
Environmental Scan of the Personal Health Record (PHR) Market

DRAFT

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Preface

This report was developed for the Office of the National Coordinator for Health Information Technology (ONC) by Altarum Institute, a nonprofit research organization. Research for this report was conducted between August and October of 2006. Work was performed under the American Health Information Community (AHIC) Program Support contract; Prime Contract No. GS-10F-0034N, Order No. HHSP233200500217U.

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1.0 Background

The current state of health care in the US results in individuals' health records typically being distributed among different insurers and providers. Personal Health Records (PHRs) are, in part, a response to the question of who better than the patient to task with ensuring medical records are accessible, correct, and up-to-date. Widespread PHR adoption has the potential to empower patients to be more active participants in their health and healthcare.

Today there is no universally accepted definition of PHRs. In 2005, an American Health Information Management Association (AHIMA) work group defined PHRs as follows:

"The personal health record (PHR) is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from the health care provider and the individual. The PHR is maintained in a secure and private environment, with the individual determining the rights of access. The PHR is separate from and does not replace the legal record of the provider."¹

In 2003, the Markle Foundation defined a 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. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies. Individuals access their PHRs via the Internet, using state-of-the-art security and privacy controls, at any time and from any location. Family members, doctors or school nurses can see portions of a PHR when necessary and emergency room staff can retrieve vital information from it in a crisis. People can use their PHR as a communications hub: to send email to doctors, transfer information to specialists, receive test results and access online self-help tools. PHR connects each of us to the incredible potential of modern health care and gives us control over our own information.”²

In 2006, the National Committee on Vital and Health Statistics (NCVHS) noted that “there is no uniform definition of personal health record in industry or government. The following attributes can vary:

- the scope or nature of the information/contents
- the source of the information
- the features and functions offered
- the custodian of the record
- the storage location of the contents
- the technical approach
- the party who authorizes access to the information.”³

¹ AHIMA e-HIM Personal Health Record Work Group. "The Role of the Personal Health Record in the EHR." Journal of AHIMA 76, no.7 (July-August 2005).

² The Markle Foundation's Connecting Healthcare in the Information Age Project "The Personal Health Working Group Final Report" http://www.connectingforhealth.org/resources/final_phwg_report1.pdf (July 2003).

³ Report recommendation from the National Committee on Vital and Health Statistics "Personal Health Records and Personal Health Record Systems" <http://www.ncvhs.hhs.gov/060622lt.htm> (Feb, 2006).

While this report does not attempt to propose a universally acceptable PHR definition, we did evaluate the broadest set of products (from paper-based health planners to PHRs integrated with insurance and provider data systems) to define the current state of the market for many attributes NCVHS described.

Previous reviews of PHR offerings have been conducted, most recently in 2006 by the American Association of Retired Persons (AARP)⁴. The PHR market is relatively immature and lacks an obvious technological or market leader. PHR products show an enormous variation in functionality; vendors are pursuing a multitude of business models and approaches to privacy and confidentiality. Security issues are diverse and changing. PHRs can be paper-based, Web-based, PC-based, or saved to a memory stick (USB). They can be standalone, tethered to other sources of healthcare data like provider and insurer systems, or robustly integrated with several sources of healthcare data.

The remaining sections of this report discuss our methodology, caveats of the reported data, and our findings. Discussions are organized by the following topics: PHR architecture, functionality and data; PHR approaches to confidentiality, privacy and security considerations; and PHR vendor business models.

This report on the state of the PHR market is submitted in the hopes of contributing to policy deliberations and assisting the promotion of PHR adoption and the removal of barriers to the goal of widespread accessibility to “lifelong personal health records.”

2.0 Methodology

We believe the future of the PHR is a patient-centric model where the consumer is at the center of the integrated medical information network.
– PHR Vendor

Data collection for this study was based on self-reported vendor responses, reviews of Web sites and product literature provided by vendors, and interviews with selected non-vendor participants (e.g., physician groups, health plans). These methods were selected to maximize the collection of usable information given strict time and regulatory constraints. Several caveats to our findings therefore apply.

First, it is not reasonable to carry out statistical tests of significance on these data as the true PHR vendor population and its variance are unknown. The sampling frame may not have been exhaustive despite our best efforts at completeness and representativeness. We do show various data cross-tabulations and comparisons of groups, but these should be taken as descriptive and illustrative, rather than statistical in nature. As with any data derived from methods other than random sampling and response, there is no way to determine the appropriate error estimate for these data.

Second, the degree of market coverage and any bias in our sampling is also not known with certainty. We made every effort to contact those vendors identified by other members of the community as the largest in the field, but without accurate data on consumer adoption rates it is difficult to assess how representative of the market the data in this report are. As a notable example, one prominent PHR vendor declined to take part in this study.

Third, the self-reported uptake and usage data were sparsely populated and not cross-validated. That is, we did not survey PHR users and some vendors declined to provide data on the current number of users of their product. This makes it difficult to weight our data by the number of active users. Given

⁴ C. Cronin. “Personal Health Records: An Overview of What is Available to the Public” http://assets.aarp.org/rgcenter/health/2006_11_phr.pdf (2006).

our understanding of uptake and usage rates, we estimate that it would take a survey of at least 200,000 randomly chosen US adults to achieve a usable analysis set of 500 respondents with current PHR experience (assuming 25% response rates and a point prevalence of 1% in current PHR usage). While there is no doubt that such an approach would supplement the data reported here and surveys related to PHR use have been done in the past, this report focuses on describing the attributes of current products with little discussion in the way of users of those products.

