) and personal (e.g. demographic data, statistics for daily activities) information. A transmission of these sensitive information out of the home environment to a HCP in the context of a treatment or to other service providers in emergency scenarios, raise several issues of data security, integrity, and protection. Before transmission, the data have to be encrypted appropriately, secured against unwanted changes and all interactions have to be recorded. In addition, communication of medical and personal information by a HET-HC must be controllable by the affected individuals. This means, each OoS living in an apartment monitored by HET-HC must be able to define in a fine-grained way which parts of the collected, aggregated or interpreted data shall leave his or her personal environment.

Using the concept of health banking with decentralized data storage based on IHE profiles employed by the LSBH owners of a HET-HC must also permit the central storage of patient identification, document reference and document metadata. Existing regional (e.g. data protection law of Lower Saxony), national (e.g. federal data protection law of Germany) and transnational (e.g. EU directive 95/46/EG) laws and policies control the legitimacy of each data storage and communication as well as the legal consequences in case of misuse. All of them have to be considered during the integration of HET-HC into LSBH. Regarding the LSBH, the informed consent of the individual forms the legal basis for data transfers using the communication infrastructure and data storage in the personal health record of this exemplary rHIS. If emergency detection of a HET-HC is used, the permission of the individual for data communication in case of such situations also has to be obtained in advance.

In Germany these necessary informed consents must be paper-based with a handwritten signature or an electronic document signed with a qualified electronic signature to be legally valid. Both, the new German health insurance card and the new identity card have the ability to generate the needed qualified signatures.

German laws on data protection also define that each individual has the ‘right to oblivion’. This means that stored data have to be erased securely and permanently according to the will of the individual. Data stored on the HET-HC could be directly erased by the OoS. Deletion of stored data from the components of the sensor-enhanced rHIS has to be performed by the operator of the infrastructure. If data of the individual were stored in information systems of service providers, these data have to be deleted as well according to the legal regulations. In Germany only HCP are allowed to keep communicated medical data, if they were used in a treatment context (legal duty of documentation). All other participants (rHIS provider and service provider) have to be bound by con-
tructual provisions to this deletion duty before any kind of data is transmitted.

6. Discussion and Conclusion

In this paper, we presented the prototype PICS, which aims for capturing, storing, merging, processing, and communicating data from sensor systems at home. The modular structure of PICS enables the HCP to customize the system to the requirements and demands of the OoS. The modular structure was used due to the large variety of available sensor systems and communication channels. Each sensor system and communication channel can be represented and embedded as an OSGi-bundle. Currently, there is no standard available to interconnect all sensor systems and communication channels. PICS can be used as the broker gathering data from all sources in a standardized way (e.g. using ISO/IEEE 11073, HL7 CDA PHMR, Bluetooth Medical profile, etc.) and making it available in a decentralized and on-demand fashion. The OSGi-bundles forward captured data to the data processor. Data processing is done on a higher abstraction level using HL7 Arden syntax [18, 19, 27]. Action rules based on data of one or more sensors can be implemented in the Arden syntax programming language, which is close to a natural language.

In addition, we presented a standards-based architecture to interconnect PICS with rHIS. Data exchange and communication can be implemented using HL7 CDA-documents. In our case we chose an exemplary health bank (LSBH) as rHIS to register such documents. However, since documents are rather inappropriate as a container for continuous sensor data streams, only placeholder-documents are registered to fit the document centered approach of the LSBH. The content of these placeholder-documents is generated by PICS only upon an OoS-authenticated request of a HCP. Thus, access information rather than real medical data is encapsulated into a LSBH registry entry, which can be used to start a conventional retrieval process by a HCP. PICS hooks the request and creates an aggregated abstract of the requested data stream into a document, defined by the access information stored in the LSBH registry entry. The created document is then delivered as usual containing always up-to-date information. Another approach would be a centralized data storage solution, which might be faster and less prone to failure than the decentralized approach, because the internet connection of users can be slow and unstable [23]. But an advantage of the decentralized data storage solution is that only parts and not all accessible data will be sent to the rHIS. Furthermore, data will only be sent upon OoS-authenticated request. Assume that PICS is installed in 1% of all 4 million households in Lower Saxony and each system is equipped with a tri-axial accelerometer sampled at 50 Hz with a resolution of 12 Bits. Then, 55.62 MBytes were sent to LSBH per household per day, which means LSBH has to handle and store 2.12 TBytes each day – only accelerometer data. Indeed, it might not always be necessary to store raw accelerometer data. But consider a third-party data processing company, which provides special services (e.g. an extensive gait analysis) the HET-HC cannot offer (due to low performance, etc.). The OoS authorizes the company to receive and analyze the data. This might be a scenario for HCP services (including cloud computing) in the future. Therefore, the architecture of LSBH was chosen to be decentralized.

A special problem when integrating HET-HC into rHIS is the coding system to machine-readable code the sensor data or aggregated information of the data provided by HET-HC. Especially, frequently used coding systems like SNOMED CT and LOINC do not yet provide codes for all kinds of sensors, e.g. power sensors. This is not a drawback of these coding systems, since such sensors were not applied in a regular clinical context so far. Next versions may contain these codes, which would enable their use in the context of HET-HC. Alternatively, specialized nomenclatures like SNOCAP-HET can provide the needed terms. This open nomenclature already contains codes to describe the measurement context and the sensors applied in a certain situation.

6.1 Future Work

A next step is to implement the presented integration of PICS into LSBH and to evaluate the system. The evaluation part will be done in a local research flat, which is planned to be inhabited by senior citizens for a longer time period (multiple months). In this real environment these senior citizens will explore a “Smart Home”. Furthermore, we are going to enhance PICS. The next step is the integration of voice control in PICS. Thereby, commands like “living room – light on” will turn on the light in the living room. In addition to a smartphone, we plan to install a distributed microphone array to control PICS.

References