

MyPHRMachines: personal health desktops in the cloud

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MyPHRMachines: Personal Health Desktops in the Cloud

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January 25, 2013

Abstract

Personal Health Records (PHRs) should remain the lifelong property of patients, who should be enabled to show them conveniently and securely to selected caregivers and institutions. Current solutions for PHRs focus on standard data exchange formats and transformations to move data across health information systems. In this paper we present MyPHRMachines, a PHR system taking a radically new architectural solution to health record interoperability. In MyPHRMachines, health-related data and the application software to view and/or analyze it are separately deployed in 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

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share their remote virtual machine session with selected caregivers, who will need only a Web browser to access the pre-loaded fragments of their lifelong PHR. We discuss a prototype of MyPHRMachines applied to two use cases, i.e. radiology image sharing and personalized medicine. The first use case demonstrates the ability of patients to build robust PHRs across the space and time dimensions, whereas the second use case demonstrates the ability of MyPHRMachines to preserve the privacy of PHR data deployed in the cloud.

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" [1]. 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]. In other words, they are Electronic Health Records (EHRs) that are owned by patients. These are usually opposed to hospitals' Electronic Medical records (EMRs), which only contain medical data generated within one specific care institution.

The research question addressed by this paper is "How can we design a sustainable and privacy-compliant IT infrastructure that facilitates at least for a patient lifetime and across the boundaries of care institutions and medical specialisms (1) the storage of raw PHR data and (2) the use of this data with specialized software?"

Sustainability in this context refers to the financial and political aspects of the health care and software industries. Point (1) focuses on raw PHR data since care

institutions may not be able or willing to provide their EHR data in "one" standardized PHR format. Tang et al. mention in their PHR adoption barrier analysis that "(US) Government can play a number of important roles in increasing PHR use. At the infrastructure level, the federal government could catalyze development and adoption of data and interchange standards for key PHR content areas." [3]. Such standards are useful and slowly emerging but we argue that regardless of such evolution patients should already be empowered with the ability to manage their own (potentially raw) data. With point (2) we aim at so-called functional interoperability (i.e., "the ability of two or more systems to exchange information so that it is human readable by the receiver" [4]).

Cloud computing offers unique opportunities for supporting long-term record preservation [5]. In this paper we present MyPHRMachines, a cloud-based PHR system that answers our research question. One of the agreed key requirements for shareability of the EHR is to break the nexus between the EHR and the EHR system [4]. The MyPHRMachines architecture clearly separates PHR data from the software to work with this data. This paper demonstrates how this creates novel opportunities for market of PHR software services without compromising patient privacy.

Commercial PHR systems positioning themselves within the cloud computing paradigm are emerging. For example, SeeMyRadiology [6] enables patients to upload their medical images and then selectively share these with caregivers. Unfortunately, such so-called software-as-a-service (SaaS) systems are typically (1) specialized for one medical function and (2) specifically programmed for web browsers. The SeeMyRadiology example indeed consists of a DICOM viewer that has been programmed in HTML 5 and related technologies. MyPHRMachines is

an academic prototype that is more generally applicable since it exposes to its users the so-called infrastructure-as-a-service (IaaS) tier of cloud architectures [7]. In a nutshell, the system provides infrastructure to (1) store and share hierarchies of patient data and (2) deploy and use specialized software in remote Virtual Machines (VMs). In principle, any type of software that runs on a desktop or server machine can be deployed to MyPHRMachines. As an extreme use case, MyPHRMachines could be used to run a conventional ("non-sharable" [4]) EMR system in a remote, patient-specific VM.

Thus, MyPHRMachines allows patients to build personal health records which are robust across the *space* and *time* dimensions:

Space. Patients relocating or simply traveling across different countries during their lifetime will always be able to reproduce their original health records and the software required to analyze/visualize those. This is often currently not possible because of the high functional and architectural heterogeneity of healthcare information systems across different countries/states [8]. By offering the ability to deploy besides data also the heterogenous execution software to MyPHRMachines, the system overcomes spatial barriers.

Time. As technology evolves, application software typically becomes obsolete. On the server-side MyPHRMachines prevents deprecation problems by virtualizing execution environments holistically. Since the hardware infrastructure is virtualized too, it can no longer wear out and therefore it does not require maintenance. The software to create the *idealized* environments on contemporary hard- and software is maintained by big vendors [9], regardless of the MyPHRMachines-specific extensions. On the client-side,

MyPHRMachines does rely on contemporary web technologies but only to realize a generic remote desktop client. Hence, also client software maintenance is decoupled from the number and complexity of PHR software services.

