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## Communications of the Association for Information Systems

#### The Future of Personal Health Records in the Presence of Misaligned Incentives

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#### Abstract:

We posit that the emergence of the independent personal health record (PHR) platforms is potentially a major development toward the cause of digitizing healthcare. Not only do these platforms empower the patients by giving them complete control over their records, but they also can help promote the adoption of electronic health records (EHRs) by healthcare providers. In a pluralistic healthcare system like that which exists in the United States, where many healthcare providers lack the incentive to adopt EHR and electronically share their patients' records with competing providers, we believe that PHR platforms can facilitate the adoption and use of EHRs in the healthcare sector.

Keywords: electronic health records (EHR), personal health records (PHR), adoption, misaligned incentives, switching costs

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#### The Future of Personal Health Records in the Presence of Misaligned Incentives

#### **I. INTRODUCTION**

Effective use of information technology, and digitization of health records in particular, is central to the debate on how to contain skyrocketing healthcare costs while improving quality. As many experts recently noted, "the implementation of electronic health records will help make sense of the disparate care that Americans receive" [Knowledge@Wharton, 2009]. Inaccessibility of previous medical records leads to one in seven hospital admissions, 12 percent of physician orders being executed not as written, and 20 percent of laboratory tests which are duplicative and/or unnecessary and requested only because previous ones are not available. Drug errors complicate one in 6.5 hospitalizations and occur in 5 percent outpatient prescriptions [Neil, 2008]. Of the more than four billion prescriptions written annually, nearly 4 percent contain errors that pose serious patient risks [Landro, 2009a]. One major reason for medical errors is that different physicians treating the same patient do not all have access to all the medical records.<sup>1</sup>

The availability of complete patient health information at the point of care delivery, together with clinical decision support systems, such as those for medication order entry, can prevent the occurrence of many errors and adverse events (injuries caused by medical management rather than by the underlying disease or condition of the patient) [Bates, Leape, Cullen, Laird, et al., 1998; Koopman, Kochendorfer, Moore, Mehr, et al., 2011]. Further, the use of electronic health records can improve staff performance quality and increase customer satisfaction through greater patient throughput [Helton, 2012]. The availability of such information would give patients and their doctors a complete up-to-date view of a patient's medical history, medications, and the like, and would allow patients to track and note any mistakes in their doctors' records. This would also facilitate better decision making (e.g., when ordering appropriate tests), identification of patients for drug recalls and outbreaks of emerging diseases, faster and more efficient clinical trials, and monitoring of bioterrorism. Anonymous patient information would be of tremendous value to researchers, as they investigate this integrated system for best practices, best providers, or even promising new ways of tackling a disease [Kohane, 2011]. Last but certainly not least, integrated electronic health records (EHRs) would improve the transparency of the healthcare system as a whole. Research on the aggregated data would allow us to see which treatments work best, which of them are unnecessary, ineffective or simply too costly, which doctors provide the best care, etc. A more transparent healthcare system would provide us with tremendous opportunities to reduce costs and usher in best practices through evidence-based medicine [Glasgow and Emmons, 2011].

Unfortunately, despite all the reported benefits of EHR, the level of adoption in the United States has been far from impressive. In fact, the \$2.6 trillion U.S. healthcare system [CMS.gov, 2011] trails several of its counterpart OECD countries in the use of EHR, and by some estimates, about 20 to 30 percent of health spending yields no benefit at all [Pear, 2011]. A government-sponsored study found that only about 17 percent of the nation's physicians use computerized patient records [Mandl and Kohane, 2008]. The statistics might be even more depressing according to a recent study: only 1.5 percent of the 3,000 U.S. hospitals surveyed reported to have an EHR system in all clinical units, while an additional 7.6 percent reported to have a basic system in at least one clinical unit [Jha, DesRoches, Campbell, Donelan, et al., 2009]. These statistics are far below the adoption rates in Western Europe (e.g., 88 percent in the Netherlands, 80 percent in Sweden, and 62 percent in Denmark). Given that much of the benefits of EHRs stem from not stand-alone systems, but systems that are interoperable with each other, these low adoption rates are in fact even more dismal than what they may seem.

