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MyPHRMachines: Lifelong Personal Health Records in the Cloud

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Abstract

Personal Health Records (PHRs) should remain the lifelong property of patients and should be showable conveniently and securely to selected caregivers. Regarding interoperability, current solutions for PHRs focus on standard data exchange formats and transformations to move data across health information systems. In this paper we propose MyPHRMachines, a patient-centric system that takes a radically new architectural solution to health record interoperability. We propose to deploy besides the medical data also the related software to the PHR system. After uploading their medical data to MyPHRMachines, patients can access them again from remote virtual machines that contain the right software to visualize and analyze them without any conversion. Patients can share their remote virtual machine session with a selected health provider, who will need only a Web browser to access the pre-loaded fragments of the lifelong PHR. We illustrate how our prototype already supports the use case of a real-world patient and discuss the research agenda required to translate this prototype into a viable solution for the international healthcare industry.

1. Introduction

In a recent review paper, Kaelber et al. define a Personal Health Record (PHR) as “a set of computer-based tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it” [8]. We adopt a refinement of this definition by distinguishing between the actual PHRs (health related data, owned by individual patients) and the PHR system that offers functionality to upload, analyze and share PHR data [6]. PHR systems differ from Electronic Health Record (EHR [7]) systems, being patient-oriented rather than caregiver-oriented. While EHR systems, in fact, store the information produced by health providers, mostly to guarantee legal compliance, PHR systems make patients responsible for their health information.

PHRs should be portable, i.e. remain with the patient, contain lifelong information, and should not be restricted by file formats or other local issues [2]. Kaelber et al. conclude from their survey that the four top PHR research opportunities reside in (i) function evaluation, (ii) adoption and attitude analysis, (iii) privacy and security solutions, and (iv) architectural solutions.

Regarding function evaluation, successful PHR systems enable patients to enter their own health information and also provide fine-grained controls to share that information with others. The HL7 organization identifies 14 PHR functions in 3 categories, for example: *Decision Support* in the *Personal Health* category, *Financial Management* in the *Supportive* category and *Auditable Records* in the *Information Infrastructure* category. Adoption and attitude analysis reveals that patients are eager to use PHR systems but fail to do this effectively so far [5]. Regarding security and architecture, the relative benefits of free-standing (third-party) PHR systems should be analyzed against those of provider-(e.g., hospital-) tethered PHR systems. We argue that free-standing systems have more potential since they enable a patient to organize his/her data regardless of a particular health provider’s concerns. Some EHR integration is however desirable to avoid manual data re-entry [4]. Kaelber et al. also give high research priority to evaluating the relative benefits and costs of different PHR architecture models.

In this paper we present *MyPHRMachines*, a patient-owned health record system based on remote virtual machines hosted in the cloud. Virtualizing medical software along with medical data has various advantages. First of all, it makes the PHR information trustworthy. Medical specialists are generally rather skeptic to new information technologies [9]. PHR systems in which PHR data have been manipulated by conversion software and displayed also by non-original viewer software may generate additional resistance. This problem has not yet been reported in literature. A second argument for incorporating the software for viewing the original data in PHR systems is of economic nature: it is much more efficient to reuse valuable legacy software than to re-build it upon each technology change.

MyPHRMachines is particularly promising for countries with a very heterogeneous architecture of systems across hospitals and other care institutions. It is also particularly promising for patients that move or travel across different countries during their life. In general, it provides a promising basis for example as PHR platform within the EU, where citizens are free to travel or relocate across countries of the union.

The remainder of this paper is structured as follows: Section 2 describes one very specific use case that motivates the relevance of systems such as MyPHRMachines. Section 3 describes the architecture, design goals, and a demonstration of the system. Section 4 describes a research and development agenda for realizing our vision of a multi-national adoption of the proposed approach. The agenda includes further investigation of issues that go beyond the technical aspects that are covered by this paper.

2. A motivating use case: multiple back injury

We consider the case of non-severe scoliosis (spine curvature of less than 20 degrees) and discopathy (intervertebral disk fracture) due to physical traumas. The diagnosis and treatment of such conditions is not an easy task and physicians often tend to waive intensive and expensive treatment referring the patient to physiotherapy or even commercial fitness clubs for palliative therapy. The condition, however, may remain latent for years and reappear in the long run. The decision to start a professional, long-term revalidation program may be postponed too long especially when caregivers lack access to prior scans and analyses. In today's situation, data that is generated during a revalidation program (e.g., endurance and strength related data) is typically not archived systematically either. We argue that also such data however should (and can) remain with the patient to facilitate follow-up diagnoses and treatments.