PHR systems typically offer functionality to share, visualize, and analyze PHR data [10]. MyPHRMachines also enables its users to share software to work with the health-related data but data and software are clearly separated in the system architecture. Having separate data and functionality also allows a finer grained delegation of access to personal health records to different stakeholders. Specifically, MyPHRMachines allows patients to selectively reveal health information to other stakeholders and it guarantees that, once shared with a stakeholder, health information cannot be improperly used or stored. First of all, the software specialists that deploy third party PHR services to MyPHRMachines never get access to patient data; secondly, even those whom have been given access to patients' remote VM sessions can cannot use or store the data/software beyond the time frame that is offered by the session owner (i.e., the patient or its guardian). Currently available PHR systems do offer selective delegation mechanisms but pose fundamental privacy threats in this context. Examples of typical threats characterizing currently available PHR systems are discussed later while reviewing related work.

Before discussing the implementation and application of MyPHRMachines, we introduce two use cases exemplifying the potential for innovation in health care brought about by our prototype. The first use case concerns radiology and, specifically, the treatment of multiple back injuries, showing how MyPHRMachines can be used to build and maintain efficiently a lifelong PHR of radiology images. The

second use case concerns genomic data analysis in the context of personalized medicine, showing how separation between data and PHR functionality allows finer grained privacy-related control over PHR data access and utilization.

The paper is organized as follows. Section 2 introduces the two use cases in different application scenarios that we use to exemplify the functionality of MyPHRMachines. Section 3 presents the design of the prototype and discusses its implementation. MyPHRMachine's potential for innovation in the healthcare domain and the limitations of our approach are discussed in Section 4, whereas related literature is reviewed in Section 5. Eventually, we draw our conclusions and discuss future work in Section 6.

2 Motivating Use Cases

In this section we introduce two use cases to support the description of MyPHRMachines implementation in Section 3. The first use case puts the accent on the *spatial* and *temporal* pervasiveness aspects whereas the second use case is used to highlight privacy-related aspects.

2.1 Radiology: Lifelong back injury condition

The first use case considers 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. PHR proponents argue that also such data however should remain with the patient to facilitate follow-up diagnoses and treatments.

This 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:

- 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 kinesitherapy for four months and is discharged with the instructions to continue performing regular sports activities, which should drain the hematoma and relieve the pain;
- after seven years (at the age of 25), the patient is still bothered by the hematoma consequences and visits a fysiotherapist, 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.
- 7. The revalidation program reduces the chronic pain.

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 have undergone 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 Systems (PACSs) of multiple hospitals. Second, our patient has never been able to show his entire medical history to caregivers. 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 IT infrastructures of hospitals and GPs 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.

Note that not only are longitudinal health records useful for assessing the evolution of individual patients better, but they also open doors for "big data" clinical research, which may generate much stronger medical evidence than conventional trials (such as [11] for scoliosis).

2.2 Personalized Medicine: Genomic diagnostics

Ginsburg et al. describe their vision of personalized medicine as follows: "tailored care is given for every individual based on their specific, molecular disease will become the standard of care. In the prototypical office visit of 2015, the physician will

examine a patient's genetic profile (stored on CD ROMs or equivalent), lifestyle, and results from objective molecular screening and monitoring tests. Algorithms, derived from previous research efforts, will be used to compute the likelihood that a patient develops a host of chronic diseases." [12]. In this paper, we do not focus on the algorithms that are needed to realized this vision. Instead, we show why MyPHRMachines should be used instead of CD ROMs to realize the above vision, mostly focusing on the PHR data privacy issue.

In order to benefit from personalized medicine, a patient needs to get a digital representation of his/her genetic profile. This involves a one-time analogue to digital conversion (called DNA sequencing [13]). The cost of this process is dropping at such a dramatic rate that it can soon be expected to be a free service for citizens of developed countries [14]. The major issue in this context becomes quality of software services to give personalized medical advice based on a genetic string. Among such quality requirements, privacy plays a prominent role. Clearly, a patient's genomic data is quite privacy sensitive, as it may reveal intrinsic limitations that among others can have a negative influence on someone's career, mortgage negotiations, social relations, etc. While, in fact, market competition among diagnostic software services is likely to foster the quality of personalized diagnosis, an open market of such services can be deemed safe only if patient privacy is safeguarded at the platform level.

Hence, in this use case we consider the case of a patient who has already sequenced his or her DNA, that is, who has stored the DNA sequencing string (PHR data) in the PHR system. The patient would like run different sorts of genomic data analysis on the DNA string. However, the patient is also concerned about the usage that the application software provider will make of the data. The patient, in

fact, is aware of many items appeared in the news about improper use of personal data health data by private medical software companies. Data made available by patients can be sold to other commercial institutions, or the information extracted from it, if leaked for instance to employers or insurance company, may influence the status of the patient relationship with such institutions.