In this opinion article, we argue that independent personal health record (PHR) platforms can potentially play a significant role in facilitating the adoption and portability of digitized health records. The Markle Foundation defines the PHR as "an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" [Markle Foundation, 2003]. An independent PHR platform provides PHR functionality to interested patients and, depending on technological constraints and contractual agreements, may allow them to import their health records from providers and share them with other providers or their loved ones. We think that an independent PHR is well-positioned to provide the appropriate incentives to the providers so that they are willing to digitize and share their patients' records, which are certainly valuable business assets.

<sup>&</sup>lt;sup>1</sup> Brian J. Neil, Chief of Clinical Informatics at the V.A. Midwest Health Care Network commented recently that one "cannot have integrated care without integrated information" (Knowledge@Wharton 2009).

In the following, we first demonstrate the importance of the problem of misaligned incentives in the adoption of EHRs in the U.S. using an analytical framework. Next, using the same framework, we discuss the ramifications of this problem in the context of sharing of EHRs. Finally, we outline how an independent PHR platform may overcome the problem of misaligned incentives through revenue sharing agreements and targeted subsidies. We conclude the article with a discussion of what lies ahead of the independent PHR platforms so that they realize their full potential.

#### **II. ADOPTION OF EHR SYSTEMS—THE PROBLEM OF MISALIGNED INCENTIVES**

The substantial difference in EHR adoption rates between Europe and the U.S. is largely due to the prevailing market structures and the misaligned incentives. In Europe's single-payer systems, the payers can (and often do) dictate what physicians must do. In contrast, each provider in the U.S. pluralistic system must make its own decision of whether to digitize its medical records, which on average can incur an implementation cost of \$14,500 per bed, with an additional \$2,700 per bed in annual operating costs [Hagen, Richmond, Vavrichek, Baumgardner, et al., 2008]. However, because those that ultimately pay for healthcare (including consumers, businesses, and federal and state governments) reap much of the savings associated with the adoption of EHR, it is difficult for healthcare providers to recoup the capital investments in EHR. Consequently, adoption is limited to those providers that compete in quality and can afford to absorb the substantial implementation costs. These providers invariably tend to be the larger hospitals or networks with the capability of providing integrated care within their system (two prominent examples being the Kaiser Permanente chain of medical clinics and hospitals and the Northshore University Health System in Illinois) rather than the small private-practice providers that make up the majority of the providers in the United States.

Further complicating the incentive problem is the presence of competitive concerns. In a competitive setting, each provider takes into account the impact of its own as well as its competitors' EHR adoption decision on long-term market shares and profits. These effects can be characterized in the following game theoretic framework (as adapted from Ozdemir, Bandyopadhyay, and Barron, 2011).

Consider a local healthcare market composed of two competing providers and a multitude of consumers. The competition between the two providers (A and B) can be conceptualized in terms of prices net of amenities, where a lower price can be interpreted as a provider either lowering its gross price or increasing its amenities to attract additional consumers. Assume that each consumer purchases one unit of a healthcare service each period and is in the market for, at most, two periods. There exist switching costs; unlike new consumers, those who have purchased the service of a provider in the first period of their lifetime is said to have established a "medical history" with that provider, and thus they incur a switching cost if they decide to purchase the service of the other provider in the next period. We assume rational expectations and forward-looking behavior on the part of consumers, such that they take into account any potential changes in their preferences for the two providers in the future when they decide which provider to work with now. Accordingly, one can determine the market share and profit of each provider through a process called *backward induction*, namely by solving for the optimal provider decisions in the second period and then substituting those solutions into the profit expressions for the first period to solve for the optimal decisions in the first period. In this context, EHR adoption decisions can be interpreted as improvements in service quality, which can potentially lead to increases in market share.<sup>2</sup>

Using the above framework, it can be shown that the profits of each provider in the four adoption scenarios can be outlined as in Figure 1. In the figure, the rows and columns indicate the adoption decisions of Provider A and Provider B, respectively. The upper and lower expressions in each parenthesis in each cell denote the profit of Provider A and Provider B in the corresponding adoption scenario, respectively.

