The demise of Google Health and the future of personal health records

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Abstract: Digital personal health systems or platforms are considered fundamental elements towards making health more predictive, personalised, participatory, ubiquitous and interconnected. Innovations are expected both in terms of technology development and business model concepts, because these systems depart from classical ideas about healthcare delivery to enable new paradigms that foster user/patient participation. This article attempts to review and analyse the reasons why Google Health failed as a technology solution for user/patient healthcare information management. Google Health was unveiled in May 2008 after a process, which included a pilot test by a major USA healthcare provider. Nevertheless, on June 24th of 2011 Google announced the discontinuation of the service, effective in 2012. Some ideas about the general status of digital platforms for personal health records (PHR) are presented and discussed as aspects which affected the low adoption rate of Google Health. Including, the absence of clear demonstrations of better healthcare outcomes of user centred healthcare, the lack of clear clinical workflows and of wellness models based on information originated from stand-alone PHRs.

Keywords: personal health records; PHR; Google Health; health information; PHR usability; patient empowerment; digital health; personalised digital health platforms.

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1 Introduction

The advent of the Web 2.0 era represents a turning point in the process of empowering individuals to "gain greater control over decisions and actions affecting their health" (WHO, 1998). Digital tools are now available to give greater involvement to individuals in health decision-making, to provide ample participation in different aspects of the healthcare process, to access, manage and create information and knowledge about illness and wellness, and to connect and interact with communities of peers to seek for support, participate in groups and exercise agency within the health system. Healthcare providers, companies and organisations have facilitated the process by beginning to adopt a patient-centred or consumer-centred approach to healthcare, which acknowledges that the individual's experiences, needs, priorities, fears and efforts should be central to the design of services, products, and facilities.

Web-based or cloud-based personalised digital health platforms are among the most important tools available today for patient empowerment. In general, these platforms allow for personal health information gathering, data aggregation, management and curation, ubiquitous accessibility, interconnection with healthcare providers, tools for illness and wellness self-management, basic decision making tools and access to networked health knowledge. When health systems are fragmented, patient work becomes a heavy burden (Unruth and Pratt, 2008), especially in trying to keep up with all the information generated from the different services and healthcare providers. Theoretically, these tools could become central in collecting and ordering this disseminated information, thereby empowering individuals by providing a greater sense of autonomy and self-efficacy regarding various disease, treatment, and wellness-related behaviours. This technology-mediated paradigmatic change would allow individuals to self-manage their health in a much more holistic way, thus provoking drastic changes in their values, priorities and practices.

Chief among the tools are the so-called *personal health records* (PHR) (Tang et al., 2006), typically described as dynamic user-controlled repositories of health data, which combined with other digital tools serve to manage personal health information, otherwise fragmented and dispersed in multiple systems, papers, files or offices. Tang et al. are emphatic in their view of PHRs as central in facilitating users' involvement in their wellness and in the decision-making process about their own care. Regardless of the modality and informational architecture of PHRs, The Robert Wood Johnson Foundation in their study of PHRs (2010a) recognised several new dynamics in the healthcare system, which originate from the new access that users, as patients or consumers, have to data, information and knowledge related to their health.

The fact that through PHRs users can become sort of health information managers alters the well-established paternalistic characteristics of the patient-doctor encounter (Angelmar and Berman, 2007) to a more participatory relationship, disrupting traditional disease management workflows. As a matter of fact, having the patient/customer aggregate data, edit his/her records and keep track of the information flow is a major departure from the traditional hospital or healthcare provider full ownership of the medical record. However, most *electronic medical records* (EMRs) systems and clinical practices are still designed with this paradigm in mind. Therefore, precisely what seems to be one of the purposes of the patient/customer empowering nature of PHRs works negatively against their adoption and spread of use, making it so far, a rather inconsistent technology that has still more promises than results.

A recent study by Wynia et al. (2011) showed from an USA survey of physicians, that only 14% used PHRs on a daily basis with their patients and 64% had never used one. In spite of that, a 2010 survey by The Markle Foundation found an increase of 7% (from 3% in 2008 to 10% in 2010) in the use of PHRs by the wider public. This increment can be attributed to the push for hospitals and other healthcare providers to adopt EMRs, which typically offer some sort of web-based PHRs. In a recent review, Archer et al. (2011) have suggested that those PHRs that are integrated into the users' primary care provider EMR systems (called tethered) have had greater acceptance in the medical community. However, the same authors argue that these PHRs are not necessarily patient-centric in conception, which should be one of the philosophical premises behind their design. On the contrary, they respond to EMR design constraints, which are based mostly on the needs of physicians, other healthcare personnel and of the host institution. For the most part, stand alone PHRs (called untethered) seem to demand higher user involvement, require health literacy and computer skills, quality of information gathered is typically distrusted by physicians, interconnection with other sources of health data is not always possible, and tend to produce workflow changes and increased demands on healthcare providers. All of which accounts for the low success rate of this kind of PHRs.