Given these caveats, our approach was thorough and rigorous. We began with an initial sampling frame of 93 vendors, which we derived from previously published lists and with discussions with the government. The following are the published references used to generate the initial sampling frame:

- American Health Information Management Association (AHIMA) Current List of PHR Vendors
- PHR Inventory Internet Sites from Office of the National Coordinator for Health Information Technology (HHS).

We took the list to be a comprehensive census of all current PHR vendors. Therefore, there is no “sampling” as such in this study. After thorough review we eliminated duplicates from the list (e.g., re-branded products) and developed a list of 89 unique PHR offerings.

2.1 Phase 1

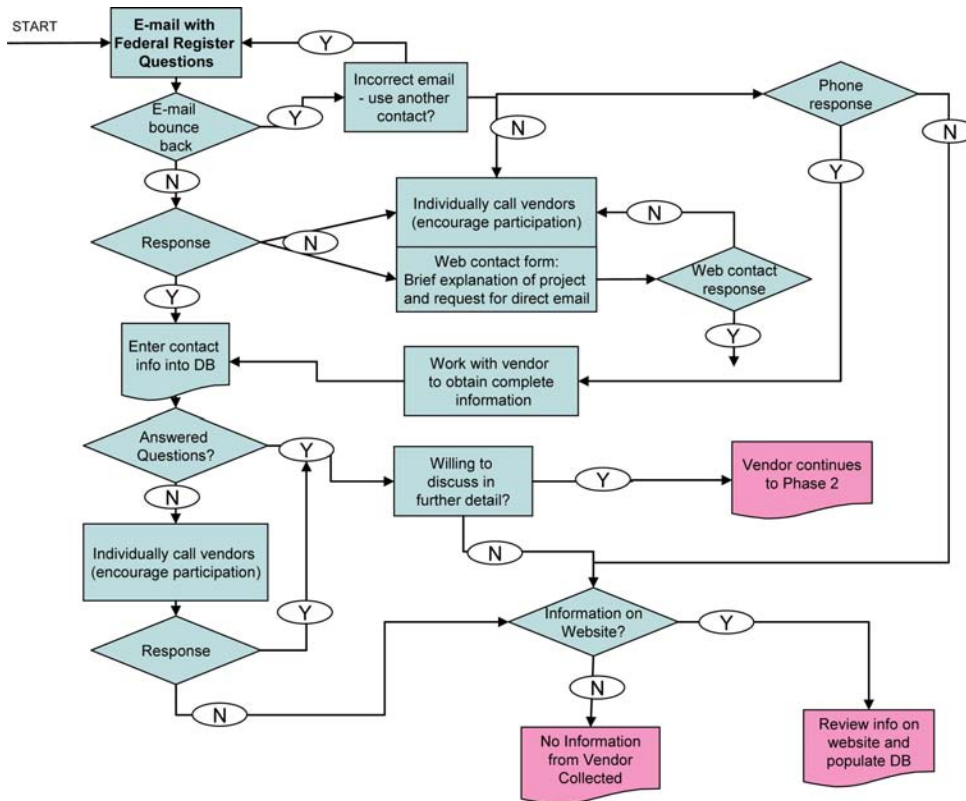
We then attempted to ask all 89 vendors on this list the following four questions as part of the solicitation of public responses for the AHIC:

1. Please provide any product literature or specifications (or a brief description of your product, including concept and distribution channels).
2. Please describe what differentiates your product in the following five areas. Also, describe any challenges you’ve overcome or currently face in these areas.
 - Functionality
 - Business model and marketing practices
 - Confidentiality, privacy and security
 - Promoting PHR adoption
 - Connectivity
3. As you are able please respond to the questions listed in the attached federal register notices about Consumer Empowerment workgroup meetings concerning functionality, interoperability, consumer outreach and incentives.
4. Would you be willing to discuss your product and any hurdles you face in further detail?

Not all vendors had direct email contact information readily available, therefore, standard emails with the attached Federal Register questions were sent to 55 vendors in early September, 2006. In addition, 15 online contact forms were filled out requesting contact information. Out of the initial 55 vendors contacted for information, 10 vendor email addresses bounced back as invalid. If another email address could be located the email was resent, if not, the vendors were placed in the “non-responsive” category for further contact attempts described below.

During both phases of our data collection, we had an aggressive approach to achieve the greatest number of responses. Exhibit 1 illustrates our data collection process for Phase 1.

Exhibit 1: Data Collection Process for Phase 1



We followed up the standard email by contacting 50 non-responsive vendors by telephone (73 calls were made to 50 vendors). During these calls we attempted to determine the correct point of contact and obtain an email address for the standard email. For all responsive vendors, we worked closely with them to obtain the information about their product we were requesting. All of the provided information was analyzed and entered into an MS Access database. All vendors who responded to Phase 1 were asked their willingness to participate in Phase 2 of our study.

2.2 Phase 2

Phase 2 consisted of administering three Web-based questionnaires. Due to regulatory constraints and the time allotted we only able to select nine vendors for each questionnaire. The following defines the topic areas of the three questionnaires which are included as appendices to this report.

1. Functionality (+Data types included in PHR)
2. Business Model (+Market Share / Marketing Practices / Consumer Engagement)
3. Confidentiality, Privacy, and Security

Each panel was administered via a Windows SharePoint Web site. We selected nine respondents to answer the detailed questions in each of the three subject areas. This selection was based on the process described below. Again we note the difference between this method and random selection; by choosing the largest vendors we achieve results similar to probability-weighted sampling, but the analogy is not exact.