 $\pi_o$  denotes the profit of each provider in the benchmark case of no adoption,

 $\Delta \pi_o$  denotes the change in net revenue due to adoption, and

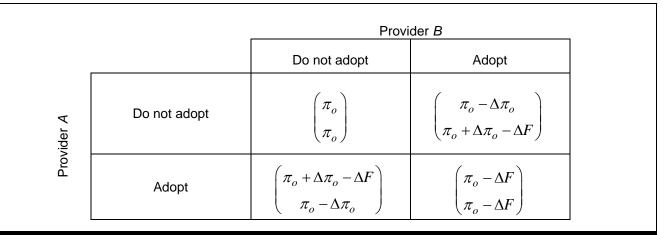
 $\Delta F$  is the cost of adoption.

It can be seen that as long as  $\Delta \pi_o > \Delta F$ , a unilateral adoption of EHR is in the interest of both providers. However, once one of them adopts EHR, the other will also adopt, in the process dissipating all the net revenue that accrues from the adoption of EHR for both providers, and leaving them with a net loss of  $\Delta F$ . Therefore, because each

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<sup>&</sup>lt;sup>2</sup> According to a 2007 Harris Interactive survey (HarrisInteractive [2007] Large Differences Between Primary Care Practices in the United States, Australia, Canada, Germany, New Zealand, the Netherlands and the United Kingdom. Harris Interactive), 54 percent of the respondents said that if they were to choose between two doctors, of whom only one used EHRs, their choices would be influenced by the availability of this technology, at least to some extent.

provider knows that the adoption of EHR will inevitably lead to a worse outcome compared to the case of no adoption, neither will adopt, even though adoption by either provider is strictly better for patients. We assume in this example that the providers are identical, but the mechanics of the game work similarly when the providers are differentiated with respect to size, reputation, or quality.



#### Figure 1. The Normal Form of the EHR Adoption Game (No Data Sharing)

In the pluralistic healthcare system of the United States, consumers and businesses stand to reap much of the benefits from improvements in healthcare through EHR deployments, and monopolistic providers will also benefit (after incurring the implementation costs), since offering a better quality of care will allow them to increase fees and/or market share. The incentive problem we have identified above, however, has serious implications for policy makers for the contexts in which providers are concerned with direct competition. The analysis clearly shows that any potential benefit of EHR adoption is likely to dissipate in the presence of direct competition, resulting in a net loss for all EHR adopters as compared with the case prior to adoption.

When private agents lack the incentive to engage in behavior that would nevertheless improve the welfare of the society, direct government intervention may prove to be socially desirable. In fact, the American Recovery and Reinvestment Act of 2009 (ARRA) calls for the "utilization of an electronic health record for each person in the United States by 2014" and allocates \$19 billion to facilitate EHR adoption by healthcare providers. It remains largely to be seen, however, whether the carrot and stick approach taken by the federal government will have a noticeable effect on the adoption levels. Even if it does, continuous and meaningful participation of providers is likely to be extremely challenging, especially when it comes to the sharing of patient information.

#### **III. SHARING OF PATIENT DATA: INCENTIVE ISSUES, YET AGAIN**

While a widespread implementation of EHR would be a major step in solving the problems of our healthcare system, it cannot be the panacea in and of itself. Electronic health records will be of limited use unless hospitals and providers share patient records among themselves, reaching across hospital systems and even health plans, especially in emergency situations.

Given the desirable welfare effects of the availability and use of EHRs on a wide scale, the federal government has been pushing for a national health information network on various fronts, and numerous regional health information organizations have been established in the past to achieve interoperability. Yet these initiatives have produced limited success at best. Middleton [2005] has argued for the provision of federal government subsidies for the adoption of standard-compliant healthcare technology. The initiative in the 2009 stimulus bill has been enacted with pretty much this objective in mind. However, even if the bill facilitates adoption as planned, there is no guarantee that providers will voluntarily start sharing patient records among themselves electronically.

Aside from technical issues such as the presence of multiple competing standards for the interoperability of EHR systems, perhaps the most challenging impediment to the sharing of EHRs among providers is, again, the mismatch of providers' incentives. Patients build up medical histories with their providers in the form of visitation records, laboratory tests, etc., the transfer of which in an accurate manner in many cases requires considerable effort. When providers implement interoperable EHR systems and share patient records among themselves electronically, it becomes very easy for a patient to transfer her records from one provider to another, in essence reducing the cost of

switching. This, in turn, may have considerable implications on the profits of providers in competitive markets that are sensitive to changes in patient mobility.<sup>3</sup> Since providers have the complete freedom to choose the data format (paper or electronic) in which to release their patients' records (a decision that does not have a direct impact on the quality of care), it is reasonable to expect them to choose the format they prefer.

