Lessons Learned from a Health Record Bank Start-up

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1. Background

1.1 Rationale for HRBs

Establishing a health information infrastructure (HII) that assures the availability of comprehensive electronic patient records when and where needed has proven to be a challenging problem. Several key obstacles have been identified: 1) privacy – the privacy of each individual’s medical records must be protected; 2) stakeholder cooperation – physicians, hospitals, laboratories, pharmacies, imaging centers, etc., must all contribute their patient records; 3) incomplete information – all the records must be electronic in order to facilitate organizing and delivering comprehensive records for each patient; and 4) financial sustainability – operational funding must be available on an ongoing basis [1]. In a recent report, 75% of HII projects in the U.S. reported this latter issue as an especially critical obstacle [2].

Health record banks (HRBs) have been defined as “independent organizations that provide a secure electronic repository for storing and maintaining an individual’s lifetime health and medical records from multiple sources and assure that the individual always has complete control over who accesses their information” [3]. Since the concept was originally described by Szolovits [4] and first called a “health information bank” a few years later by Dodd [5], it has been studied and cited worldwide [6–13]. Recently, health record banks have been proposed as a solution to the health information infrastructure problems noted above [14]. In contrast to the commonly used distributed architecture for managing electronic health records, where each pa-

Keywords
Health record bank, health information infrastructure, health information exchange, personal health records, electronic health records, business model, clinical system implementation

Summary
Introduction: This article is part of a Focus Theme of Methods of Information in Medicine on Health Record Banking.
Background: In late summer 2010, an organization was formed in greater Phoenix, Arizona (USA), to introduce a health record bank (HRB) in that community. The effort was initiated after market research and was aimed at engaging 200,000 individuals as members in the first year (5% of the population). It was also intended to evaluate a business model that was based on early adoption by consumers and physicians followed by additional revenue streams related to incremental services and secondary uses of clinical data, always with specific permission from individual members, each of whom controlled all access to his or her own data.
Objectives: To report on the details of the HRB experience in Phoenix, to describe the sources of problems that were experienced, and to identify lessons that need to be considered in future HRB ventures.

Methods: We describe staffing for the HRB effort, the computational platform that was developed, the approach to marketing, the engagement of practicing physicians, and the governance model that was developed to guide the HRB design and implementation.

Results: Despite efforts to engage the physician community, limited consumer advertising, and a carefully considered financial strategy, the experiment failed due to insufficient enrollment of individual members. It was discontinued in April 2011.

Conclusions: Although the major problem with this HRB project was undercapitalization, we believe this effort demonstrated that basic HRB accounts should be free for members and that physician engagement and participation are key elements in constructing an effective marketing channel. Local community governance is essential for trust, and the included population must be large enough to provide sufficient revenues to sustain the resource in the long term.

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In an HRB, privacy is protected because individuals control access to their own records, thereby setting their own custom-tailored privacy policy. Stakeholder cooperation is assured because the patients request that their records be deposited in the HRB and generally have a right to do so. Under U.S. law (the Health Insurance Portability and Accountability Act [16]), such requests must be honored, and the information must be provided electronically if it is available in digital form. Incomplete information (especially the absence of ambulatory care records critical to HII success) can be avoided if the HRB provides free or subsidized electronic health record (EHR) systems to office-based physicians, thereby permanently removing the financial obstacles to EHR adoption. Finally, a number of sustainable business models are possible using HRBs, which can leverage the new value created by the medical information itself [17].

Concerns about HRB security arise from the misguided belief that information security is improved by dispersal of data. However, it is well established that a properly protected centralized database such as an HRB is actually more secure than the equivalent distributed system [18]. First, the mechanism for immediately locating and retrieving each patient’s records in a distributed system is subject to the same security vulnerabilities as a central data repository. Second, aggregating data from disparate sources doubles the risk of interception, since data are transmitted twice for each use: once from the storage site to the aggregator, then again from the aggregator to the end user. Third, data in a central system can be protected more easily because it is “much easier to enforce strict security access controls when there are fewer doors or when the entry points are centralized” [19]. Fourth, protection from unauthorized “total access” to the entire database is provided by double encryption of the data, with one key held by the HRB and the other by the patient. Finally, employing multiple community-based HRBs limits the amount of data in any one system, establishing an upper limit to the consequences of any possible breach. Overall, it is clear that HRB security is in fact superior to what can be achieved with a distributed system.