2.3 Requirements for a PHR system

In this section we discuss a set of requirements for PHR systems directly derived from our two use cases. In the next section we demonstrate that MyPHRMachines is able to satisfy such a set of requirements, whereas later in the paper, while discussing related work, we show that current PHR systems available commercially or in the academic literature can satisfy the requirements partially or only in very specific application scenarios and configuration settings.

From the first use case of radiology, we derive a set of requirements capturing the need to build PHR systems that are robust across the space and time dimensions of information sharing for the patient. Specifically, requirement RA1 focuses on the *space* dimension, whereas RA2 captures the *time* dimension.

- RA1. PHR systems should allow patients to reproduce their medical data to
 any interested care institution, irrespective of the physical location of those
 and/or the maturity of their IT support;
- **RA2.** PHR systems should allow patients to reproduce their lifelong medical history to any interested care institution.

The set of requirements derived from the second use case of personalized medicine captures important privacy-related features that PHR systems should have

to protect the owner of PHR data, that is, the patient. Privacy is about the ability of the data owners to selectively reveal data to interested actors and to be assured that, once shared, their data cannot be used improperly (e.g., for commercial purpose or for extracting sensitive information about the patient).

- RB1. PHR systems should allow patients to selectively share their PHR data to interested care institutions;
- RB2. PHR systems should ensure that PHR data shared by patients will not
 be used improperly by the care institutions with whom such data are shared
 or by providers of application software.

3 Design and Implementation of MyPHRMachines

In this section we first present the technical architecture of our prototype. Then, we discuss the implementation of our two use cases.

The main idea behind MyPHRMachines is to leverage the cloud for allowing patients building their own personal health data repository and share these data with different care institutions. In the current implementation, patients have to manually upload the data they obtained from care institutions, e.g. in a DICOM CD, in the repository. In a near future, we envision that care institutions could directly push patient data to the repository. Once stored in MyPHRMachines, patients can flexibly share these data with any other care institution or interested stakeholder. Access to MyPHRMachines, in fact, requires only a Java-enabled browser, and access to a selected part of the repository can be easily granted by patients to any care institution, e.g. a GP,, a hospital, or an insurance company. Moreover, by

leveraging virtualization, MyPHRMachines also allows care institutions to make available specialist software required to view and/or analyze health-related data. In this way, caregivers need not be able to run specialist software, since they can get access to this software directly from the cloud.

3.1 Technical Architecture

Figure 1 shows the technical architecture of MyPHRMachines, identifying, besides the components constituting MyPHRMachines, also the components of the frontend *Client*.

The prototype reuses parts of SHARE [15], a mature system using a cloud infrastructure to make computational research results more accessible and reproducible. The key technological components have therefore undergone various development cycles, which adds to the robustness of MyPHRMachines technical architecture. In this section, we do not focus on the functionality already provided by SHARE and simply reused within MyPHRMachines.

Within MyPHRMachines, we distinguish between the *Execution* and *Storage* layers. Each Virtual Machine (VM) in the execution layer represent the virtualization of specific application software (or a software bundle) serving the purpose of either viewing or analyzing patients' health data. Patients can log into MyPHRMachines and decide which VM to load in a given session using a standard Web portal. The *Hypervisor* is a generic piece of software to start, stop, clone VMs, and control their Internet access. In our prototype, we decided to use VirtualBox, an off-the-shelf hypervisor. Being heavily used in several industries, VirtualBox benefits from periodic functionality updates and security reviews. Note that, as discussed more in depth later, the VMs for specialist software are stateless and deprived of Internet

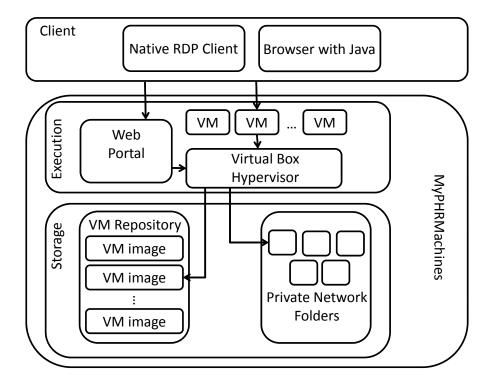


Figure 1: Technical architecture of MyPHRMachines.

access.