Criteria Used for Selecting Panel Participants

The process of panel selection took into account the following general considerations:

1. Had the vendor indicated a willingness to provide further detail? If yes, it warranted a panel inclusion.
2. Did the vendor's response to Phase 1 provide sufficient detail such that Altarum analysts could answer the panel questions? If yes, it warranted panel exclusion.

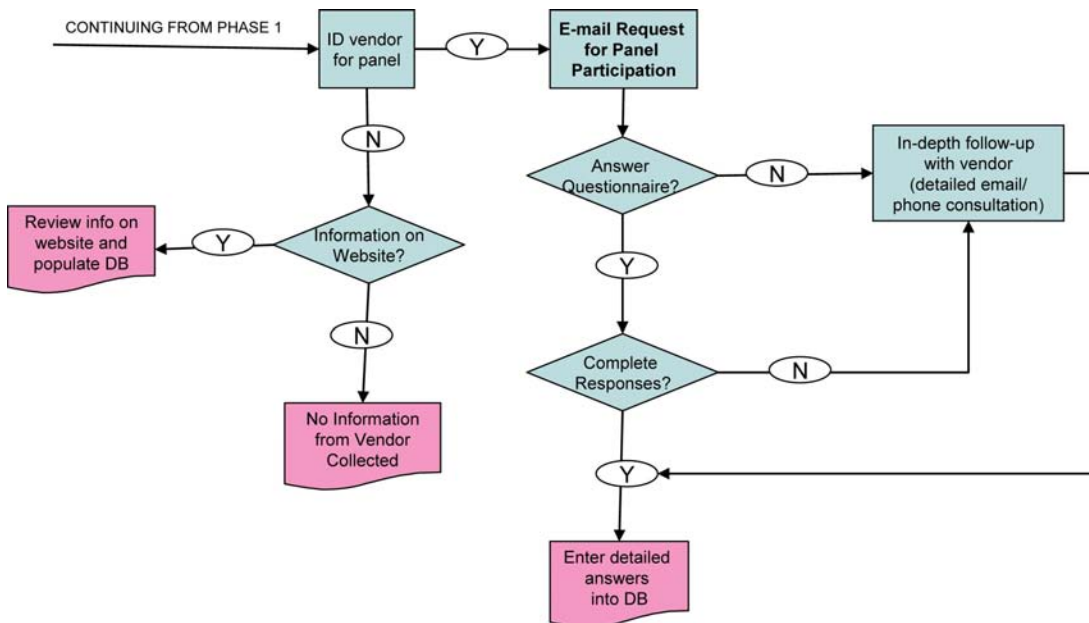
In addition, Table 1 shows the individual considerations that were used to select representative vendors for inclusion.

Table 1: Panel Selection Criteria

Panel	Critical Concept
Functionality	Market share (equivalent to probability-weighted sampling on population)
Business Model	Multiple targeted market segments; Multiple marketing practices
Confidentiality, Privacy, Security	Multiple architecture types

Since only those vendors who expressed an explicit willingness to participate were considered for Phase 2, we had a much shorter process soliciting participation. Our method in obtaining full involvement of panel participants is shown in Exhibit 2.

Exhibit 2: Data Collection Process Phase 2



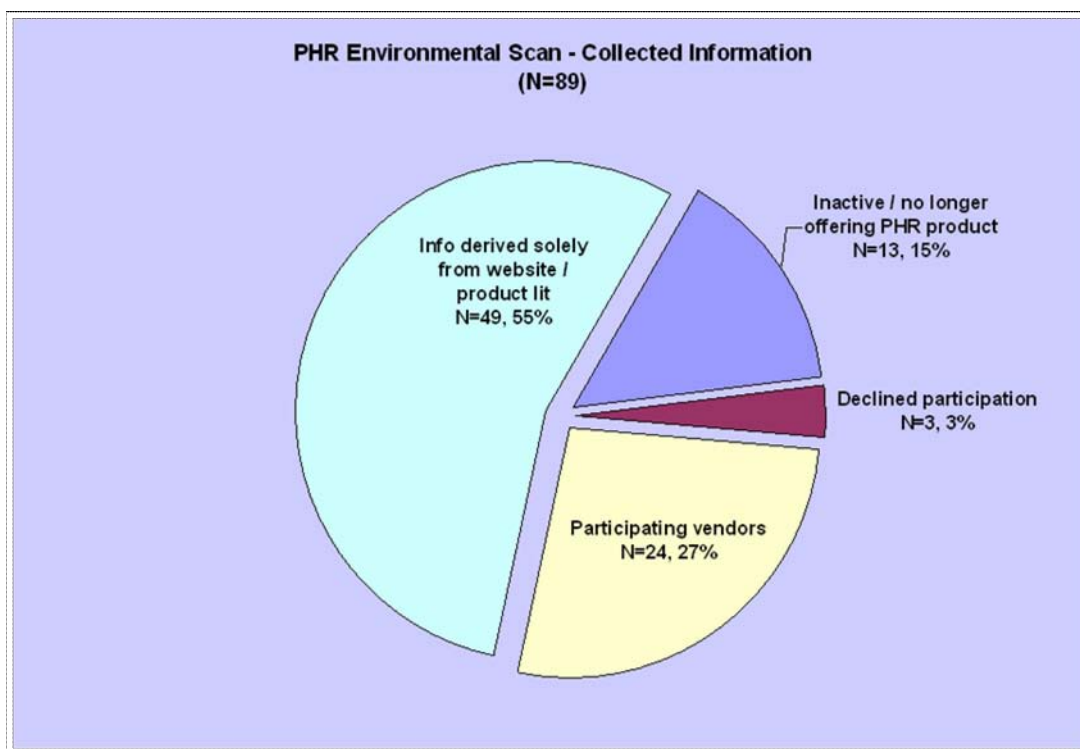
For those vendors selected to participate in the panels, personal emails were sent in early October 2006 containing an individual ID, password, and instructions on how to complete the online form. We worked with the vendors to complete all panels in a timely and complete manner. In some cases, in-depth follow ups were required to obtain complete information. At the conclusion of this process, all answers were entered into our project database for further analysis.