The framework we outlined in the previous section can be extended to a setting where providers' EHR sharing decisions can unilaterally impact the switching costs (e.g., by adopting different policies regarding the format of data to hand out to outgoing established patients). We carried out extensive simulations<sup>4</sup> to gain insights and observed that even if both providers may profit from an electronic data sharing arrangement compared to the benchmark case of no electronic data sharing, and hence enter into a data sharing arrangement, each may have the incentive to deviate and give outgoing established patients their records on paper. The incentive to deviate, if any, is more pronounced for the better/larger provider. Furthermore, we found that the incentive to renege on a data-sharing arrangement increases further as consumers become less forward-looking. This is because, when consumers do not look ahead, each provider benefits (in the next period) from unilaterally raising its own switching costs, as it limits the mobility of established patients. Consumers can often be myopic or discount the future impact of their current decisions regarding healthcare since they are less likely to think of future periods at a time when their immediate thoughts are centered around their current illness. This is especially true if the type of illness is not chronic in nature, and the consumers do not expect to be back with the provider at regular intervals.

Thus, the presence of provider heterogeneity and myopic consumers are two reasons that may prevent providers from sharing their records electronically. This observation is consistent with the findings of Hillestad, et al. [2005], who conclude that even though interoperable EHR systems could result in a large social surplus (estimated to be in the range of \$142–\$371 billion), they are unlikely to be realized in the current pluralistic healthcare system. In this context, sharing of EHRs can be achieved through new regulation or via the intervention of a private entity if it can create the necessary incentives for data sharing. Therefore, an independent PHR platform can play a significant role to that effect.

#### IV. THE PERSONAL HEALTH RECORD (PHR) PLATFORM AND WHY IT MATTERS

One of the most interesting developments in healthcare technology as of late is the emergence of personal health records (PHRs). The Markle Foundation defines the PHR as "an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" [Markle Foundation, 2003]. Other definitions of PHRs have emphasized data sharing between providers and patients [Kim and Johnson, 2002] and the ability of patients to manage their health more independently, for example, through remote monitoring of chronic diseases [Tang, Ash, Bates, Overhage, et al., 2006]. The common thread throughout these definitions is the emphasis on patient involvement in the delivery of care.

Healthcare experts have for long opined that increased patient engagement in their healthcare can improve quality and outcomes and ultimately help control spiraling costs [Kaelber, Shah, Vincent, Pan, et al., 2008]. A patient who is in regular contact with her healthcare providers may help lower costs through improved lifestyle choices, care coordination, and adherence to recommended care. A widely cited report from the Institute of Medicine recommend ten "rules" for improving healthcare quality and suggests that the success of six of these rules depends directly on patients' involvement in their care [IOM, 2001]. The Markle Foundation examined the current state of patient engagement and decision-making activities, and PHRs figure prominently in this process [Markle Foundation, 2003]. Thus, PHRs are a key factor in improving patient involvement in their care and, thereby, serve as an important means to help address quality and cost issues.

Currently, there are two major forms of PHR. The first type, which has lately received much publicity, is the "standalone PHR" being offered by a private entity such as Microsoft. The second type, dubbed the "integrated PHR" [Tang and Lee, 2009], is really the patient extension of a provider's EHR.<sup>5</sup> While both types are beneficial to patients, the integrated PHR offers very little in terms of portability and ownership of medical records. Because the extension is tightly integrated to the EHR and controlled by entities other than the patient, the data cannot be transferred to another PHR platform when needed. Therefore, stand-alone PHRs offer a more complete value

<sup>&</sup>lt;sup>3</sup> The effect on profits is magnified since the demand for healthcare is relatively inelastic (as providers are often paid indirectly through insurers or the government), and thus the loss of a patient is felt acutely.

<sup>&</sup>lt;sup>4</sup> This investigation was done for a variety of parameters in the model, such as the values of providers to the consumers, the proportion of new customers in the market, switching costs, and the degree of consumers' forward-looking behavior.