The advent of cloud computing in the form of software as a service (SaaS) models seemed like an interesting solution to solve issues in PHR design related to data portability among platforms, independent access and management, more complete record keeping and mobile use. By 2008 market researchers expected a rapid growth of cloud-based PHRs from around 20 million to 85 million in 2012 (Chilmark Research, 2008). Also, around 2009 the firm Frost and Sullivan predicted the European market size for remote patient monitoring, of which PHRs are one of the main components, to be in the tone of 292 million Euros (Abadie et al., 2011). The reasons for such continuous growth and interest in this technology, in spite of the roadblocks encountered, are the existing trends towards making health more predictive, personalised, participatory, ubiquitous and interconnected. In this regard, a more recent study by Frost and Sullivan (2012) showed that 44% of 586 respondents from the healthcare industry surveyed online, still considered PHRs and patient portals among the hot topics in the market of connected health around the world, but particularly in Europe.

The offering of the cloud-based product Google Health in 2008 was received with high expectations by users, healthcare providers, technology companies and developers, because the above mentioned problems could be addressed in a broader way. However, in June of 2011 Google Health followed the same path as many other smaller providers that crashed in their intent of positioning in the difficult PHR market, leaving behind many questions and some lessons for future entrants. In the following sections some of the problems faced by the implementation and dissemination of Google Health are discussed with the intention of evaluating the future of personalised digital health platforms in the consumer health market.

2 Google Health: the rise

Typically, in PHRs, users access their own personalised record in order to gather, edit, manage, organise and share their health information from different sources, providing a

complete health record that is available to them online at any time. PHRs are built from a complex mixture of different types of data originated from a wide variety of sources such as a hospital EMRs, pharmacies, laboratories, clinicians, home instrumentation, insurance companies, employers, family members and the users themselves. However, as mentioned in the previous section, their design should strive to decrease the asymmetry of information in the doctor-patient relationship and not just to provide a simple extension of physician centred and healthcare provider owned EMRs. One of the key features of an advanced PHR has to be its ability to import and export data and information within the health system where it is integrated, otherwise, as Tang et al. (2006) adverted, PHRs can easily become *information islands* with low-quality and incomplete information about an individual, making the tool quite irrelevant.

In an unprecedented strategic move, Google attempted to capitalise on their popularity and consumer-driven approach to bring in 2008 a PHR to their customers, entering this way the difficult market of PHRs. Google Health was unveiled as a cloud-based, stand alone health data repository and end-user interface, with the possibility of interconnection to an ecosystem of health related information sources and services. Two major sections, profile and notices/feeds composed the health data repository. In the first one a health summary could be populated and updated by the user through the user interface using a subset of the continuity of care record (CCR) standard. The notice feeds or queries could be sent by third parties, in the form of lab results, prescriptions, immunisations, hospital discharges, alerts, prescription warnings and so on, and they were associated with the user's profile in a progressive manner through a notices/feeds panel. Users were required to sign up with data providers such as pharmacies, laboratories, hospitals, clinics, insurance companies, in order to import data from them, or with a partner third-party application, to allow access to their Google Health data in order for the application to write notices and feeds and read the user's profile. Google also embedded its search capabilities into the application, both for health-related topics, as well as for doctors and hospitals, which also interacted with Google Maps.

The data structure used by Google Health was based on the CCR standard for health data and information exchange developed in collaboration between the ASTM International and several medical associations. The CCR provides a snapshot in time of the pertinent clinical, demographic, and administrative data for a specific patient, allowing time and source stamped data from multiple sources, to be brought together in a single format into the PHR (Benson, 2010). Each profile defines an XML schema using a Google Health pragmatic *subset* of the CCR, including sections for demographics, actors, medications, results, immunisations, problems/diagnoses, allergies and alerts, procedures, vital signs, functional status. CCR codes medications using RxNorm or national drug code (NDC) standards, lab tests using CPT (procedures) and LOINC, and vital signs and diagnoses using SNOMED-CT and ICD-9 [http://code.google.com/apis/health/ccrg_reference.html#GoogleHealthUIMapping (accessed 21 November 2011)]. CCR is not so much a messaging standard but a summary standard, a really big message that contains almost everything that has happened to the patient (Trotter and Uhlman, 2011). Using a simple, clean and straightforward design CCR embraced the XML format to provide human readability and good expressing power. Additionally, it is rather simple to convert CCR format to continuity of care documents (CCD) the HL7 standard that is used by many of the large EMRs vendors.

The Google Health Data API, which was released in conjunction with Google Health repository, allowed client applications to view and update health content in the form of Google Data API feeds. Any client application could create new entries, edit or delete existing entries, request a list of entries, and query for entries that match particular criteria. As mentioned, notices or feeds were the means by which an application interacted with the user's profile. For that purpose Google embedded CCR content within an ATOM entry (similar to RSS feeds), which allowed changing the content of the target document that received the feed. Google Health offered a diversity of libraries in different languages like Protocol, .NET, Java 1.5, PHP and Python, with full documentation, detailed examples and ready to run code (Sunyaev et al., 2010a).