2.3 Participation & Data Collection

Exhibit 3 shows the participation among the 89 original vendors identified as eligible to participate. We identified 13 vendors that either went out of business or are no longer offering a PHR product. As the vendor lists we used were approximately one year old, a 15% drop-out rate was in the expected range for an immature market. Previous analyses of PHR vendor attrition showed similar average annual rates of vendor exit from this market. Of the remaining 76 viable vendors of PHR products: 24 participated by contributing data and product literature, 3 explicitly declined to participate; and 49 appear to still be in business but were non-responsive to our requests. The 32% of active vendors that participated represented considerable variation in architecture, functionality, business models and approaches to privacy and security.

For the 49 non-responsive vendors, we reviewed their commercial Web sites and available public records to obtain complete information from as many vendors as possible. After several attempts to email or call vendors, we attempted to answer the questionnaire data using publicly available information. This was done by reviewing product literature, checking vendor Web sites and conducting Google searches for additional information on the implementation of that product. The main information available through this approach yielded functionality/data elements and, to a lesser extent, business model and confidentiality, privacy, and security information. All information gathered from the Internet was entered into the database and marked as such. Using the Internet, we were also able to find additional information to supplement information provided by participating vendors.

Exhibit 3: Collected Vendor Information



We were able to glean different kinds of information about each of the PHR products and had different levels of confidence about types of information for each product. All results shown in this report indicate the number of PHRs that the results are based on and that is noted in all graphics (e.g.,

N=89 in the above exhibit). This is important to note as some results were based on small samples. Throughout this report, we are more confident in those results which are based on larger samples of PHR products as denoted by the N value in each graphic.

3.0 Architecture, Functionality and Data

Consumers have a preference in the form factor of the PHR that they use... a ‘one size fits all’ approach to providing a PHR does not work. By providing desktop, portable and online solutions for how patients will store, manage, and share their personal health information, [the vendor] is directly addressing consumer adoption issues such as patient privacy concerns and interoperability.
–PHR Vendor

The functionality of vendor offerings is wide-ranging and stems from market immaturity and differing focal points of purpose. Some offerings are meant to address the needs of chronically ill patients to coordinate their encounters and records to allow them to better manage their condition. Others are focused on obtaining patient-provided data to be used in case of emergency or by primary care physicians to improve diagnosis and management.

3.1 Architecture

Architecture is the technical framework behind how a PHR is designed and implemented (e.g., approach to data storage, inputs, interfaces). In this context, architecture is different from functionality which describes the operational characteristics of a PHR (the ability to do certain tasks using the PHR). In many respects a PHR’s architecture defines what elements of

functionality are feasible. Architectural characteristics of PHRs can be categorized in the groupings shown in Table 2. PHRs that do not send or receive data from another system are characterized as “standalone”. The data in standalone PHRs are input by the consumer or provider (via fax, photocopier, or email). A number of the standalone PHRs offered the ability to store provider records that were scanned or faxed as images in the PHR. Providers would need to fax medical records to the patient or directly to the vendor.

On the other end of the spectrum are integrated PHRs that have the capability to send and receive health information from other systems. Examples of such systems could include claims systems, provider electronic health records/medical records (EHR/EMR), laboratory information systems, and pharmacy benefit manager systems. Somewhere in the middle are PHRs that are ‘tethered’ to one or more data systems, but not fully integrated with them.

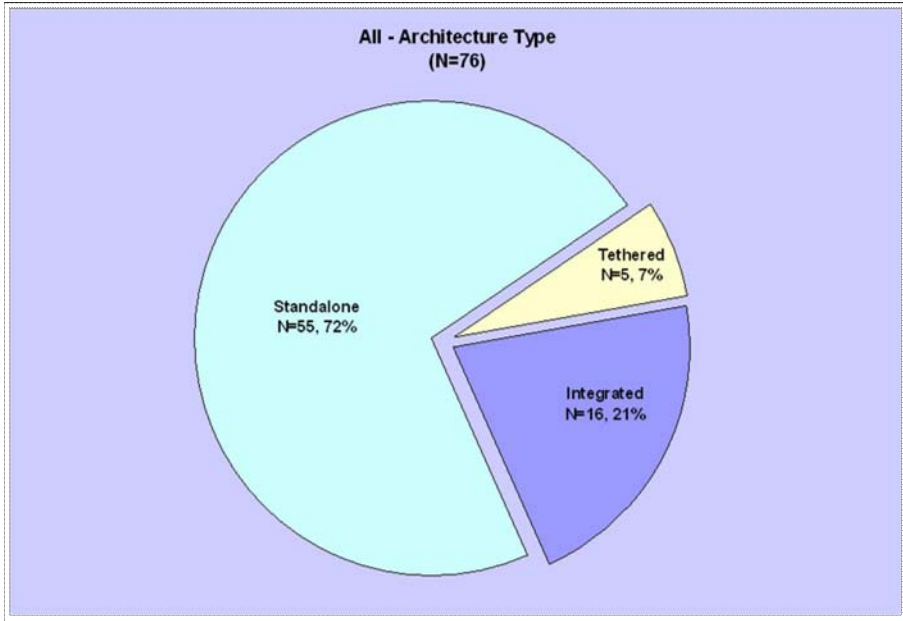
Table 2: Description of Architecture Types