<sup>&</sup>lt;sup>5</sup> There exists a third type, where the PHR is an application that resides on the patient's personal computer. Patients have hardly adopted this type of PHR.

proposition in terms of portability and data ownership for patients and interoperability for public policy makers. We henceforth focus mainly on stand-alone PHRs.

One of the notable PHR platforms is pioneered by Microsoft, called HealthVault, which is being piloted by the Mayo Clinic as well as other large hospitals like New York Presbyterian. The new PHRs come with application interfaces that facilitate integration with providers' clinical electronic records, so that patients (at their own discretion) can push information from the PHR into the EHR or pull information from the EHR into the PHR (e.g., Healthvault users can push and pull their information to and from Mayo Clinic's HealthManager system). These PHR tools with standard interfaces and data structures empower the patients in building a comprehensive digital history of their health and easily sharing those records with the related parties on the platform as they see fit.

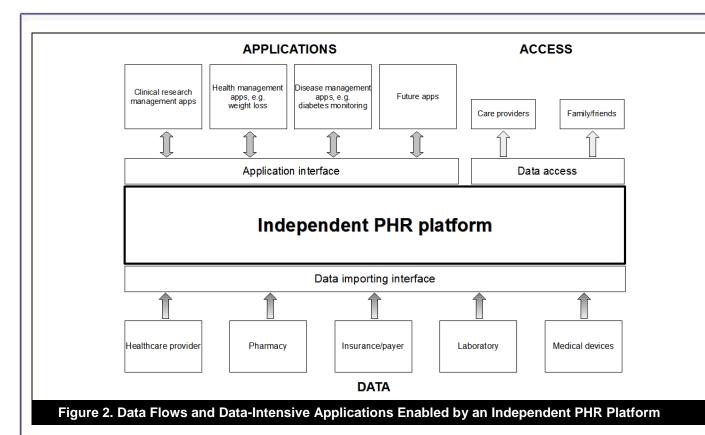
Most physicians are not connected to these platforms as of now, and thus consumers have to enter their own information in order to gain any benefit from these systems. However, there is a momentum toward greater acceptance. Microsoft HealthVault works with many third-party health application providers from where consumers can import data directly and then manage it centrally on the platform. HealthVault can also connect with many health monitoring devices such as a blood-glucose meter or a heart-rate monitor to track readings and relay them to physicians [Landro, 2009b]. The platform has released their application programming interfaces (APIs), so that several manufacturers of medical equipment for measuring body weight, body mass index, blood pressure, blood sugar, etc. are now developing devices that directly transmit patient data to the PHR platforms. Such automonitoring software can dramatically increase patient compliance. For example, in a study involving 348 Colorado patients with hypertension, patients were divided into two groups, with one group sent home with blood pressure cuffs that automatically uploaded the readings online, while the other group met their doctors monthly to check their blood pressure. After six months, patients in the home-monitoring group were about 50 percent more likely than the other group to have their blood pressure under control [Brown, 2010].

Figure 2 provides the schematic of the independent PHR platform model, specifically in the context of the various entities it interacts or will interact with and the data that it will share with those entities. We foresee three types of interfaces to the platform: Applications, Access, and Data. The Data interface will allow the patient's health records from various sources to be entered into the PHR platform's database. These data sources include the primary physician, specialists, hospitals, laboratories, pharmacies, insurance companies, Medicare, and other payers, as well as medical devices that have the capability to stream data. The Applications interface controls how external applications access an individual consumer's PHR with the consent of the consumer at the chosen level of data granularity. Based on one's health profile, consumers can be alerted about promising clinical trials or recent health articles of interest. The Access interface will allow the patient to give selective access to third parties (such as care providers or concerned loved ones, an important feature especially for the elderly).

HealthVault probably represents the most complete and advanced independent PHR platform that shows all these interfaces. As pointed out earlier, it is already working with several large healthcare providers like Mayo Clinic to import patients' data directly into its system. It is also working with device makers like OneTouch (blood glucose monitors), Homedics (blood pressure monitors), DailyCare (ECG monitors), Polar (heart rate monitors), Omron (pedometers), Tanita (weight scales), and MedApps (remote health monitoring) so that such devices can directly enter the patient data into the system as soon as they are recorded without any need for human intervention (this corresponds to the Data importing interface that we show in Figure 2). HealthVault has built interfaces for the information systems of large pharmacies like CVS and Walgreens, so that patient medication information can be imported directly from the pharmacy sites. HealthVault users also benefit from information from organizations like the American Diabetes Association and the American Health Association that is tailored to their specific conditions, empowering them to take care of their own health.