The storage layer includes the repository of VM images, i.e. virtual disks containing a bootable operating system and additional applications. Patient-specific VMs are simple instances of these VM images. In order to publish new VM images, software vendors go through the following procedure: first, they use the MyPHRMachines portal to clone an existing VM image that contains the right operating system and perhaps some additional libraries of interest. At this stage, only the vendor can instantiate the VM image. Also, at this stage, the vendor can modify the VM image (install new software, adjust configuration files, etc.). Finally, the vendor "publishes" the VM image for other users of MyPHRMachines. These

users cannot change the published VM image since their personal instance of the VM image is stateless. By keeping VM instances stateless, one can deploy updates at the VM image level (which is much more scalable and secure than trying to do this at the level of patient-specific VMs).

The PHR data are stored into network folders, which remain private folders within the MyPHRMachines domain. The latter feature, combined with stateless VMs deprived of Internet access, guarantees the security, specifically privacy, of the patients health-related data. In particular, even if software in one of the VMs is programmed with some sort of malware, this will not be able to push PHR data outside the network domain of MyPHRMachines.

Clients can view remote VM sessions using the Remote Desktop Protocol (RDP [16]). Therefore VM sessions can be viewed in any Java-enabled Web browser without installing any additional software, by using a simple applet-based RDP viewer. For operating systems not supporting Java, e.g. iOS, a native RDP [17] client is required. All communications between the execution Web portal and the hypervisor are delivered via SSH, a secure and stable communication protocol.

The UML sequence diagrams in Figure 3 and Figure 4 show two typical interaction scenarios supported by MyPHRMachines, i.e. starting a new VM session and sharing access to a VM between a patient and a medical expert in a care institution. The sequence diagrams are based on the conceptual model of MyPHRMachines shown in Figure 2.

When starting a new VM (see Figure 3), patients retrieve the VM image from the VM repository and the PHR data from their private network folders. The PHR data are then mounted into the VM. By default, all PHR data of the logged in patient are mounted when a new VM is instantiated. Before sharing access to a

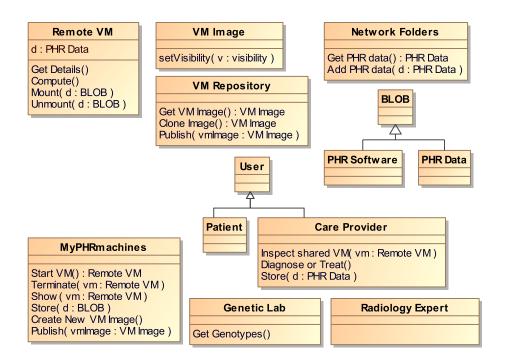


Figure 2: Conceptual model of MyPHRMachines.

VM, however, patients can selectively unmount those folders that are considered too sensitive to be shared with a given care institution.

Sharing access to VMs (see Figure 4) is implemented by allowing patients to forward, e.g. by email, a long, ciphered string identifier of a VM session. Using this identifier, the user at the care institution is able to access the VM even without having a system account, i.e. without the need to login. The downside of this solution is that, without additional security measures, the access delegation message could be intercepted by malicious Internet users. We argue, however, that care institutions are likely to have secure messaging tools in place and, therefore, we do not consider this as a major threat. Note that patients may decide to shutdown a VM, for instance in case they realize the care institution to which access they

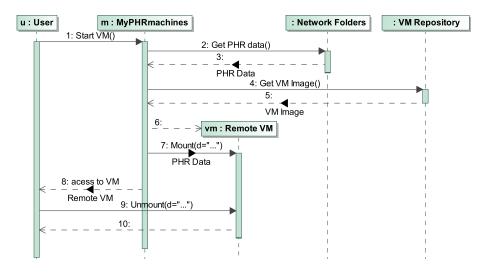


Figure 3: Starting a new VM session in MyPHRMachines.

granted access is misusing their PHR data.

After having presented the technical architecture of our prototype, we can now go back to the requirements listed in Section 2 and discuss how MyPHRMachines addresses explicitly all of them.

About requirement **RA1**, PHR data can be stored by patients using the cloud storage provided by MyPHRMachines. When required, PHR data can be easily

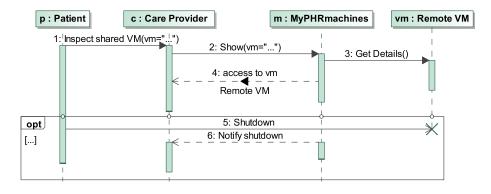


Figure 4: Sharing a VM session in MyPHRMachines.

exposed to care institutions, e.g. a physician, as long as an Internet connection and a Java-enabled browser are available. As demonstrated before, access to VMs is granted by forwarding a ciphered VM identifier by e-mail to care institutions. About requirement RA2, PHR data will be available in principle forever within MyPHRMachines to be shared among patients and care institutions. Moreover, the application software required to view and analyze such data will also be always available. In particular, MyPHRMachines enables the virtualization of any type of operating systems and application software. These will remain available to patients and care institutions even when they become no longer in use or accepted in practice.