Architecture Type	Description
Standalone	Depends solely on patient input as a conduit for transmission of medical record data. This includes paper-based PHRs; PC-based and portable-storage PHRs where the member can carry data on a portable device (e.g., CDROM, DVD, smart card, or USB flash drive); and, Web-based PHRs where the data is housed separately and is not connected to or updated by another data system.
Tethered	Provides read-only access to one or more data systems; akin to a “viewer” of health records or health claims data. Data entered by the patient is not pushed or pulled into another data system (e.g., an EHR) and can only be viewed through the PHR.

Integrated	Provides read and write access to one or more data systems; may include data-level integration across systems and/or may be viewed through other non-PHR interfaces (e.g., an EHR).
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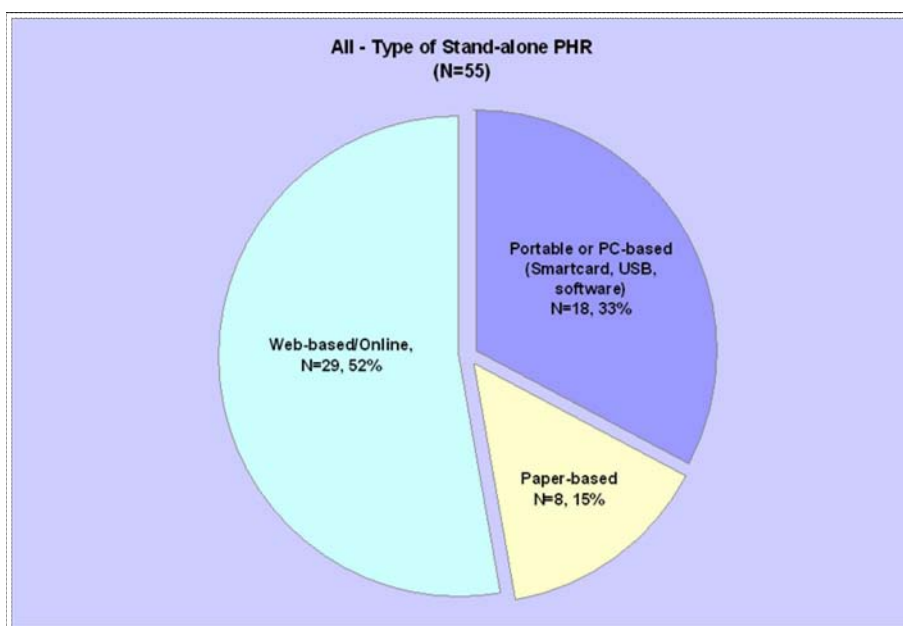
Altarum characterized 76 active PHRs into these architectures. The integrated PHRs were either offered by vendors who also had some type of electronic provider system or they were PHRs marketed by vendors to health insurers or health systems.

Exhibit 4: Vendor by Architecture Type



The majority of PHRs were classified as standalone, 72% (See Exhibit 4). However, the number of integrated PHRs is growing as a number of health plans are beginning to offer PHRs to their members. The current health plans that offer PHRs have either developed the PHR or have re-branded a PHR offered from a commercial vendor. On average, Web sites for tethered and integrated PHRs contained much more information than those for standalone products. A number of the standalone PHRs were small companies that have just recently started (within the last year).

Exhibit 5: Type of Stand Alone PHR Vendors



Standalone PHRs were further classified into Web-based (52%), paper-based (15%), or portable/PC-based PHRs (33%) (See Exhibit 5). Providers may be able to view the data within the PHR, however, this is typically achieved through paper-print outs, or portable storage devices. In some cases providers can log in to a PHR portal through the Internet with a password (normally supplied by the patient). However, this could become cumbersome if the provider's patient population were using multiple PHR products. In addition, a number of the PC-based PHRs had portable devices that could be purchased for an additional fee.

Architecture dictates to some degree the accuracy and completeness of the information contained in the PHR. As mentioned above, the information contained in PHRs are mainly entered by the owner (i.e., consumer). There are some cases where the PHR contains information sent in by the provider (e.g., faxed, emailed, photocopied and stored as a PDF file). However, there can be data accuracy and completeness issues when patients are entering their own health information due to health literacy levels or other factors. PHRs that are integrated with other health information systems likely more accurately represent some data elements. However, in standalone Web-based PHRs—where the provider can be given access to view the patient's PHR over the Internet—some issues of accuracy and completeness can also be remedied since the provider can check what is in the PHR. In addition, concerns about patient privacy may limit the types of information that are entered into a PHR⁵. One PHR vendor interviewed confirmed that there is a concern with what could be released through HIPAA under a court order⁶, which may dissuade some consumers from entering information or some PHRs from housing certain types of information.

⁵ Endsley, S., Kibbe, D.C., Linares, A., and Colorafi, K., An Introduction to Personal Health Records, <http://www.aafp.org/fpm/20060500/57anin.html>, May 2006.

⁶ Conversation with PHR vendor on October 18, 2006.