Most importantly, Microsoft has made its application programming interfaces available to the health information software industry so that specialized applications can be built around diseases and conditions. One promising new startup is Keas.com, which allows users to import their health records from PHR platforms, and use the data to create easy-to-understand colored charts that show a patient's current status, as well as to create personalized plans for the patient to reach her health goals. Other examples include diabetes monitoring equipment providers who have built customized applications around their devices so that patients can proactively take action if their blood glucose readings go beyond the desired range (all these examples correspond to the Application interface in Figure 2). Finally, HealthVault users can give access to their data to family members, care providers, and doctors, so that these responsible parties can take action on the patient's behalf as and when necessary (this corresponds to the Data Access component in Figure 2).

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For all these advantages to accrue to the patients, a fundamental requirement is the sharing of patients' records by healthcare providers, and, as we mentioned in the previous section, these healthcare providers may lack the incentive to share their patient records electronically. More specifically, as part of the framework we introduced in the previous sections, we have discussed a scenario in which both providers would benefit from mutual data sharing through interoperable EHR, but that such an outcome may not be attained due to the providers' strategic behavior, since each may have the incentive to unilaterally renege on the data sharing arrangement. In this environment, an independent PHR platform represents an alternative, market-based approach for solving the incentive problem. Our analysis suggests that a key advantage of the platform is the requirement that each participating provider makes available electronic records to a third party. This eliminates a provider's ability to unilaterally raise switching costs for consumers through its policy on the format in which the patient data is shared (e.g., giving hard-copy rather than electronic records to prior established patients who wish to switch to a new provider) and thereby supports an equilibrium with electronic data sharing.

Thus, by signing on the providers, possibly with a subsidy to induce participation or by providing costly software services, a PHR platform can offer a service that reduces switching costs across providers and provide patients with up-to-date online access to their medical history. However, this all depends on whether the platform can profit from the combined economic benefit of digitization and sharing of medical records while ensuring that all key decision makers (including the providers, insurers, consumers, and researchers) have proper incentives to participate in the new environment.

With careful design and a good implementation plan, independent PHR platforms may indeed be able to offer their services profitably in a number of ways while fully respecting and protecting the privacy of patients (any sign of weakness on the privacy front would be fatal for any platform). For example, consumers who come to trust a platform for unbiased health information will be more likely to use other services offered by that platform. Collaboration with medical researchers is another potential source of revenue. Medical researchers frequently need volunteers for their studies. Through the mining of the voluminous health records it maintains, the PHR platform can alert the subscribers who are potential matches for the new medications, devices, or procedures and ask for their voluntary participation. The subscribers should be allowed to exercise complete control over which experiments to participate in, and at no time should the experimenters have access to any subscriber's record unless the latter expressly allows it.

Obviously, the PHR platform would be able to collect a fee from the researchers for this service. Patients can agree to anonymously share select contents of their health records (perhaps in return for a fee, a discount, or a donation to a charity) and also participate in ongoing surveys. Further, by tapping into the databases populated by software that

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stream data from personal medical devices into the PHR platform, researchers would be able to study diseases, medications, and procedures in far greater detail than what can be achieved today—once again providing an opportunity for the PHR platform to collect fees. The availability of such data would also allow care providers to proactively monitor and treat patients, who otherwise might have been oblivious to their health risks. With proper privacy safeguards in place, activities like these can be beneficial to not only the PHR platform but also to the consumers and the society at large.

Yet another option for PHR platforms to generate revenue is through tie-ups with various commercial entities from which patients can buy goods and services, a strategy that is currently being aggressively pursued by Microsoft HealthVault (as outlined earlier). These entities include pharmacies (patients will undoubtedly find it advantageous to have the platform automatically replenish their medication and supplies, while pharmacies will want to be part of a system that automatically track usage and reorder medications), medical equipment (such as diabetes monitoring equipment, blood pressure measurement equipment, body weight and fat measurement equipment, etc.) suppliers who can create brand loyalty through informative articles, and companies that provide counseling on various health issues such as weight loss or cholesterol management.