Before going public, Google Health was pilot tested at Cleveland Clinics as a tethered PHR. In this case, around 1600 Cleveland Clinics patients were able to have access to portions of their EMR but at the same time, the hospital EMR was able to receive patient information generated outside the clinic. If patients set up their Google Health account to receive feeds, in the form of medication refill orders or results, from retail pharmacies, labs and other healthcare providers, as well as home care information, they could push that information into the Cleveland Clinic EMR system, making it available to clinicians (Finkelstein, 2009).The results of the pilot study do not seem to have been published, but they must have been favourable because the official launching of Google Health occurred right after the pilot was finished. Additional connections with a number of data providers were negotiated by Google, including Beth Israel Deaconess Medical Center in Boston, medication related services like Walgreens, Medco, Longs Drug, and Rx America, records from Minute Clinic/CVS and lab results from Quest Diagnostics (Tan, 2010). Links to several PHR providers were also available. For example, NoMoreClipboard (http://www.nomoreclipboard.com/about-us/partners), a stand-alone PHR platform that delivered the data either in digital form or in paper form as required by the user's healthcare provider, allowed their users to link their accounts with Google Health in order to share information between the two applications. NoMoreClipboard would then help users of Google Health deliver their health information and medical records to physicians and services that were treating them but did not have electronic connectivity.

In spite of all these efforts of Google Health to grow in the market of PHRs, very few evaluations can be found in the literature. Archer et al. (2011) suggest that a sustainable PHR implementation depends on positive results in terms of adoption, use, satisfaction and usability. Adoption issues involve both the consumer/patient side and the healthcare provider, but it is usability the main determinant for the adoption of a PHR. The question of who adopted Google Health and why, and how it was used has not been investigated thoroughly yet. Therefore, the usability of Google Health and how its implementation affected communication protocols and workflows within hospitals, clinics and third party services did not seem to have been properly evaluated or at least disclosed as a determinant for its discontinuation by Google.

In a work by Sunyaev et al. (2010b), at least 25 criteria were suggested for the evaluation of the usefulness and success of a PHR system. They went on to compare Google Health with HealthVault, another stand-alone PHR platform launched in 2007 by Microsoft, without major differences between the two, but with some suggestions in functionalities that were missing in Google Health like the lack of a profile search feature and of secure messaging. Peters et al. (2009) conducted an independent comparative study between Google Health and Microsoft HealthVault in the areas of usability, utility

(usefulness and features) and security/privacy/trust through user experience with both systems. In the study, 30 participants performed seven tasks in both platforms and rated them afterwards. The overall conclusion of the study was a user preference for Google Health. Participants liked how Google Health's interface allowed quick and smooth data entry. This result is similar to that of Sunyaev et al. (2010b) who found Google Health's user interface to be more appealing to users than HealthVault's. Also, Peters et al. (2009) found that the drug interaction feature of Google Health was ranked as the most appealing feature of both platforms. Regarding security/privacy/trust HealthVault was preferred due to its strong brand, visual design, and perceived information content.

In a similar investigation, Liu et al. (2011) interviewed 18 end-users, aged 18 to 55 years old from different backgrounds and computer skills, who were presented with a list of specific tasks to be performed using standardised reference patient data. These tasks were designed to mimic the types of everyday activities in which end-users might engage. Issues regarding computational functionality, medical terminology, personalisation, familiarity and comfort, collaboration, communication, integration, data quality and privacy, security and trust were evaluated from the interviews along with other beliefs and opinions that they expressed. Five clinicians were also interviewed in relation to the patient-clinician scenario, regarding what they were expecting to see from their patients in a PHR and how they would integrate a PHR in their practices. The results showed some of the complexities inherent to the regular use of PHRs and their adoption and incorporation in medical practice. For example, regarding privacy and security, some users feared that their PHRs would become publicly searchable in Google search engine. Those that were already familiar with other Google products were concerned that the company would end up knowing too much about them if they trusted also their health information, especially if the login information used for the PHR was the same as in other Google products. Also, the fact that their health data was in the cloud was perceived by some as less secure than if they had full control of it in their computers.

In this case, Google Health business model becomes important to the perception of security. Among many users, the offering of the PHR free of charge created concerns as to from where Google was getting its profits and how they were using their health information. This preoccupation is well in agreement with previous public opinion research were patients expressed strong concerns that their information may be used for purposes other than their own care, fears of identity theft or fraud, or worries about the possibility of their information getting into the hands of marketers. All of these valid concerns makes less likely that consumers would readily trust an Internet company such as Google with their health information (Robert Woods Johnson Foundation, 2010b).

The military health system (MHS) created project MiCARE to provide a PHR tethered to the EMR of the 400-bed Madigan Army Medical Center. Patients were given the choice of implementing their PHR either in Google Health or HealthVault. Do et al. (2011) carried out a study of the impact of the PHRs from the standpoint of their clinical functionalities and integration to organisational practices of the healthcare provider. In the experience, both Google Health and Microsoft HealthVault PHRs produced disruptions in the healthcare providers' clinical workflow. For example, a better integration of patient originated data into the provider's clinical workflow was needed. Another issue that affected clinical workflows had to do with the availability of sensitive data in the patient's PHR, like lab results related to sexually transmitted diseases findings, pregnancy results, and positive cancer findings, before the provider contacted the patient to explain the results.