Our use case concerns the medical history of a real patient of the Belgian healthcare system affected by the above mentioned condition. For reasons of privacy, the case has been made anonymous. The medical history of the patient can be synthesized as follows:

1. At the age of 15 the patient injures for the first time his back in a home maintenance task and receives chiropractor care to relieve acute stress between the shoulders;
2. At the age of 18, the patient experiences a wintersport accident, leading to a severe hematoma in the lower back; a RX scan is made and analyzed at the foreign holiday location, after which the patient is sedated and transferred to his home country, where he undergoes various medical scans (RX, MRI, bone scan with

chemical tracer); the patient is referred to kinesiotherapy for four months and is discharged with the instructions to continue performing regular sports activities, which should drain the hematoma and relieve the pain;

3. after seven years (at the age of 25), the patient is still bothered by the hematoma consequences and visits a physiotherapist, the patient undergoes a new RX and MRI scan but the physiotherapist does not find noteworthy problems; the specialist does notice a non-severe scoliosis between the shoulders (cfr., point (1)) but no treatment is prescribed;
4. the patient is referred to a neurologist, who orders a new bone scan (the old one being at another hospital and not retrievable); the bone scan again does not reveal bone traumas that can clarify the lower back pain that the patient is suffering from. The patient and doctor agree to remove at least a hematoma cyste that has resulted from the wintersport accident;
5. after four years (at the age of 29), the patient still has back pain and asks his GP for further advice; the patient receives acupuncture and massage therapy, without noticeable improvements to the patient's condition;
6. after one year (at the age of 30), the patient visits another team of specialists (an orthopedist cooperating with a neurosurgeon working outside of a hospital). The orthopedist again asks for RX and MRI scans but also inspects the previous MRI scan (which is supplied on a laptop by the patient). The patient is recommended to carry his own CD copy of the new test results from the hospital to the specialist, since transmissions of CDs have sporadically failed for other patients. The specialist discovers the discopathy (intervertebral disk fracture), which may have been caused by the wintersport accident (12 years before). Since surgery only has an 80% success rate, the patient engages in an intensive lower back revalidation program. This should also reduce pain caused by the scoliosis.

The diagnosis and treatment of our patient could be improved in several ways. First, for minimizing the treatment costs and patient stress, the patient should not undergo more than once the same scan or, generally, examination, unless strictly required for formulating a diagnosis. In our case, specialists often ordered a new scan for our patient because either old scans were not available/retrievable or simply to avoid the burden of performing a perhaps lengthy search in the hospital Picture Archiving and Communication System (PACS). Second, our patient has never been able to show his entire medical history, including scans. Specialists, in fact, often based the diagnosis only on the exams

that they ordered. In this regard, the diagnosis of the discopathy could have been anticipated if the patient would have been able to consistently show his complete medical history to all the specialists and institutions that he visited. Eventually, our case shows that hospitals and GPs IT infrastructures are not sufficiently integrated yet to provide a lifelong EHR for our patient. The situation gets even more critical when integration is required among institutions in different countries. Poor integration may result from poor communication within national networks or from adopting different standards, for instance for scan acquisition and visualization.

MyPHRMachines¹ is built to solve the problems stressed by our use case. In particular, it allows (i) secure lifelong management of patient medical records, since data are stored in the cloud and do not have to be carried around by patients [15] and (ii) a Software as a Service (SaaS) approach to data visualization. The SaaS approach implies that, besides medical records, interested stakeholders can access also the technology required to visualize/analyze the records as a service.

Note that the problem and our solution are not simply confined to the realm of back injuries and medical imaging. The above mentioned issues regarding lifelong, integrated management of patient data may be easily encountered in other domains, such as patients affected by diabetes type II or severe dental care issues, especially when they move between different countries throughout their life.

3. A cloud-based PHR system prototype

MyPHRMachines is a prototype that leverages virtualization and remote desktop technologies to create and maintain rich and lifelong PHRs in the cloud. The prototype reuses parts of SHARE², a mature system for making computational research results more accessible and reproducible [13]. The key technological components have therefore already undergone various development cycles and its technical architecture is considered robust. In this section we first revisit our running example to discuss the functionality provided by my MyPHRMachines. Then, we review the main technological features embodied into our prototype. Eventually, we present the implemented use cases and discuss future developments of the prototype.