Innovative use of IT, possibly through integration with other third-party applications, can produce unforeseen benefits. An analogy might be the social media platform Facebook, which has been extremely successful with its Open Graph API to enable application developers build their products around a Facebook user's online social existence. This has enabled Facebook to dominate over its competitors and increase its value enormously to its shareholders. Such innovative uses of a shared IT platform will inevitably happen in the context of healthcare as well. For example, by importing travel plans from sites such as Triplt.com, a user can be alerted about current health advisories from the Center for Disease Control that are specific to the geographic areas on her itinerary. Anonymized health data can be used for effective public policy, such as keeping track of immunizations of children within a locality. All these benefits provide revenue opportunities for the independent PHR platforms.

While the PHR platforms, consumers, and other private parties would definitely gain from the controlled sharing of health records, the key question is whether healthcare providers would play along with such an arrangement. In order to be successful, a PHR platform will need to offer meaningful financial incentives to providers, from providing subscriptions to their patients for free to perhaps even subsidizing their EHR adoption by giving away a "cloud-based" EHR system. In some cases, substantial financial incentives may have to be offered because moving health records from physician offices to the PHR platform marks a profound shift in terms of the ownership of these records from physicians to patients. Such shift effectively makes these records much more portable than before, thereby reducing the switching costs for patients and impacting the competitive dynamics in the sector. We would expect their client bases from the competition, and hence the platforms will have to make the extra effort to enroll them. Note that large providers are precisely the segment that Microsoft is focusing on right now.

#### V. A LONG ROAD AHEAD

PHR platforms will have to overcome significant challenges before they can aggregate health records of patients and profit from them in a way similar to how financial information aggregators do. Perhaps most importantly, privacy concerns are amplified because health data for many consumers is the most sensitive type of personal information. For example, HealthVault announced and posted strict privacy policies prominently on its website, giving consumers the complete rights to decide what data to share and with whom, as well as the ability to close their accounts and delete their complete account histories at any point in time. Clearly, implementing and assuring the strictest privacy standards will be an absolute business necessity for the PHR platforms rather than a public service.

However promising the PHR platforms might be, they have their share of limitations, and more importantly, problems. At a fundamental level, an independent PHR platform is, after all, a private business entity. Its raison d'être is that it can effectively profit from the benefits of portable health records to the society. In the process, it siphons off a part of that benefit as private profit, a surplus that theoretically could have been returned to the public if instead, say, the federal government had undertaken such an exercise. Further, the market is saturating with multiple competing independent PHR platforms, even though theoretically one universal platform suffices. The presence of multiple independent platforms can lead to the storage of redundant patient records in the system with varying degrees of completeness depending on which provider updates its data to which platform and with what frequency.

Another potentially serious concern is that a single health condition can generate data from multiple sources. For example, a primary physician might refer a patient to a specialist, who in turn orders several laboratory tests and an

MRI scan, where each service gets reimbursed by multiple payers (such as private insurance, Medicare, and the patient). Each of these data sources may use different codes for conditions.<sup>6</sup> Recently, a patient at Boston's Beth Israel Deaconess Medical Center found that the list of conditions in his new Google Health record included serious diagnoses he had never received from his doctors, all due to misclassifications by insurance companies [Wangsness, 2009]. Such occurrences are not hypothetical and may increase in number with the mass adoption of PHRs. The problems will be compounded if patients maintain their health records in multiple PHRs, as it will not be clear which PHR the doctor should believe in case of discrepancies. Another potential drawback of PHRs is that they may help propagate erroneous records much quicker than ever before, although patients' newfound control over their records will likely mitigate the severity of this problem.

We also see a need for government regulation that explicitly bars the use of the health records maintained in private PHR platforms by third parties such as potential employers, insurance companies, and landlords, so that a person's health record can never be the basis for any discriminatory action, and that any attempt to access or use PHR data for such purposes is to be considered a felony. Also, consumers will need to be educated about potential fall-outs of sharing information with third-party applications, since information, once shared, cannot be taken back, even if the consumer changes his mind at a later point in time.