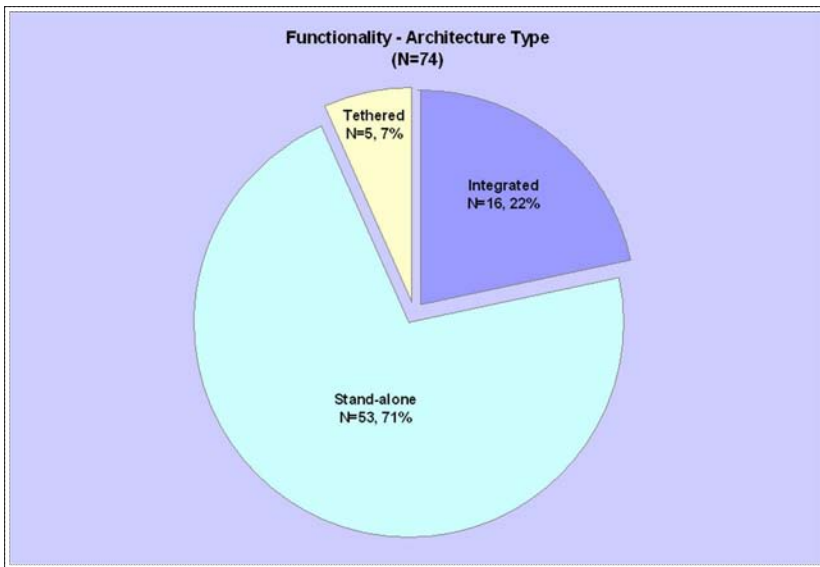
3.2 Functionality

Members also appreciate—and increasingly expect—direct access via PHRs to information on benefits, eligibility and financial statements.... – PHR Vendor

From the 76 active PHR products, functionality information was obtained for 74 of the products. The remaining two were a PHR offered by Intel and one by a joint effort between Intuit and Ingenix. The Intel product is a PHR offered to Eskaton Senior Residences and Services members and is a one-year pilot program. Eskaton is a not-for profit senior care provider (includes health and housing) in Northern California. This product is an Internet-based PHR where information is faxed in by the provider and member and housed in a repository⁷. However, the member is the sole owner of the data and controls who has access to the records. The

Intuit/Ingenix product will be a Quicken branded PHR and is targeted for release in the middle of 2007⁸.

Exhibit 6: Functionality for All Vendors

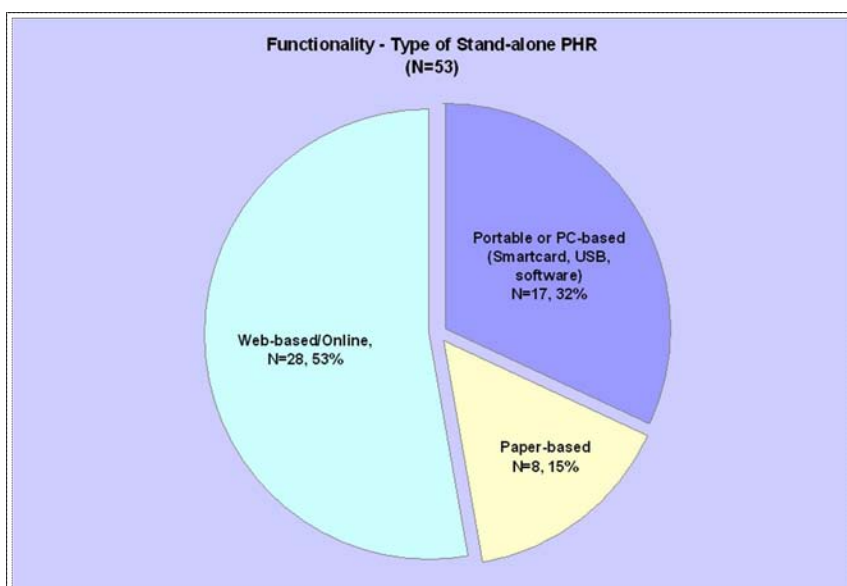


As seen in Exhibit 6, for the 74 PHRs evaluated in the functionality section, standalone PHRs made up over 70% of the PHRs we analyzed to describe functionality and data elements. 7% were tethered and 22% were integrated.

⁷ Eskaton Residents Explore the Use of Personal Health Records, <http://www.agingtech.org/item.aspx?id=189&CA=1>, July 2006.

⁸ Monegain, B., Ingenix, Intuit Team Up to Take Charge of Healthcare Paper, <http://www.healthcareitnews.com/story.cms?id=4803>, April 16, 2006.

Exhibit 7: Functionality for Stand Alone PHRs



The majority of standalone PHRs were Web-based (53%). About one third of the PHRs were software made for a home computer or portable device to be used with a home PC. The remainder, 15%, were paper-based (see Exhibit 7). Table 3 below, describes the various attributes of functionality we examined.

Table 3: Definition of Functionality Attributes

Functionality	Definition
Appointment Scheduling	Can the PHR allow the consumer to schedule appointments (e.g., view open dates and times)? This would not include emailing the provider with available dates and times.
Deductible/Copay Tracking	Does the PHR allow the consumer to keep track of how much they have paid into their health insurance deductible or the total amount they have paid in co-payments?
Discharge Instructions	Does the PHR capture patient specific discharge instructions?
Multiple Languages	Does the PHR have the ability to be translated into languages other than English?
Multiple View	Does the PHR support multiple views of the data it contains (e.g., does it present information differently to providers)?
Online Communication Ability	Does the PHR support online communication between the patient and the provider (e.g., secure messaging or email)?
Patient Education Information	Does the PHR show other types of patient information (e.g., educational materials, information on over the counter or alternative drugs/therapy, or links to health care information on the Internet)?
Patient Outcomes	Does the PHR capture patient self-reported outcomes (e.g., reaction to drugs, whether or not the consumer's condition is improving)?
Patient Reminders	Does the PHR give patient reminders for appointments or wellness checkups (e.g., annual exams, mammograms, immunizations)?
Prescription Refill	Does the PHR include the ability to order pharmacy refills?