1.2 Objectives

The purpose of this report is to describe the experiences and lessons learned from a health record bank startup, known as eHealthTrust™, which began in 2010 in greater Phoenix, Arizona (USA). By sharing the details, observations, and challenges from this effort, we hope to identify lessons that will in turn help to guide and inform future health record bank development projects.

1.3 Assumptions

1.3.1 Essential Patient Records

Achieving the cost and quality benefits of HII requires comprehensive, longitudinal records for each individual. While most HII efforts have focused primarily on hospital records, the vast majority of medical care occurs in the outpatient setting. As a result, the care coordination benefits of the HII derive primarily from more complete ambulatory records. An HII can therefore be effective with only discharge summaries, imaging reports, and test results from hospitalizations, combined with outpatient data. Accordingly, outpatient records were initially planned to be the primary elements in our HRB. Later, we planned to establish electronic connections to hospitals to receive discharge summaries, test results, and text reports (pathology, radiology, etc.).

We also initially excluded digital images from the HRB to avoid the substantial storage and communications costs that these data would entail. We decided that interpretive reports of such images would be sufficient for our initial implementation.

1.3.2 Community Characteristics

Local and regional HII approaches have been more successful than statewide or national efforts and can more easily provide comprehensive medical records for each individual since most medical care is provided close to home and local governance enhances trust in the entity. Several characteristics of the Phoenix community made it attractive for introducing an HRB. First, the population of about 4 million is relatively large, reducing the percentage of market penetration needed to achieve a given subscriber count. Our first year subscriber goal was 200,000, just 5% of the population. Second, there was no existing “health information exchange” (HIE) operating at any scale in the area. While we were not particularly concerned about an HIE from the perspective of competition, since we believed that we could offer much more to both patients and the community, including a sustainable business model based on patient payments, we nevertheless considered it an advantage to avoid competing for attention with another entity working to make electronic health records more generally available. There was a grant-funded Medicaid-based pilot that had briefly operated in the Phoenix area, and a provider-launched HIE developing in nearby Tucson, AZ, but these were still small operations. Third, and perhaps most important, there was a local health information technology leader who wanted to lead this initiative. We believe that such a trusted, local leader is an essential ingredient for success.

1.3.3 Market Research

In preparation for starting the HRB, we engaged a national market research firm, with extensive experience in consumer products, biotechnology, and information technology, to assess demand for our product. In particular, we wanted to determine if consumers would pay a modest one-time fee to sign up for a lifetime HRB account. In an online survey of a stratified, randomly selected nationwide population sample, 20% of respondents indicated that they were likely to pay for the service if it was recommended by their physician.
funding, we minimized our budget so that we needed only 600 customers to sign up to pay our expenses through our first month of operation. This was considerably less than our conservative estimate that only 1% (2,000) of our expected 200,000 first year customers would enroll in the first month.

Our ongoing strategy was to market actively to physician groups as we directly signed up early adopter consumers. We began discussions with likely prospects several months before the service was rolled out to consumers. As physician groups agreed to participate, we planned to subsidize their EHR systems using the capital generated from early consumer sign-ups. We also planned to initially pay staff and operational expenses from this same revenue stream.

### 1.3.5 Revenue Sources

As indicated, our key initial revenue source was to be consumer signup fees ($99 each). Free accounts that allowed consumers to enter their basic information themselves (medical conditions, medications, and allergies) were available to engage folks not yet ready to pay for a full-featured account. This basic information could be printed on an “In Case of Emergency” ("ICE") card that could be carried in a purse or wallet.

### 1.3.4 Financial Strategy

Total capitalization of the company was under $400,000, which we believed would be sufficient for technical HRB deployment using open-source software and the staff and operational costs for our initial market entry. To accommodate this very modest funding, we minimized our budget so that we needed only 600 customers to sign up to pay our expenses through our first month of operation. This was considerably less than our conservative estimate that only 1% (2,000) of our expected 200,000 first year customers would enroll in the first month.