The requirement **RB1** is implemented as a feature of the execution Web portal. When launching a VM, in fact, patients can select only part of their PHR data currently available within MyPHRMachines to be shared with a given care institution. Eventually, the requirement **RB2** is forced by design because, as we discussed before, VMs do not have Internet access and, therefore, the PHR data used by them cannot be pushed outside the domain of MyPHRMachines to pursue improper use. Having VMs without Internet connection may represent a limitation of our prototype. This issue is discussed more in depth in Section 4.1.

3.2 Use case implementation

Demo instructions for the two use cases are available on a companion Website ¹. In this section we provide a brief walkthrough of the use case implementations.

Figure 5 and Figure 6 show the interaction models of the radiology and personalized medicine use cases, respectively.

https://sites.google.com/site/myphrmachines/demo-phr

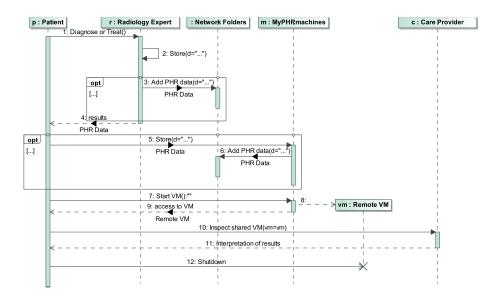


Figure 5: Interaction model of the radiology use case.

About radiology, the patient obtains PHR (radiology) data, e.g. a DICOM CD, from the radiology provider r. The sequence diagram in Figure 5 shows two options for loading PHR data into MyPHRMachines, i.e. by the Radiology provider (cfr., the first opt block in the sequence diagram) and by the patient (cfr., the second opt block in the diagram). Note again that automatic file transfers from PACS archives to MyPHRMachines network folders has not yet been implemented. Once the radiology data is in MyPHRMachines, the patient starts a VM and shares the access to this VM with provider c. The diagram also shows the case in which access to the same VM is granted by the patient to a care provider c in case, for instance, a physiotherapist from another hospital.

About personalized medicine (see Figure 6), the patient first acquires the DNA sequence from a specialized care institution (such as *baseclear* [18]) and then stores it into MyPHRMachines. MyPHRMachines can also provide VMs with

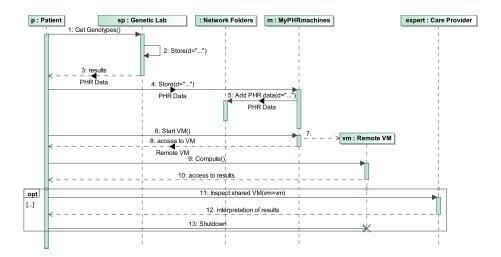


Figure 6: Interaction model of the personalized medicine use case.

genome sequence file converters (cfr., [19]) but for the sake of simplicity we focus on genomic diagnostics in this paper. In order to receive genetic counceling, the patient starts a new VM with software specialized for genome analysis and grants access to it to a medical expert.

Figure 7 shows the menu shown to the patient after having logged into MyPHRMachines, i.e. the execution Web portal. The patient in this case has access to three VM images. Two of these images (the ones whose name starts with *Radiology*) can be used for the radiology use case while the third one is designed to support the personalized medicine use case.

For the radiology use case, one VM is designed to run the DICOM viewer that is provided on most DICOM CDs. The DICOM viewer is loaded by clicking on one of the virtual CD icons (see Figure 8, where scans have been made anonymous to be shown in this paper). By loading different radiology scans into this VM, the patient will be able to reproduce his or her entire medical history (as far as radiology is concerned) to caregivers anywhere in the world. A second radiology

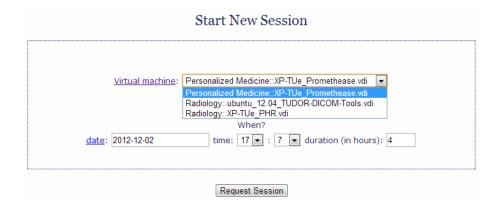


Figure 7: Execution Web Portal.

related VM contains a specialized DICOM viewer that can also visualize DICOM data in case a viewer has not been embedded in the hospital-provided DICOM CD (or DVD). This is the case for example for CDs containing DICOM data of Cone Beam Computed Tomography (CBCT) scans. Even more radiology related VMs are conceivable in practice but since that does not provide new insights into the MyPHRMachines platform, we refrain from discussing them here. By demonstrating two radiology VMs instead of just one, we stress that in MyPHRMachines the PHR data is clearly separated from the application software required to view it.