The pilot study also showed some of the complications that could arise when a patient restricted access to some information, which may lead to lower provider acceptance of the PHR as a useful tool. This study clearly underlines some of the difficulties that PHR marketing has. Just their mere availability is not enough to attract users if they are not fully integrated in the healthcare delivery process. This would require mature healthcare providers that are comfortable sharing EMRs and engaging with their patients, actively promoting patient's to use a service like Google Health, and integrating it into their clinical workflow. In this way the PHR system creates value for the patient, the physician and the institution.

A common criticism of the Google Health design and implementation process was that it did not take into account user/patient real needs. Moore (2011) from Chilmark Research, a blog specialising in trends in healthcare information technology, expressed that "few consumers are interested in a digital filing cabinet for their records. What they are interested in is what that data can do for them", a question that Google Health was not able to answer clearly. However, apparently Google did follow up with actual users through surveys, interviews, and usability studies to understand how well Google Health was meeting their needs as expressed in their research blog (Mueller, 2010). These studies seemed to indicate that an emphasis in wellness was needed in the platform, which should include: wellness tracking, manual entry and automatic data collection from devices, a wellness dashboard, goal setting and progress monitoring and personalised pages for user related information, charts and blogging. The new interface was made available to users as a clear effort to tackle other audience and increase its membership. After Google Health launched the new user interface in September of 2010, the design team kept evaluating the usability and impact of the new layout on users, with the idea of improving even further the interface.

3 Google Health: the fall

According to Google, when they launched Google Health, the goal was to create a service that would give people access to their personal health and wellness information (Brown and Wiehl, 2011). However, realising that Google Health was just being adopted by certain groups of users like tech-savvy patients, high risk patients and their caregivers, and more recently fitness and wellness enthusiasts, and not having the desired impact in the everyday health routines of millions of people, Google pulled out one of their core values, "*i*t's best to do one thing really, really well", and decided to discontinue Google Health as of 1 January 2012.

The discontinuation of Google Health and the deprecation of the Google Health API have proven clearly that the market for PHRs is very complicated even for powerful and innovative companies such as Google. The experience seems to corroborate the importance of doing the homework of responding to some of Peter Drucker's fundamental questions (Drucker, 2008). Two of them seem to be quite relevant in this case: Who is the customer? And, what does the customer value? In the case of Google Health, although originally the customer was thought to be the regular user of medical services or their caregivers, even from the pilot trial with Cleveland Clinics, a second customer came into play, the healthcare provider organisation. Moreover, the inclusion of third party players such as pharmacies, labs and payers, added another kind of customer

into the equation. With the inclusion of wellness and self-management applications, newer customers entered the complex mesh of interconnected entities in what seemed at first a simple data repository.

Looking at the problem from the patient's side, Krasner (2011), who was part of the original Google Health team, offers some insights. First, the patient as a customer is very dependent on the healthcare system, particularly regarding his/her health information, which typically is under the stewardship of a physician or an institution. She argues that this traditional model is very difficult to break only by transferring the role of organising the medical information to the patient, without offering additional incentives. Besides, moving data across a large variety of systems becomes a burden due to heavy security requirements, which slows down interconnections between systems. This is why people with serious conditions, those with disabilities, the elderly, and their caregivers, as well as parents of small children, highly motivated athletes or health conscious individuals are the most likely candidates to use a PHR (Archer et al., 2011). The rest most likely would worry about health data when sickness strikes. The second point Krasner makes is the overwhelming amount of data that can be gathered in a PHR and the format in which it is presented to the potential users, which may require some sort of health literacy to make sense of what is presented, but which in many cases can be completely irrelevant to other users to which access has been granted to the PHRs, like an attending physician. The problem here is how meaningful and sustainable a PHR is in the long run or if the tendency is to abandon its use because of its lack of positive impact in the life of users.

Individual tailoring, personalisation, goal setting, tracking, and behavioural feedback seem to be the key for PHR sustainability. This has prompted other companies to begin innovating in the design of new personalised health platforms that combine games, self-management, and smart devices to make it simple to keep records up-to-date (Carter, 2011). Basically, instead of tackling to the immense amount of possible users of PHRs, these new approaches seek to focus on specific groups of users that have specific needs. These are PHRs that limit their scope to some well-defined tasks or which specialise in very specific sets of data or information. These new type of platforms will blend PHRs with social media introducing a communal perspective to health in order to foster conversation, collaboration and support.