Exhibit 8: Frequency of Functionality Attributes of All Architecture Types

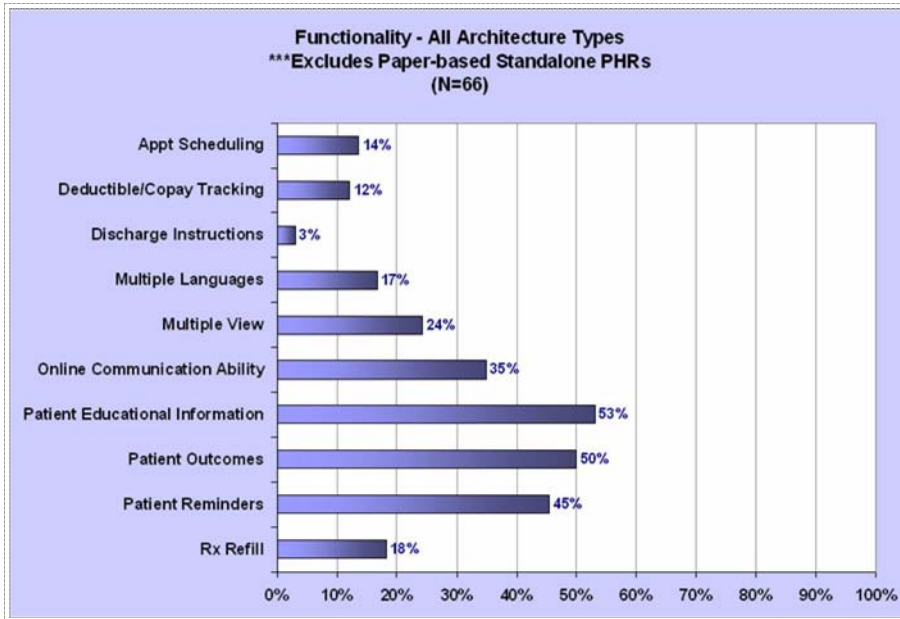
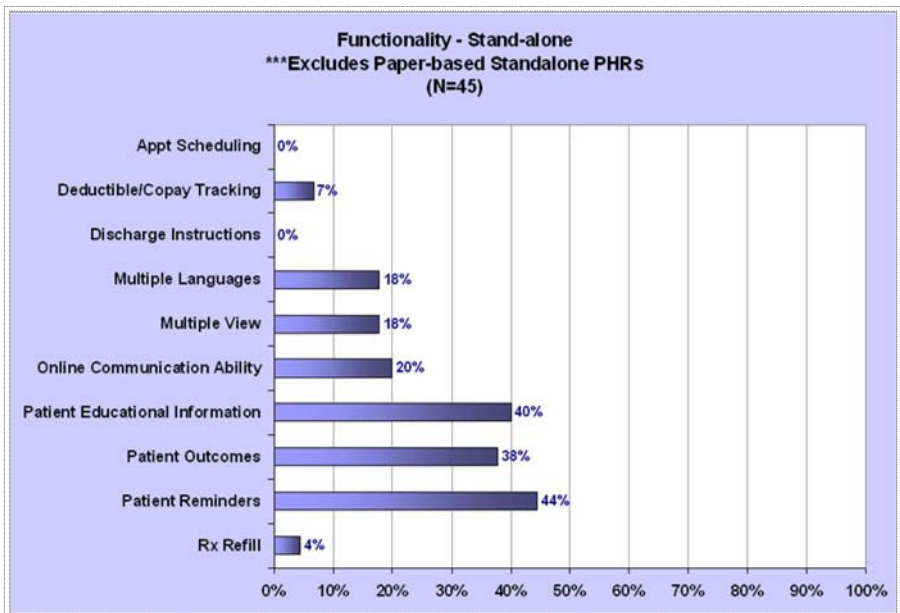


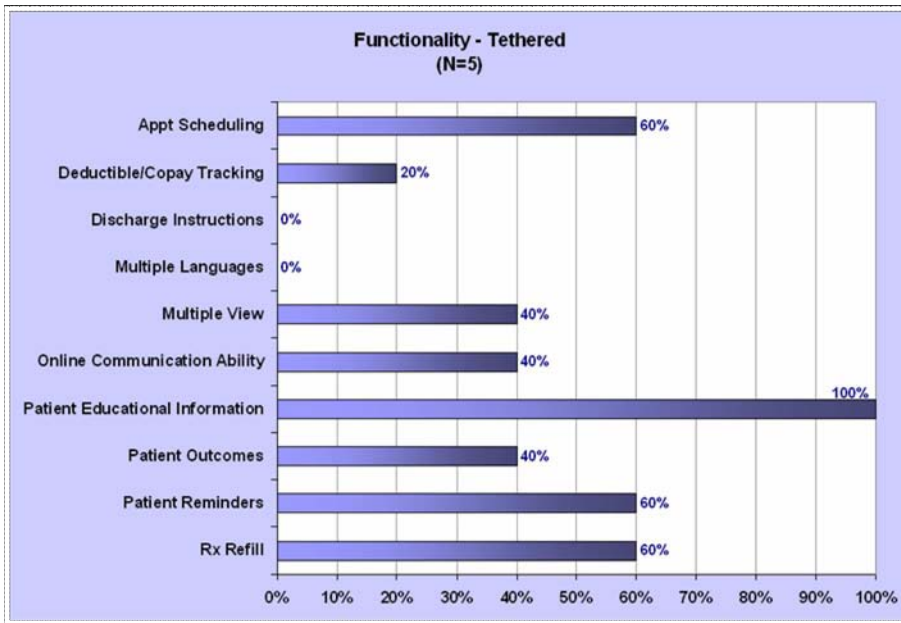
Exhibit 8 illustrates the difference in availability of the functionality attributes across all architecture types. At least 53% made patient education information available whereas only 3% made discharge instructions available to the consumer. At least 50% of the PHRs allowed patients to track their outcomes and had patient reminders (e.g., calendars, general “pop-up” reminders). Appointment scheduling, prescription refills, and the tracking of deductibles and co-payments were low among current products. Note: Paper-based standalone PHRs (N=8) were excluded in the functionality analysis since many of the features rely on Internet connectivity.