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### Table 1

Summary of health record bank market research: In an online survey of 1,044 representative U.S. consumers, respondents read the following description of the HRB account and were asked about their purchase intent: It’s a secure account for your medical records that works much like a bank account. You and any of your doctors can add and retrieve information at any point (with your permission), ensuring that you receive better, safer care at lower costs by avoiding unnecessary tests and reducing medical errors. It is offered by an independent, secure organization that exists to protect your privacy. Having an updated electronic health record also means physicians can easily access your medical information anytime, including during an emergency or when you travel, your prescriptions can be filled more easily, vaccination records are always available, you will avoid filling out clipboard information at each doctor’s office.

<table>
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<th>Key Results</th>
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<td><strong>Inclination to purchase service today with physician recommendation</strong></td>
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<tr>
<td>Willing 65%</td>
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<tr>
<td><strong>Expected annual fee</strong></td>
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<tr>
<td><strong>Would purchase for children</strong></td>
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<td><strong>Would purchase for parents</strong></td>
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<tr>
<td><strong>Reminder services</strong></td>
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<td>Would purchase</td>
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<td>Would purchase for $50 or more annually</td>
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In addition to the “premium” medical record account (with the one-time $99 fee), we also offered a package of three applications ("apps") for $39/year. First, there was the “peace of mind” app that promptly notified consumer-designated loved ones if an emergency physician accessed their records (indicating they were receiving emergency treatment). Second, the “prevention advisor” app that, based on demographics and the information in their medical record, used established guidelines [20] to remind consumers about tests and procedures necessary to maintain their health (e.g., immunizations and screening tests). Finally, the third “medication refill reminder” app notified consumers electronically when a medication refill was needed and then, with consumer approval, sent a refill request to the relevant pharmacy on behalf of the consumer. These applications, while easily implemented, were not actually deployed.

We also anticipated inviting third party application developers to market their own apps in an “app store” where consumers could decide whether to utilize (and pay for) them. We expected that this would be a source of substantial revenue later in the development of the company.

Advertising to consumers while they accessed their medical records was also planned, but never implemented. The idea was to ask subscribers if they were interested in seeing ads related to their medical conditions. Then advertisers would be invited to submit targeted messages for a fee. Those consumers who did not wish to receive ads could opt out for a small annual charge (e.g., $5/year).

Finally, we expected to generate revenue from the use of the medical data (with opt-in consumer permission) for research. On enrollment, consumers would be asked if they were interested in being notified if they qualified for any clinical trial, provided that no one else was notified – not their family, their doctor, or the researchers – at no charge. Most consumers would be happy to receive such a free service. Then, we could solicit researchers looking for potential clinical trial subjects that met defined criteria. We could search the HRB records for patients meeting the study qualifications and send them electronic...
messages describing the research, including contact information of the researchers so consumers could indicate their interest in participation. The researchers would be told only how many account-holders received notifications, thereby protecting the privacy of potential subjects. Researchers would gladly pay substantial fees for this service, since finding qualified clinical trial participants is typically very challenging [21]. When consumers agreed to participate in a specific research study, they could easily designate those portions of their medical records from the HRB that they wished to share electronically with the researchers.

Consumers would also be asked if they were willing to allow their data to be aggregated with others into anonymized reports that would be available to researchers for a fee. These reports would be similar to those produced by the U.S. Census Bureau, using statistical disclosure control techniques to assure that no individuals can be identified. A material portion (e.g., 30%) of the revenue generated from these reports would be shared on a pro-rata basis with consumers who contributed their data. These “data contributors” would therefore have an “interest bearing” health record bank account that could earn a few dollars each year. This is analogous to savings accounts in financial institutions, where many small deposits are aggregated to make loans, and a portion of the interest the bank receives for those loans accrues to the depositors. Since over 80% of consumers support the use of their data for medical research with their permission [22], we anticipated that most HRB account holders would choose to include their data in such research reports.