In responding to Drucker's questions, other possible stakeholders of PHRs are the healthcare providers. The experience with Google Health has shown that these customers cannot be left out as an important component of the PHR ecosystem. Studies have repeatedly demonstrated that provider recommendations played a strong role in patient use of the PHR (Barlow, et al., 2008). But, healthcare provider adoption of PHRs is strongly affected by the possible benefits that it provide to them, in terms of, for example, reimbursement, costs savings, and customer/patient satisfaction. As mentioned in the introduction, PHR adoption has grown 7% in two years, mostly with tethered systems offered by the providers, especially those from large organisations like Kaiser Permanente or Veterans Administration Hospitals. However, it seems that one player in constant relationship with the patient, and therefore, quite influential in self-management of different conditions, the primary care physicians in small practices, was forgotten by Google as key for PHR adoption. Going back to the study by Wynia, et al. (2011) that showed that only 14% of the surveyed physicians used PHRs on a daily basis with their patients, it is clear that the health system is a long way from providing adequate processes for the incorporation of PHRs as an important tool in the practice of medicine. Google chose to market their PHR mainly to consumers, and in the launching process involved

some large providers as their flagship experiments, but neglected to include physicians and smaller size providers in their marketing scheme. This clearly led to a poor adoption of their service.

One problem with providers is that the role of PHRs within their clinical workflows is still unclear. Questions about what portions of the EMR should be released to the patient's PHR and when within the clinical workflow should this happen, need to be properly answered, especially because that information has to be meaningful and useful to the patient. Otherwise, the provider would be overwhelmed by the amount of requests for clarification and explanation of results, procedures and diagnoses. In this relationship between users/patients and their care teams through PHRs, questions about appointment scheduling, online prescription refills, online consultations and personalised self-management of certain health procedures need still to be addressed.

The other segment of stakeholders involved in Google Health was the third-party data providers. Google Health started with just a few third party data providers, and only was able to attract some more during the time it was active. The question here is why it was so difficult to get data providers on board? Perhaps the lack of incentives for insurance companies, labs or pharmacies to share data voluntarily with Google Health users may account for it, especially in a fragmented and commercialised health system. As a result, in many cases, due to the lack of digital data being pushed automatically into their PHRs, users had to enter many records manually. In order to cope with this, Google Health offered a well-designed interface with preset forms for conditions, medications, allergies, procedures, test results, and immunisations, with lists from which to choose the condition or treatment.

Trotter and Uhlman (2011) have said that Google Health will have more influence in the PHR market as a result of the way it was ended. On one side, users of Google Health who had created their network of data and service providers, which added information and value to their PHRs, will not be able to recover the semantic complexity of their records, as they were stored in Google Health. For some computer savvy users this implies a couple of years worth of health related data that will have to be transferred to others systems such as HealthVault. Obviously, in the data or format conversion process a lot of problems and losses will be present. The big question that this introduces is how reliable and durable should PHRs be, in order to safeguard the user's valuable and critical 'lifelong' health data, as the Markle Foundation definition puts it (Vincent et al., 2008). For the time being, Google Health has decided to keep user data until 2013, giving users enough time to transfer their records to a new suitable PHR.

Among the alternatives for data migration, Google suggested Microsoft HealthVault as a destination and the Direct Project Protocol as the transport protocol for the secure exchange of encrypted medical data (Google, 2011). The Direct Project has been the product of an open collaborative effort to openly share health data between healthcare providers who have established trust, using universal addressing and access (Direct Project, 2010). Through the use of a wiki, an open code repository and a blog the protocol was built by a community of participants in a record time. Although not a direct endorsement of the protocol itself, Google was in a way influencing the future of data transfer for personalised digital health platforms. One month after the discontinuation of Google Health, Microsoft offered a tool based on the Direct Project messaging standard for the secure exchange of encrypted medical data. With the tool, a Google Health account holder can send his/her profile to HealthVault as an encrypted message, using the

Direct Project standards. The data can be later accessed once the user creates a HealthVault account (Microsoft, 2011).

4 The future

Technologically speaking the idea of personalised health records has been around for quite some time already. It does not seem to be overly complex, especially because many of the software tools and devices required have been under development for several years and have been tested in different health applications. As a matter of fact, in their analysis of their hype cycle for healthcare applications and systems (Handler, 2010), Gartner classifies PHRs among those ideas that have not found an adequate way to fulfil the need for which they were originally intended. There have been many problems in making this technology live up to its expectations, difficulties that start with the adoption process where a strong resistance is produced by those advocating a more traditional approach to care, the sluggishness in the implementation of health data exchange systems among healthcare providers, the lack of studies that can produce new standards based on patient centred care, which in turns affects the current structure of the reimbursement system, and the absence of adequate and convincing business models that can make the technology attractive to investors. Google Health represents just the latest example of another failed initiative, one that was expected to have a broader impact due to the characteristics of the organisation behind it.