3.1. Running Example Revisited

Figure 1 provides a dynamic view on the MyPHRMachines architecture. In the following we clarify the architecture by means of scenarios from our running example.

The top left corner of the figure shows two hospitals where PHR data is generated, for example, the RX and MRI scans discussed in Step 2 of our running example. In our example, the patient's general practitioner (GP, shown at the right) can nowadays receive a digital copy of the scan results. However, this was not the case for the first scans at the time described in Step 2 in Section 2. In order to build our example lifelong PHR, the secretary of the example patient's GP has recently contacted all the aforementioned hospitals for digital copies of the patient's scan results. As a result, the patient's GP has received digital copies of most scan interpretations and notes of the aforementioned specialists. Any Belgian patient can request nowadays a free CD copy of his radiology scans. The CDs contain image files, associated DICOM metadata as well as a Microsoft Windows-specific DICOM viewer. The companion website of this paper³ provides instructions to experiment with an example PHR consisting of some copies of such CDs.

At the time of writing, the patient's GP can also directly access the PACS of some local hospitals. Problems however still arise when patients receive care from other physicians than their home GP: depending upon the region, hospitals in a different city/province/country at some point lack system integration. Using MyPHRMachines, patients can preserve their personal copy of their medical data online such that any physician (another GP or a specialist in a foreign country) can promptly access their complete PHR conveniently later. The system ensures that any type of software that happens to be needed for viewing this data can be executed transparently from a simple browser window.

It should be noted that the above demo in MyPHRMachines is based on a virtual machine image that is not specific to the example patient. Instead, the image only contains Microsoft Windows. Such images are displayed at the middle right of Figure 1. MyPHRMachines ensures that when a specific patient starts a virtual machine, all of that patient's PHR data is mounted to the virtual machine behind the scenes (cfr., the arrow "*mount PHR*" in the figure).

The DICOM example from our running example does not require specific software in the MyPHRMachines virtual machine (the CDs start their embedded DICOM viewer automatically). We envision however also the situation where insurers (or governments) provide special purpose software as a service to their customers (or citizens). MyPHRMachines supports that SaaS scenario by enabling such stakeholders to clone existing virtual machine images, install additional software and share the resulting new image to patients in a specific MyPHRMachines group. To evaluate this functionality in the prototype, one should click *create* in the main MyPHRMachines menu (cfr., Figure 3). Since the associated workflow is inherited from the SHARE codebase, further details have been published already [13].

¹<http://is.ieis.tue.nl/staff/phr/myphrmachines/>

²<http://is.ieis.tue.nl/staff/pvgorp/share/>

³<http://sites.google.com/site/myphrmachines/>.

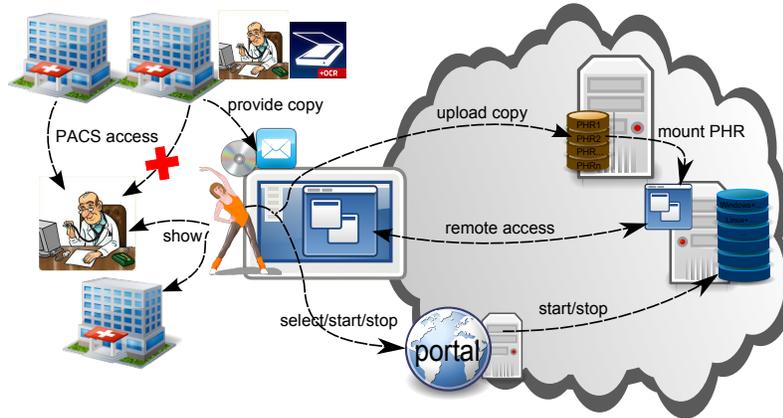


Figure 1. Architecture for PHRs in the cloud.

While our running example is based on DICOM content, MyPHRMachines can be used by our patient to store and make available any kind of personal health information generated in a lifetime. For instance, the intensive lower back revalidation program undergone by our patient has generated a large amount of data about progress in muscular strength. These data could also be stored by the patient in MyPHRMachines and the related proprietary software would be made accessible as a service via remote VMs.