2. Methods

2.1 Staffing

The health record bank had a staff of about 15 people, most of whom were part-time. Leadership was shared by the Chairman of the Board (WAY) and the full-time CEO.a

Our technical team of five included a full-time senior systems engineer, two EHR specialists, a health information management professional, and a controlled vocabulary consultant. The remaining positions represented the marketing team that covered strategy, planning, messaging and communications, web site development, direct channel sales, and advertising. However, everyone in this for-profit company was involved to some extent in marketing and sales discussions.

2.2 Establishing HRB Platform

We contracted with a local secure data center, used by several large health care organizations for their electronic patient records, for server space and internet connectivity using our own hardware, with available on-demand virtual servers that could be added rapidly if needed to accommodate high levels of usage. The data center provided 24/7 security personnel who restricted physical access to authorized personnel only, using iris scanning for authentication. The location of our servers (in this large facility) was unmarked and known only to us and a handful of senior data center personnel. In addition, all data on our servers were encrypted. We utilized the open source Tolven software [23] and the open source relational database PostgreSQL [24] to store clinical data and to provide access to consumers and physicians. Using standard tools, we established a sophisticated web site that including marketing videos, product information, company information, enrollment, and payment capabilities. The web site also served as a portal to access health record bank accounts.

Physicians, hospitals, and other sources of medical record information could make deposits using standardized export functions into the Tolven HRB from their EHR systems. It also was our intention to provide downloading capability to allow imports of HRB data for individual patients (with patient permission) into clinician EHRs, but this was never implemented for reasons outlined below.

2.3 Marketing

2.3.1 Direct to Consumer

Our direct-to-consumer marketing began in October, 2010, with billboard advertising supplemented by modest levels of internet advertising. We also established a presence on Facebook and Twitter. We rapidly transitioned from billboards to radio advertising with 30- and 60-second spots on one popular adult station. We contracted with a public relations firm to assist with obtaining earned media (e.g., interviews, news stories). While our total marketing budget was small (under $100K), media data indicated that we reached a significant percentage of the population with more than one message.

2.3.2 Physicians and Physician Channel to Consumers

We began contacting physician groups several months before our direct-to-consumer marketing campaign began, and had discussions with several dozen such groups. We offered physicians either a free EHR (if they did not have one) or monthly payments up to $300/physician for regular deposits of EHR data from their patients into the HRB. In the latter case, the physicians would need to contact their vendors to acquire an appropriate interface (at their expense). In exchange for this EHR benefit, we asked physicians to strongly recommend HRB accounts to their patients and to facilitate enrollments on-site when patients were in their offices for a visit. For physicians electing a free EHR, we would allow them to choose from a list of established vendors of off-site subscription-model systems, all of which had agreed to establish interfaces to the HRB and make their systems available in exchange for discounted license payments from the HRB. This was advantageous to the EHR vendors because it eliminated marketing and sales expenses, since the HRB would promote their systems in the community.

2.3.3 Other Channels

Another marketing channel we explored was emergency medical technicians. (EMTs). The idea was to provide EMTs...
with the ability to access the medical records in an HRB account while in transit to a medical emergency. Then, instead of having virtually no information upon arrival, the EMTs would know the patient’s medical history and immediately be prepared to address the current problem appropriately. We were able to spend time in the Phoenix area emergency call center to familiarize ourselves with the process of dispatching EMTs and were confident we could design an HRB interface that would be helpful.

We had several meetings with senior Fire Department leaders, who readily agreed that having patient history information prior to arriving at the scene of a medical emergency would be extremely helpful. Not surprisingly, however, they were reluctant to deal with a new startup company and wanted to see a demonstration of a fully operational prototype before making any commitments. In addition, the decision-making and approvals regarding new initiatives within the Fire Departments was slow due to bureaucratic and governmental constraints.

2.4 Governance and Trust

Several months after starting operations, we also recruited a volunteer Advisory Board of community leaders to help guide our efforts and engender the trust of our prospective customers. We were pleased that a number of well-known and prominent leaders were supportive of our objectives and willing to assist. We met regularly with this group and reviewed our progress and plans. Their advice and counsel were consistently helpful. In retrospect, we should have established this Advisory Board earlier, since we found that the affiliation of community leaders with our efforts was very positive.