The VM for the personalized medicine use case combines the DNA data of an anonymous patient available on the Internet with the open source Promethease software as application software, in this case to *analyze* the PHR data. Figure 9 shows an example report generated by the software within MyPHRMachines. Note that the information generated by VMs cannot by default be pushed out of the MyPHRMachines network domain by a possibly malicious implementation of the application software, Internet access is by default disabled for VMs. The Promethease software, however, happens to require an Internet connection for dynami-

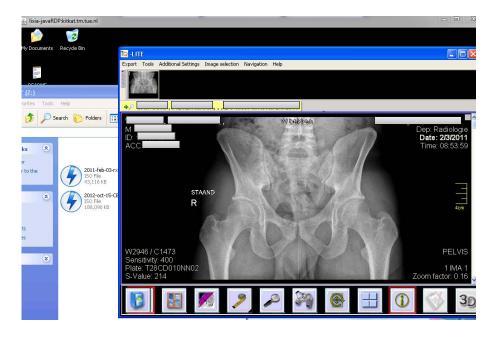


Figure 8: Radiology scan within MyPHRMachines.

cally fetching the latest expert rules for genome interpretation. For such cases, MyPHRMachines VMs can be given Internet access through a virtual network proxy. MyPHRMachines platform administrators can define fine-grained policies, e.g., to give the trusted Promethease virtual machine access to the Internet address of the genomic expert rule repository. This demonstrates how MyPHRMachines can be used with application software requiring Internet access for execution. An alternative solution would be for the application software vendor to routinely update its provided VM image with the latest expert rules for genome interpretation.

For both use cases, access to a running VM can be delegated by the patient simply specifying the email address of the caregiver. The caregiver will receive an email with a secure URL to access the running the VM. In this way, access to patient health records can be delegated by patients to any care institutions or stake-

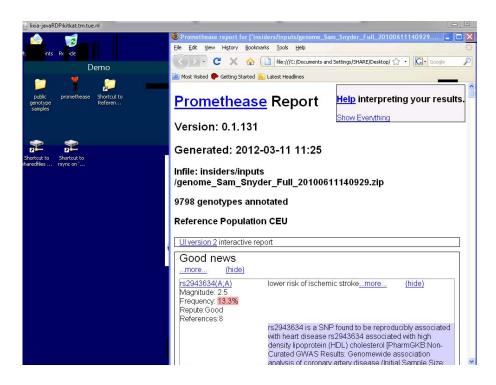


Figure 9: Genomic data analysis within MyPHRMachines.

holder requiring so. Following requirement **RB2**, the shared VMs do *not* enable one to download the patient-owned medical data. Instead, the data is only made available for temporary diagnostic purposes. This functionality is implemented as a feature of the web portal (so it did not require any use case specific programming).

4 Discussion and Limitations

In order for MyPHRMachines to become a viable solution to achieve health care cost reduction and quality of care improvement constantly advocated in modern societies [20], researchers will have to pay attention to several issues arising from the contextualization of MyPHRMachines in the complex health care ecosystem.

A useful frame of reference in this context is the one of institutional theory, which has often been used to address the shortcomings of technological and business innovation in health care [21, 22], predicating that organizations are often influenced by normative pressure, arising internally or at the industry level, leading them to choose legitimated elements that have often the effect of directing attention away from task performance and social welfare. There are several examples of such normative pressures in health care. The US government imposing a prospective-based, against cost-based, payment system in Medicare in 1983 is an example of external pressure which has shown to be non beneficial to attain cost minimization in the US health care system. An example of internally arising pressure is the relative power of physicians and administrative managers, which is often a determinant of the success or failure of new technologies in hospitals, such as electronic clinical guidelines [21].

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 of several institutional factors that may hinder their success. According to institutional theory, the relationship among *processes*, *people*, *business models* and our proposed solution, in particular, needs further investigation.

Regarding *processes*, we need to investigate how MyPHRMachines will impact administrative and clinical processes currently in place in health care institutions. For instance, administrative processes are usually driven by data available in local EMRs, which may be inconsistent with the data possessed by the patient. Another factor influencing the success of our solution can be the management of the coexistence of patients adopting and non-adopting personally-owned health care records, since we cannot assume complete penetration of such a technology without gov-

ernment sponsoring, at least in the initial transitory period.

Regarding *people*, MyPHRMachines represents a technological innovation that may disrupt current medical practice and patient behavior. As such, we need to investigate its acceptance and possible adoption by different types of users, such as patients, physicians, or administrative personnel.