The Google Health experience has revealed that the PHR is still an emerging technology that requires a better alignment among the fragmented elements of the healthcare system for its diffusion. However, in the United States, the push for tethered PHRs will grow quickly due to the US American Recovery and Reinvestment Acts (ARRA) requirements for 'meaningful use', which in its Stage 2 requires healthcare providers to populate with relevant patient information a PHR within 36 hours after discharge (PwC Health Research Institute, 2011).However, even though this is a major move toward patient participation in the administration of their own health information, it still has some limitations. In the first place because consumers have little choices in terms of what PHR system they can use to keep their personalised records. In general, they are caught up with whatever tethered PHR is offered by the healthcare provider, without the power to choose any other product more adequate to their own needs, or able to collect information from a variety of health information sources. The second question that remains is how users, and their doctors, will use this sudden outburst of health data that populates their PHRs according to this regulation (some recent examples of how this data is being used can be found in Baldwin, 2012).Google Health showed that neither the health system nor the regular users are still fully prepared to integrate this information into new models and workflows of user engagement in health-related decision making and management involving independent PHRs, making their adoption process slow and inorganic.

Baird et al. (2012) have also dealt with some of the conflicts and contradictions that exist between the current spectrum of laws and regulation that apply to PHR development, and the cultural norms of web-based markets, where potential users are to be found and where they will manage their health information. The tension here lies in the strict rules and regulations regarding health information privacy and security that are typically expected by users and what has become customary in terms of how private

information is to be used by web-based service providers in other fields. This somehow limits the possibilities of innovation in terms of business models applicable to PHR development beyond the rapidly spreading tethered configuration.

As mentioned earlier, the cloud computing, free of charge, model used by Google Health created a lot of concerns in terms of privacy and security. Particularly, because due to the characteristics of the service offered, the Health Insurance Portability and Accountability Act (HIPAA), which enforces privacy and security regulations, did not apply. In this regard, Kaletsch and Sunyaev (2011) came up with some typical questions, threats and risks that should be evaluated by PHR developers in order to ensure user privacy and security. Among the list proposed and evaluated are: threats posed by the handling of user identification features, especially during registration questionnaires and when joining social networks or communities; threats regarding the use by third parties of the medical information collected by the service provider and stored in the cloud; unsecure use of web analytics tools to produce targeted advertising based on the users activity on his/her PHR; legal issues regarding data transport and manipulation beyond national borders; risks in terms of indiscriminate use of communication tools, including SMSs, chats or email, especially when secrecy of the information can be violated; and questions about infrastructure outsourcing, more commonly in the form of storage clouds which are out of the control by the PHR service provider. These questions bring some challenges to the design and privacy engineering of PHRs, but at the same time affect the business model to be used and the awareness of the users about possible health information privacy violations.

Given the difficulties expressed so far, and from Google Health's short-lived experience, it is therefore fundamental to consider in greater detail what could be the drivers for the further development of cloud-based personalised digital health platforms in a number of health applications and for a variety of populations that can benefit from more individualised care. Using Hwang and Christensen's (2007) definition, business models for personal health platforms, such as PHRs, could be developed if it is demonstrated that these technologies help users, in performing their work as patients, or in managing their health and wellness, more "efficiently, conveniently and affordably" [Hwang and Christensen, (2007), p.1331]. Moreover, there should be enough evidence and awareness that they provide benefits to the individuals that use them and that the paradigmatic change that they propose to the health system is viable and sustainable in the long run. To quote one recent study in this regard:

> "There is increasing evidence that such services based on remote patient monitoring and personal health systems reduce death rates, and avoid recurring hospitalization in a cost-effective manner. However, proving beyond doubt their medical effectiveness, safety and reliability is of utmost importance for life critical systems; far more than in other realms of ICT applications." [Abadie et al., (2011), p.8]

It becomes clear that PHR developers must tackle portions of the market from where a more widespread adoption can follow and innovative business models can be developed, and clear demonstrations of the usefulness of the technology can be achieved and disseminated. One such example is the case of chronic patients, where PHRs could become central to the management of the information about disease processes within a more sophisticated ecosystem that has several other important constitutive elements, each one requiring developments and innovations of its own. However, as has been suggested

previously in this article, Google Health failed as innovation and disruptive model in this field because it seemed disconnected and was unable to foster ecosystem development. The required alignment of the new healthcare models and workflows developed around the use of PHRs or personal health systems, the co-creation of new interactions and models from the ecosystem based around the new model of care (Honka et al., 2011) and the adequate laws, policies, reimbursement policies, incentives that promote this model of care as valid and cost reducing, were too immature at the time of Google Health launching. However, these considerations somehow set the research, development and implementation directions in the years to come.

One of the advantages of the GH initiative (and also with Microsoft HealthVault) was that a technology enabler outside of the healthcare domain was behind it. As such, it was offered widely, based on the popularity of Google as sponsor, and without restrictions to users and healthcare providers for its adoption. These characteristics have allowed the observation in more detail of some of the peculiarities of the PHR market and some of the needs in terms of innovations in the healthcare delivery modalities, in the technologies involved, in the business models required and in the cultural, societal and governmental interactions and interventions.