We established the HRB as a for-profit entity so that it was possible to raise capital. While a non-profit HRB is possible, and arguably preferable, capitalizing such an entity essentially requires the voluntary cooperation of existing healthcare stakeholders, many of which are skittish or even opposed to the type of disruptive innovation represented by an HRB (even though it is ultimately beneficial to them). The ideal arrangement (Figure 1) would be a community non-profit that contracts with a for-profit HRB. The community non-profit then can “regulate” the for-profit HRB by means of the contract between the entities. Until or unless government regulation of HRBs is initiated (somewhat analogous to regulation of financial banks), we believe the model depicted in Figure 1 is the best available alternative.

2.5 Other Activities

In addition to our technical and marketing activities, we performed the usual range of essential administrative tasks. In addition to the typical legal agreements and banking arrangements, we also needed to develop a custom-tailored, clear, and understandable customer agreement that protected both account-holders and the organization. While these types of activities are routine in any business, the time and effort required represented a substantial fraction of the attention of such a small organization.

3. Results

3.1 Lack of Enrollees

Unfortunately, fewer than ten consumers signed up for the service. Switching our marketing focus from billboards to radio had no discernible effect, although traffic on the web site was higher when the radio ads were running. As a result of the lack of signup revenue, we experienced immediate and serious cash flow problems.

3.2 Physicians Reluctant to Recruit Patients for Service Requiring Payment

As we had ongoing discussions with prospective physician groups, it was clear that they were uncomfortable recommending HRB accounts to their patients unless the accounts were free. This issue did not arise in our early discussions, which were focused on explaining the HRB concept and business model. It was not until physician groups were seriously interested that they considered the implications of recommending the service and raised objections. One large physician group agreed to participate on the condition that the accounts to their patients were free. We were forced to agree to this condition, but hoped that subsequent physician groups would not insist on this. We obtained a legal opinion that payments the company would make for an EHR on behalf of physicians did not violate U.S. laws and regulations regarding “kickbacks,” nor was it an ethical issue since the entire activity promoted better patient care.
3.3 Insufficient Capital for Alternative Business Model

Without the signup revenue from a reasonable number of early adopters of HRB accounts, we did not have sufficient funds to continue operations. As soon as we realized that more capital was needed to pursue a “freemium” business model (i.e., where the basic product is free and revenue is generated from charges for premium services), we undertook an urgent search for additional investment, but were not successful. Not wanting to disappoint our initial physician group, we did not finalize their participation agreement. Instead, we shut down the business in April, 2011.

4. Discussion

While we still believe that our market research is accurate and there is substantial demand for HRB services, it is clear that the cost of making large numbers of consumers aware of the HRB concept and a specific local HRB is much larger, and the time required to do so much longer, than we anticipated. In retrospect, this was our most significant error. We were so anxious to start the business and so confident that it would be immediately appealing to consumers that we failed to be realistic about the time and costs of direct-to-consumer marketing, especially since this was an entirely new and unfamiliar service.

It became clear to us that the most feasible method for establishing an HRB is to offer free accounts to consumers exclusively through physicians. This has multiple benefits: 1) It assures more complete information by providing EHRs that make patient data electronic; 2) It ensures that electronic patient data will be deposited in the HRB by physicians; 3) It ensures rapid patient signup for free accounts recommended by physicians; and 4) It provides a large and rapidly growing customer base to purchase optional apps or services (thereby generating revenue).

However, without any fees for opening HRB accounts, the capital requirements are greatly increased. Sufficient funds must be available to establish and operate the business until revenue from apps grows sufficiently to cover these expenses. We estimate this capital requirement to be about $5 million. While this is substantial, it is a justifiable investment for a business that can easily yield substantial profits at scale in just a single large community.

Therefore, our recommendation to future HRB entrepreneurs is to use physicians as the marketing channel to consumers. This strategy is much easier to execute because of the “View, Download, and Transmit” (VDT) requirement of Meaningful Use Stage 2 [25], reflected by the growing interest in implementation of the “Blue Button Plus” capability for consumers [26]. In order to continue receiving incentive payments under the Meaningful Use program, providers must enable their patients to view, download, and transmit their medical records in a standard format. As a result, all the EHR vendors are implementing standard export capabilities that could, at the request of the patient, be used to send information to an HRB account. The VDT requirement is fully effective for all providers seeking incentive payments starting in 2014. In effect, it eliminates the necessity for an HRB to deploy multiple EHR interfaces and providers to acquire EHR export modules to enable HRB deposits. This greatly simplifies HRB implementation. Upon signup, patients would designate the HRB to receive VDT transmissions from all their providers, thereby ensuring the flow of standardized electronic records.