Eventually, regarding *business models*, research is required to understand how to make our solution economically profitable in the health care 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. Moreover, we argue that MyPHRMachines can become a success only by exploiting its complementarity to existing PHR and EMR systems. At least in the initial diffusion period, the use of the system should be suggested to citizens for whom the requirements addressed in Section 2 are particularly critical, such as people continuously travelling, for instance because of business-released issues, around the world, or to citizens in need of specific advanced analysis that could reveal privacy sensitive information. The identification of a profitable business model for our solution is object of our current work.

4.1 Limitations

We distinguish the limitations of our work into the ones relating to the functionality of MyPHRMachines as currently implemented and the ones relating to the research method adopted for its evaluation. The limitations addressed here represents the focus of our ongoing and future work.

About the functionality, MyPHRMachines is likely to lead to numerous personal application islands, in which each patient collects heterogenous PHR data

and application software. This can lead to a very chaotic repository of health information and related functionality that can be very hard to maintain for the average patient. The issue should be overcome by focusing on a careful design of the management interface of MyPHRMachines, that is, the interface used by patients to upload, share, and, generally, organize their PHR data. Such an interface should be intuitive and hide all the technical details, related for instance to file formats and software installations. Technical details should only become relevant when data are shared with caregivers or when patients need to directly access their own PHR data. Another limitation previously identified is the lack of Internet access for the VMs. In principle, this prevents a VM to call external (Web) services and, therefore, to combine together such services, e.g., pipelining genomic diagnostics services available on the Internet. We argue, however, that the same services can be deployed within the trusted domain of MyPHRMachines and be available to all patients to be used. Moreover, we clarified that, for trusted virtual machines, controlled access to specific Internet addresses can be configured by means of a web proxy. Users should be properly informed of the kind of VM session they are running: a session without Internet access can be trusted blindly while a session with controlled Internet is only as trustworthy as the Internet sites for which the proxy allows access.

We argue that software providers that aim at building an image of trustworthiness should *prove* their trustworthiness by providing a MyPHRMachines VM that is self-contained, i.e., that can work without services on the public Internet. For the use case of personalized medicine, we have demonstrated how MyPHRMachines reveals that Promethease is not yet designed this way. MyPHRMachines provides the connection proxy mechanism to overcome the limitation that Prometh-

ease would simply fail without access to its online knowledge base. We argue that packages such as Promethease should simply be enriched with a local copy of that knowledge bases. Then, privacy can be guaranteed completely. This may boost public trust in online diagnostic services even if they are provided by institutions that would have financial benefits from gathering and exploiting patient data.

We can identify a set of straightforward extensions deriving directly from the analysis of the use cases in Section 2, such as advanced access delegation control and integration with existing EMR systems. The former enables patients to specify finer grained access control policies to stakeholders interested in their PHR data. The latter is required to free the patient and caregivers from the burden of transferring to the PHR system all health information and, consequently, is likely to foster adoption. In our opinion as developers of MyPHRMachines, from the technical implementation standpoint, both extensions do not represent a substantial obstacle.

About the research method, MyPHRMachines is currently fully implemented using real PHR data and real medical application software. The system, however, has not yet been experimented in clinical settings by real patients. Thus, the above discussion remains at a qualitative level, based on the analysis of the literature and qualitative interviews with key healthcare stakeholders. Experimentation with actual patients will allow us to evaluate the *people* institutional factor related to MyPHRMachines adoption. 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 [1,23]. In this direction, we are currently planning an experiment where MyPHRMachines will be used in a small patient community setting that still requires, however, patient interactions with multiple care institutions, from GPs, to hospitals and insurance companies.

In their survey, Kaelber et al. conclude 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. In this paper, we address three of the above research concerns, that is, evaluating the functionality provided by the system and discussing the architectural aspects related to the implementation of the system. Since MyPHRMachines has not been used yet in a large clinical study, it is only possible to assess the attitude of intended users towards the system qualitatively.

5 Related Work

We can first classify current PHR solutions into free-standing (3rd party), provider-tethered, and integrated PHR systems [24]. Free-standing PHR systems are standalone software applications that help patients maintaining their personal health information. Provider-tethered solutions are implemented and made available by a single care institution. In terms of number of users, the most successful PHR solutions belong to the latter category, with examples ranging from the EPIC MyChart system [25], tethered from hospitals using the EPIC EHR, and MyHealtheVet [23], promoted by the US Department of Veterans Affairs. Besides increasing efficiency, by reducing the need for patient data collection or duplicate clinical exams, provider-tethered PHRs promote a more *stickier* relationship between the provider and the patient. At the same time, however, this type of PHRs do not address the *space* dimension in the continuity of care envisioned for PHRs. An interoperability problem remains, in fact, when the patient seeks care from a caregiver outside of the network of the provider of the PHR. Kaelber et al. have demonstrated theoreti-

cally that the large-scale deployment of such PHR systems would have significant economic drawbacks [26].