To conclude, it is worth to recapitulate some of the issues expressed in this article. The rise and subsequent demise of Google Health has made even more evident that:

1 there is a need for more personalisation and contextualisation in the navigation of PHRs

2 there as an opportunity for extensive use of mobile devices to access PHRs

3 more work is necessary towards the incorporation of PHRs into innovative but also proven healthcare delivery models and the development of best practices and the involvement of healthcare providers around PHRs

4 in particular, PHRs haven shown promise within an ecosystem for remote follow up of chronic disease management

5 a trusted win-win relationship between users, technology developers, healthcare providers and governmental institutions has to be fostered

6 more research and documentation is needed to obtain more evidence about the benefits of the use of these technologies in the improvement of the quality of life of the users, increased accessibility to their own care, and the improvement of healthcare quality at lower costs.

References

Abadie, F., van Lieshout, C.C.M., Pascu, C., Baum, P., Hoikkanen, A., Valverde, J. and Maghiros, I. (2011) 'Strategic intelligence monitor on personal health systems (SIMPHS): Market structure and innovation dynamics', *Eur. Commission Joint Res. Centre Inst. Prospective Technological Studies*.

Angelmar, R. and Berman, P. (2007) 'Patient empowerment and efficient health outcomes', in *Financing Sustainable Healthcare in Europe: New Approaches for New Outcomes 2007*, Finish Innovation Fund (Sitra), retrieved 17 November 2011 [online] http://www.sitra.fi/julkaisut/muut/The_Cox_Report.pdf?download=Download+pdf.

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K.A. and Straus, S.E. (2011) 'Personal health records: a scoping review', *J. Am Med Inform Assoc*., Vol. 18, pp.515–522.

Baird, A., Raghu, T.S. and Tulledge-Scheitel, M. (2012) 'The role of policy in the prevention of personal health record (PHR) market failure', *Journal of Information Technology and Politics*, Vol. 9, No. 2, pp.117–132.

Baldwin, G. (2012) 'Is the industry ready to get personal?', *Health Data Management* [online] http://www.healthdatamanagement.com/issues/20_4/phr-personal-health-records-consumers-clinicians-44241-1.html?zkPrintable=true (accessed 29 May 2012).

Barlow, J., Crawford, W., Heyl, R., Lansky, D., Moghadam, O., Nazi, K., Sands, D., Tang, P. and Wald, J. (2008) *The Value of Personal Health Records*, Center for Information Technology Leadership, Charlestown (MA).

Benson, T. (2010) *Principles of Health Interoperability HL& and SNOMED*, Springer-Verlag, London.

Brown, A. and Weihl, B. (2011) 'An update on Google Health and Google Power Meter', *The official Google Blog* [online] http://googleblog.blogspot.com/2011/06/update-on-google-health-and-google.html (accessed 22 November 2011).

Carter, B. (2011) 'The retirement of Google Health: what it means for the personal health record', *Cerner Blog*, 27 June [online] http://www.cerner.com/blog/google_health_what_it_means_for_the_PHR/?langType=1033 (accessed 24 November 2011).

Chilmark Research (2008) *iPHR Market Report: Analysis and Trends of Internet-based Personal Health Record's Market* [online] http://chilmarkresearch.com/available-reports/ (accessed 29 May 2012).

Direct Project (2010) *The Direct Project Overview*, 11 October [online] http://wiki.directproject.org/file/view/DirectProjectOverview.pdf (accessed 24 November 2011).

Do, N., Bamhill, R., Heermann-Do, K., Salzman, K. and Gimbel, R. (2011) 'The military health system's personal health record pilot with Microsoft Health Vault and Google Health', *J. Am. Med. Inform. Assoc.*, Vol. 18, No. 2, pp.118–124.

Drucker, P. (2008) *The Five Most Important Questions You Will Ever Ask About Your Organization*, Jossey-Bass, San Francisco (CA).

Finkelstein, J. (2009) 'Wired for health', *Cleveland Clinic Magazine* [online] http://cchealth.clevelandclinic.org/cover-story/wired-wellness (accessed 21 November 2011).

Frost and Sullivan (2012) 'What is hot in the health industry: trends, opportunities and challenges through the eyes of key players in the healthcare sector in 2012' [online] http://www.slideshare.net/FrostandSullivan/whats-hot-in-the-healthcare-industry-trends-opportunities-and-challenges-through-the-eyes-of-key-players-in-the-healthcare-sector-in-2012/download?skip=true (accessed 29 May 2012).

Google (2011) 'How to move off of Google Health', *Google Health Help* [online] http://support.google.com/health/bin/answer.py?hl=en&answer=1347989 (accessed 24 November 2011).

Handler, T. (2010) *Hype Cycle for Healthcare Provider Applications and Systems, 2010*, Gartner Industry, Research Note G00205364, 27 July.

Honka, A., Kaipanene, K., Hietala, H. and Saranummi, N. (2011) 'Rethinking health: ICT-enabled services to empower people to manage their health'; *IEEE Reviews on Biomedical Engineering*, Vol. 4, pp.119–139.

Hwang, J. and Christensen, C. (2007) 'Disruptive innovation in health care delivery: a framework for business-model innovation', *Health Affairs*, Vol. 27, No. 5, pp.1329–1335.