5. Conclusion

Health record banks (HRBs) represent a feasible and effective approach to health information infrastructure, addressing the key requirements of protecting patient privacy, ensuring stakeholder cooperation, enabling complete electronic records, and providing a sustainable business model.

Ideally, an HRB startup should be undertaken in a large community (millions) to facilitate substantial enrollment and revenue generation at the low levels of penetration that are inevitable in the early stages. The community approach also minimizes the number of healthcare stakeholders that need to be connected to the HRB, while still retaining the ability to capture the majority of relevant health records for the entire population. Substantial initial capital is needed to cover operational expenses until such time as revenue from optional patient apps is sufficiently large.

A freemium business model should be used, providing free HRB accounts to anyone, while imposing charges only for optional services. The key revenue stream involves compelling apps for patients (see details in 1.3.5 above). Third parties should be invited and encouraged to deploy additional apps in the HRB ecosystem, with revenue shared between the HRB and the developer.

Additional sources of revenue include advertising to patients (and “opt-out” fees for those not wishing to receive advertising) and research use of the HRB medical.

Table 2

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<tr>
<th>Key lessons learned</th>
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<tr>
<td>1. Developers of HRBs should avoid undercapitalization. Substantial initial capital (in the range of US$5 million or more) is needed.</td>
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<tr>
<td>2. Basic HRB accounts should be free. Sources of revenue include reminders and alerts, advertising to patients, and fees from researchers and public health organizations for reports and assistance in finding clinical trial subjects.</td>
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<tr>
<td>3. Physicians are the most effective marketing channel to consumers. When physician EHRs are subsidized, deposits of electronic records into the HRB are assured, and physicians will assist in recruiting consumers for HRB accounts to improve patient care.</td>
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<tr>
<td>4. HRBs should be developed locally, but in a relatively large community (population in the millions). Most medical care is local, so comprehensive records are available in the community and there are fewer information sources to be connected.</td>
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<tr>
<td>5. Local community governance is essential for trust. A Governing Board of community leaders that reasurers the community that the HRB is following good privacy and security practices is the best available option until or unless government regulation of HRBs is established.</td>
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records with consumer permission. For the latter, appropriate sharing of revenue generated from researchers with HRB account holders will help to incentivize consumers to allow the use of their data.

A Governing Board of community leaders helps to reassure the general public that the HRB can be trusted, and is operating with policies and procedures that protect privacy and security of their private medical record information. Ideally, it should be possible for the Governing Board to replace the HRB operating entity if it does not fulfill these obligations.

While the effectiveness of HRBs has not yet been demonstrated in the U.S. setting, and despite the challenges that we faced in our undercapitalized initial experiment, the approach suggested by our experience in Phoenix is very promising. Physicians are motivated to accept ongoing EHR subsidies in exchange for recruiting their patients for free HRB accounts. Patients are very likely to accept such free accounts with the recommendation of their physician. They also are likely to pay modest amounts for reminders and alerts of compelling value, thereby ensuring profitability of the HRB at scale. This can be supplemented by other revenue sources, such as advertising and research use of the data (with permission and sharing of revenue with subscribers). These lessons are summarized in Table 2. We believe that another HRB startup that applies these techniques with sufficient initial capital is likely to be successful.

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References


Disclosures

Dr. Yasnoff (President) and Dr. Shortliffe (Chair of the Advisory Board) have leadership roles in the non-profit Health Record Banking Alliance (HRBA, www.healthbanking.org). Dr. Yasnoff was a principal in the Phoenix eHealthTrust project described in this report. Although Dr. Shortliffe was not involved with that company, he served as Founding Dean of the University of Arizona College of Medicine campus in Phoenix just prior to the introduction of the HRB project, had entered into planning discussions with Dr. Yasnoff and Mr. Tritle, and is a proponent of the health record banking model (see [14]).