3.2. Architectural Features

The following features characterize MyPHRMachines and similar cloud-based platforms such as SHARE:

IaaS MyPHRMachines leverages industrial-strength virtualization software (i.e., Oracle’s *VirtualBox* hypervisor) to execute *virtual* machines. By relying on that technology, the platform enables the execution of legacy software (e.g., a Microsoft Windows XP-based DICOM viewer) even long after the computer hardware from the corresponding decade has become obsolete. This light-weight approach is promising since (i) computing technologies evolve so quickly that it may become too expensive to upgrade viewers for complex PHR data because of hardware and operating system changes, and (ii) even when PHR oriented software is upgraded over time, one may want to access the original PHR data, i.e., without data conversions, using the original software (this is especially true for image-based diagnosis, as in our example). Since the physical machines can be maintained and upgraded as a service transparently by professional organizations, this is often called *Infrastructure as a Service* (IaaS [12]).

Remote MyPHRMachines executes virtual machines on *remote* servers. The prototype already provides load

balancing across multiple servers to satisfy the scalability requirements of the envisioned large-scale adoption. By means of remote desktop technologies, patients can access their PHR machines from devices that would otherwise be unable to inspect the PHR. Figure 2 for example shows how the aforementioned Microsoft Windows-specific DICOM viewer can be accessed remotely from a tablet, using MyPHRMachines. In general, the client device only requires Java (or a native client for the Remote Desktop Protocol [10]). No MyPHRMachines-specific programming is required as new client devices emerge, which guarantees the durability of the architecture.

SaaS As already discussed while revisiting our running example, the MyPHRMachines architecture also supports the *Software as a Service* (SaaS [11]) paradigm. MyPHRMachines enables vendors (or brokers) of expensive medical data software to provide temporary (perhaps pay-per-use) access to this software via a virtual machine (VM).

Secure MyPHRMachines ensures that only the patients can access their PHRs, unless they explicitly delegate access temporarily to a different entity. Beyond role-based access control, MyPHRMachines ensures that its virtual machines do *not* have general internet access. Consequently, even if a machine would be infected by malware (viruses, trojans, etc.) no PHR data can be transferred to malicious internet locations behind the scenes.

3.3. Design Goal: Make it Look Simple

The PHR-specific functionality of MyPHRMachines is implemented as a PHP based web portal. The design goal for this portal is to hide as much as possible the complexity

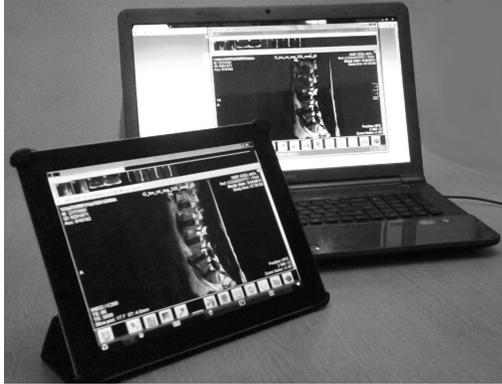


Figure 2. Accessing DICOM CDs in the cloud.

of the underlying technologies. We have prioritized two use cases for ongoing development on the prototype:

Session Sharing MyPHRMachines should make it trivial to delegate a virtual machine session to others. This enables patients to delegate access to a specific item in their PHR to a medical specialist. This functionality can then be used to support a discussion with a medical specialist in order to optimally leverage scarce contact time. Figure 3 shows how we have realized this functionality: when patients enter the medical specialist's email address, the specialist will receive a unique URL for accessing the patients' remote session with just one click. The specialist, or caregiver, does not require a MyPHRMachines account and will also not need the password of the patient. Patients can terminate the session after the doctor's appointment and the URL will be useless afterwards.

EHR Import MyPHRMachines primarily aims to empower active patients that wish to build a lifelong PHR pragmatically, regardless of inter-hospital agreements or (inter-)national standards. The system may however be extended with connectors that enable care organizations or national health data repositories to supply patient-owned data automatically in MyPHRMachines. This would benefit all MyPHRMachines users but particularly those patients that are less pro-active (or IT-enabled).