#### **VI. CONCLUSION**

Although the prospect of widespread sharing of electronic health records in the United States remained rather bleak until recently, the emergence of PHR platforms stands to change the status quo. If they become successful, consumers will benefit greatly, as the platforms will put them back in charge of their own data and enable the delivery of new value-added services. Furthermore, data aggregation and sharing will introduce transparency into the system and eventually allow efficiency gains. Considering that PHR platforms represent a viable market-based solution to the problem of misaligned incentives, we think they deserve a careful attention in the debate on facilitating the adoption and use of EHRs in the healthcare sector. Therefore, the government should allocate resources to explore these private solutions and develop well-thought-out regulation to mitigate undesirable fall-outs of their widespread adoption, so that the platforms can live up to their promise.

Aside from overcoming the technical challenges and allaying privacy concerns, the key issue for the independent PHR platforms is ensuring the participation of a critical mass of providers. It remains to be seen whether providers on a grand scale will respond to the financial incentives and agree to share their patients' medical records digitally.

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*Editor's Note*: The following reference list contains hyperlinks to World Wide Web pages. Readers who have the ability to access the Web directly from their word processor or are reading the article on the Web, can gain direct access to these linked references. Readers are warned, however, that:

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<sup>&</sup>lt;sup>6</sup> To further compound the problems, different hospitals and clinics may use different encoding standards, such as ICD-9 and SNOMED-CT, which have very different data vocabularies. ICD-9, which is common among insurers for billing purposes, has a much smaller vocabulary compared to SNOMED-CT. ICD-9 is adequate for billing purposes but often lacks the vocabulary in capturing the specific conditions in the way a doctor would have intended to describe it. Unfortunately, in many cases, ICD-9 represents the only way that the data about the patient's condition is encoded digitally, since it is often only the billing process that ends up capturing a medical incident within a computer system. To compound these problems even further, billing codes are often misapplied by "coders" in trying to feed something acceptable into a claims payment system, resulting in conditions being recorded in a manner the doctor may have never intended.

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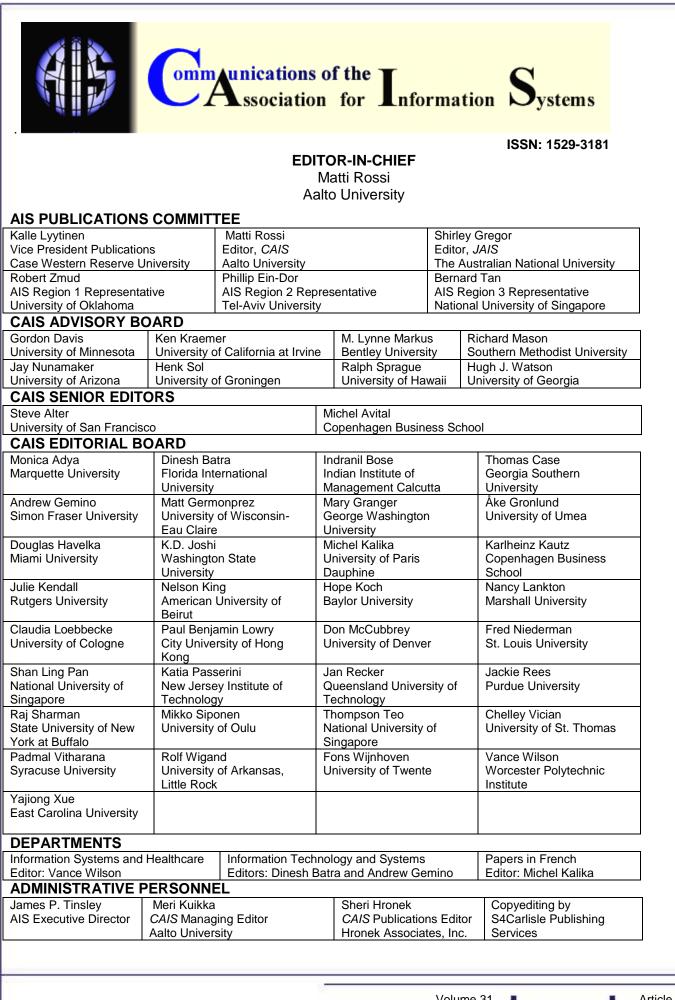
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