Kaletsch, A. and Sunyaev, A. (2011) 'Privacu engineering: personal health records in cloud computing environments', *XXXII International Conference on Information Systems (ICIS 2011)*, Shangai, China, 4–7 December.

Krasner, M. (2011) 'The PHR school of hard knocks', *The Health Care Blog* [online] http://thehealthcareblog.com/blog/2011/06/29/the-phr-school-of-hard-knocks/ (accessed 22 November 2011)

Liu, L., Shih, P.C. and Hayes. G.R. (2011) 'Barriers to the adoption and use of personal health record systems', *Proceedings of the 2011 iConference*, ACM; 2011, Seattle, Washington, pp.363–70 [online] http://bit.ly/fJTDhB (accessed 22 November 2011).

Markle Foundation (2011) *Markle Survey on Health in a Networked life 2010*, January [online] http://www.markle.org/sites/default/files/5_PHRs.final__0.pdf (accessed 18 November 2011).

Microsoft (2011) 'Microsoft delivers online encrypted email using Direct Project security protocols', *Microsoft News Center*, 2 February [online] http://www.microsoft.com/presspass/press/2011/feb11/02-02msdirectprojectpr.mspx (accessed Last 22 November 2011).

Moore, J. (2011) 'RIP Google Health', *Chilmark Research*, 24 June 24 [online] http://chilmarkresearch.com/2011/06/24/rip-google-health/ (accessed 4 October 2011).

Mueller, H. (2010) 'Focusing on our users: the Google Health redesign', *Research Blog* [online] http://googleresearch.blogspot.com/2010/09/focusing-on-our-users-google-health.html (accessed 22 November 2011).

Peters, K., Niebling, M., Slimmer, C., Green, T., Webb, J. and Shumacher, R. (2009) *Usability Guidance for Improving the User Interface and Adoption of Online Personal Health Records*, User Centric Inc., Oakbrook Terrace (Illinois) [online] http://www.UserCentric.com (accessed 22 November 2011).

PwC Health Research Institute (2011) *Putting Patients into 'Meaningful Use'*, in *The Business Implications of Health Reform Series*, PricewaterhouseCoopers Health Research Institute [online] http://pwchealth.com/cgi-local/hregister.cgi?link=reg/putting-patients-into-meaningful-use.pdf (accessed 25 November 2011).

Robert Woods Johnson Foundation (2010a) 'Personal health records 101', in *The Power and Potential of Personal Health Records* [online] http://www.rwjf.org/pr/product.jsp?id=49989 (accessed 4 November 2011).

Robert Woods Johnson Foundation (2010b) 'Chapter 7: personal health records: business models, open platforms and challenges ahead', in *The Power and Potential of Personal Health Records* [online] http://www.rwjf.org/pioneer/product.jsp?id=51252 (accessed 22 November 2011).

Sunyaev, A., Chornyi, D., Mauro, C. and Krcmar, H. (2010b) 'Evaluation framework for personal health records: Microsoft HealthVault vs. Google Health', *Proceedings of the Hawaii International Conference on System Sciences*, Kauai, Hawaii, 5–8 January.

Sunyaev, A., Kaletsch, A. and Krcmar, H. (2010a) 'Comparative evaluation of Google Health API vs. Microsoft HealthVault API', *Proceedings of the Third International Conference on Health Informatic*s, 20–23 January, Valencia, Spain, pp.195–201

Tan, J. (2010) *Adaptive Health Management Information Systems*, Jones and Bartlett Publishers, Boston.

Tang, P., Ash, J., Bates, D., Overhage, M., and Sands, D. (2006) 'Personal Health Records: Definitions, benefits, and strategies for overcoming barriers of adoption', *Journal of American Medical Informatics Association*, Vol. 13, No. 2, pp.121–126.

Trotter, F. and Uhlman, D. (2011) *Meaningful Use and Beyond: A Guide for IT Staff in Health Care*, O'Reilly Media, Sebastopol (CA).

Unruth, K. and Pratt, W. (2008) 'The invisible work of being a patient and implications for health care: (the doctor is) my business partner in the most important business of my life, staying alive', *Proceedings of Ethnographic Praxis in Industry Conference (EPIC)*, November, pp.40–50.

Vincent, A., Kaelber, D., Pan, E., Shah, S., Johnston, D. and Middleton, B. (2008) 'A patient-centric taxonomy for personal health records', *Proceedings of the AMIA Symposium*, pp.763–767 [online] http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2656090/pdf/amia-0763-s2008.pdf (accessed 24 November 2011).

World Health Organization (WHO) (1998) *Health Promotion Glossary*, Geneva, WHO/HPR/HEP/98.1 [online] http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf (accessed 26 November 2011).

Wynia, M., Williams Torres, G. and Lemieux, J. (2011) 'Many physicians are willing to use patient's electronic personal health records, but doctor differ by location, gender and practice', *Health Affairs*, Vol. 30, No. 2, pp.266–273.