4. A research and development agenda.

From a technical standpoint, we need to improve in several ways the system we implemented before it could be deployed in production. A first issue regards the need for a secure messaging platform between the actors using

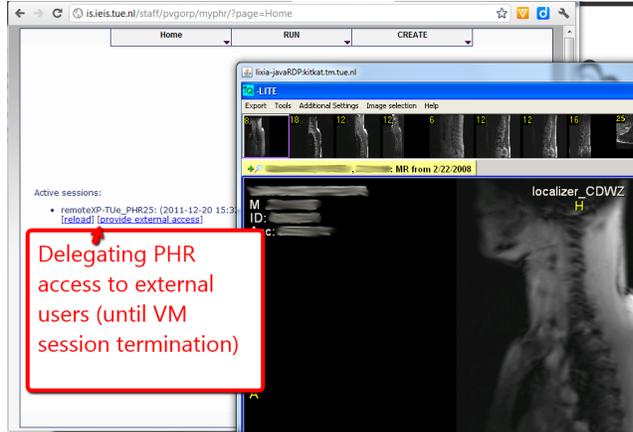


Figure 3. Delegating access to a session.

MyPHRMachines. In our running example, hospitals would use the secure messaging for example to push DICOM data to MyPHRMachines. Moreover, secure messaging would be used when sending caregivers URLs in the context of session sharing.

Further refinements to ease the use of MyPHRMachines are still needed. For example, the user interface for uploading PHR data is not yet usable for average computer users. We have not given this high priority yet, since we primarily aim at exploring new ways of working while intuitive file uploading features have already been developed in commercial platforms such as CloudShare⁴ and LabSlice⁵.

Eventually, the patient identification system represents a fundamental issue. Our system will need to be integrated with information systems of several caregivers, such as hospital information systems, administrative tools of insurance companies, national data centers such as the Dutch Health Hub⁶, etc. In such a connected scenario, patients have to be univocally identified. Patient identification is a long standing challenge in the practice of EHR system integration [14] and in fact complementary to the functionality of MyPHRMachines.

MyPHRMachines is a technological solution to empower patients managing their own clinical data and healthcare records. In order for it to become a viable solution to achieve healthcare cost reduction and quality of care improvement constantly advocated in modern societies [1], however, researchers must pay attention to several issues arising from the contextualization of MyPHRMachines in the complex healthcare ecosystem.

While in this paper we discussed the technical feasibility of a solution improving state of the art, future research should look at patient-owned health records in the context

⁴<http://www.cloudshare.com/>

⁵<http://www.labslice.com/>

⁶<http://www.dutchhealthhub.nl/>

of several institutional factors [3] that may hinder their success. The relationship among processes, people, business models and our proposed solutions, in particular, needs further investigation. Regarding processes, we need to investigate how MyPHRMachines will impact administrative and clinical processes currently in place in healthcare institutions. For instance, administrative processes are usually driven by data available in local EHRs, which may be inconsistent with the data possessed by the patient. Another factor influencing the success of our solutions can be the management of the coexistence of patients adopting and non-adopting personally-owned healthcare records, since we cannot assume complete penetration of such a technology, at least in the initial transitory period. Regarding people, MyPHRMachines represents a disruptive technological innovation and, as such, we need to investigate its acceptance and possible adoption by different types of users, such as patients, physicians, or administrative personnel. This is important since review results have already pointed out that the positive attitude of patients towards PHRs does not translate automatically into their effective adoption [8].

Eventually, regarding business models, research is required to understand how to make our solution economically profitable in the healthcare ecosystem. While, in fact, adopting our solution may reduce the cost of data exchange and exam retake, the costs related to the implementation and maintenance of patient-owned records has to be taken into account. The identification of a profitable business model for our solution is object of our current work.

5. Conclusions

In this paper we presented MyPHRMachines, an innovative PHR system that takes a novel approach to interoperability. A prototype implementing a real-world use case has demonstrated the feasibility of our approach. In the short term, future work will concern the technical improvement of our prototype, focusing on aspects such as secure messaging and unique patient identification across heterogeneous health information systems. In the longer term, we want to assess the impact of our system on the complex healthcare ecosystem, looking at viable business models for its utilization, its impact on business processes, and its acceptance by healthcare practitioners. We foresee that transformation-based interoperability approaches will have to co-exist with virtualization-based approaches. Therefore, we will deploy PHR transformation software as virtualized services to MyPHRMachines. Then, users can not only work with PHR fragments in native data formats but also with derived representations in standard formats. The latter representations support the semantic linkage of PHR fragments into a coherent structure while the former representations can be used to leverage virtualized legacy software.

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