MyPHRMachines can be classified as an integrated PHR solution [24]. Integrated PHRs are free-standing solutions that collect information from a variety of information sources, such as EMRs, insurance claims, pharmacy data, or data entered directly by patients. Integrated solutions, such as Google Health or Microsoft HealthVault [27] are less successful in terms of adoption when compared to provider-tethered solutions [25, 27]. Patients, in fact, are required to proactively experiment with the technology without being pushed in doing so by a given provider. Moreover, the interoperability of the PHR with other proprietary systems and, more generally, the provider willingness to trust and use the PHR, are not guaranteed.

The MyPHRMachines solution overcomes such typical limitations of integrated solutions. First, it makes the PHR information trustworthy, delivering original PHR data and related application software to care institutions [28]. Second, it limits the amount of technical knowledge required by a caregiver to access PHR data, since only a Web browser is required once the patient grants access permission. Eventually, it clearly overcomes the issue of interoperability among health care institutions of different solutions, by requiring only an Internet connection and a Java-enabled browser to access PHR data.

Taking a more technical perspective, we can compare MyPHRMachines against other solutions along the architecture and privacy dimensions.

As far as architecture is concerned, PHR systems rely on a client-server, Webbased architecture [29], where PHR data can be entered or uploaded manually by the patient or possibly directly uploaded by caregivers. Traditional PHR systems

remain repositories of health-related data, which still require external application software for data visualization or analysis. On the one hand, MyPHRMachines preserves the benefit of a Web-based client, i.e., patient and caregivers only need a browser to access data, but, on the other hand, MyPHRMachines extends the scope of traditional PHR systems by allowing to run the original application software to visualize and analyze data through virtualization. MyPHRMachines' architecture also implies that the patients have no longer to manually enter their health-related data, since it allows even patient to directly enter into the PHR system the PHR data as originally produced by caregivers. Such data will be mounted in the virtual machine running the required application software.

As far as PHR data privacy is concerned, Web-based PHR systems usually allow patients to collect and store digitized health information, but they usually implement only very simple selective access delegation policies [30]. About commercial systems, PeopleChart ², for instance, allows separating private and public health information and defining specific roles (e.g., provider or caregiver) to access the information classified as public.

Note that, in a business perspective, MyPHRMachines naturally inherits the strengths and weaknesses of cloud computing as the technology for implementing and delivering IT services [7]. About strengths, besides the positive impact on data security and confidentiality already discussed, cloud computing and virtualization facilitate the management of IT infrastructure and application software while, at the same time, allowing more flexible billing methods, such as pay-per-use. The cost of PHR systems is a largely unexplored field [31], which will benefit from more flexible and measurable billing methods. About weaknesses, cloud-based

²http://www.peoplechart.com

applications are opaque by definition, since management of data services, and infrastructure is delegated to the cloud provider. Such a relationship between cloud providers and recipients has to be regulated by detailed SLAs, the definition and analysis of which is still an open research field [17].

6 Conclusions

In this paper we presented MyPHRMachines, a novel PHR system. Leveraging virtualization techniques, MyPHRMachines allows patients to build lifelong personal health records. The records can then be shared by patient with any caregiver or, generally, stakeholder interested in those. MyPHRMachines allows also the virtualization of the application software required to view and/or analyze health records. The combination of virtualized health data and application software enables building health records robust across the space and time dimensions. Patients seeking care by caregivers in different geographical areas will be able to reproduce their original health records, no matter the limitations imposed by the heterogeneity of health care information systems architectures. Moreover, as technology evolves, patients will always be able to use original software to view and and analyzed data, even tough this becomes obsolete and possibly no longer supported by caregivers information systems.

We discussed the implementation of a prototype of MyPHRMachines and we showed its usage in two use cases, i.e. in radiology and in genomic analysis for personalized medicine.

Besides a clinical experimentation, to fairly assess patients' propensity in using such an innovative PHR system as MyPHRMachines, we are currently working

on extending our prototype in several ways. One of the major extensions regards creating an App market for application software, through which medical software providers could compete to provide the best suited functionality required by patients. We are also surveying practitioners to understand specific use cases for which MyPHRMachines becomes a unique enabler. Practitioners are also helping us to understand viable business models to foster MyPHRMachines adoption in practice.

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