Exhibit 10: Stand Alone Functionality Attributes



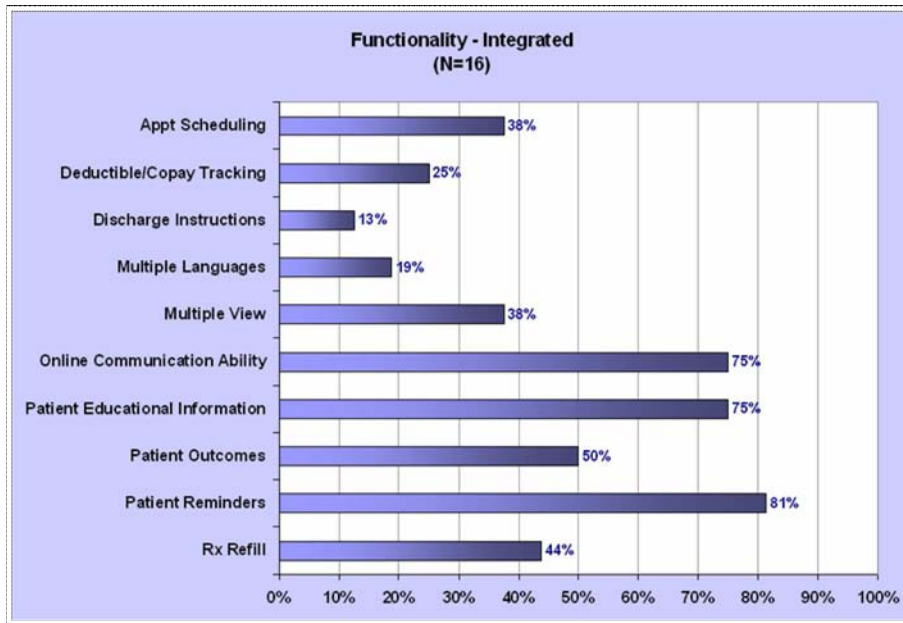
Standalone PHRs that are Web-based and PC-based do not offer appointment scheduling and online communication with providers (see Exhibit 10). Only one standalone offered prescription refills but this was done through the vendors Web site (secure platform) that allowed ordering prescriptions from the physician. While some of the standalone PHRs offered online communication (20%), this was only done if the provider agreed to install a component on their end or participate with a given email address. As compared to the types of information that can be housed in standalone PHRs, they do not have as much functionality. However, if the primary purpose of PHRs is to keep track of the consumers health information (i.e., to have it all in one place), the additional functionality may not be needed.

Exhibit 11: Tethered Functionality Attributes



While the sample size was small for tethered PHRs, the functionality is somewhat similar to integrated PHRs. Exhibit 11 demonstrates the frequency of functionality attributes in tethered PHRs. All tethered PHRs provided patient information (in the form of links to health care sites or within the PHR itself). Three tethered PHRs offered appointment scheduling and pharmacy refilling capabilities, however, one out of the three did not offer the ability to communicate with providers online.

Exhibit 9: Integrated Functionality Attributes



Integrated PHRs consistently offered more functionality than standalone and tethered PHRs (see Exhibit 9). At least 75% of the integrated PHRs support email communication or secure messaging between the patient and their providers. However, for PHRs not offered by health systems, the providers typically would have to use the EHR that is supplied by the same vendor or be part of the network. This also holds true for the ability to electronically schedule appointments and refill prescriptions via the PHR. The patient reminder functionality was available for over 80% of the integrated PHRs while only 13% had the ability to contain discharge instructions.

...we strongly recommend that physician compensation systems reimburse for eVisits. Unless medical correspondence with patients is fairly compensated, full clinician adoption will never be achieved.
– PHR Vendor

One barrier to the functionality of online communication between patients and providers (in general and through PHRs) could be the lack of reimbursement for time spent outside of the office visit. Many health insurance companies do not currently reimburse for online communications (emails) or Web visits. Some health plans offer provider reimbursement for online communication with the patient through technology offered by Relay Health. Secure messaging offers more federal privacy rule compliance than emailing physicians.⁹ However, as more health insurers begin reimbursing for online communication there may be an increasing trend of PHRs to offer this functionality.

⁹ Kreit, B., Electronic Patient Visits Gaining Attraction, <http://www.newcoalition.org/Article.cfm?artId=19597>, September 1, 2006.

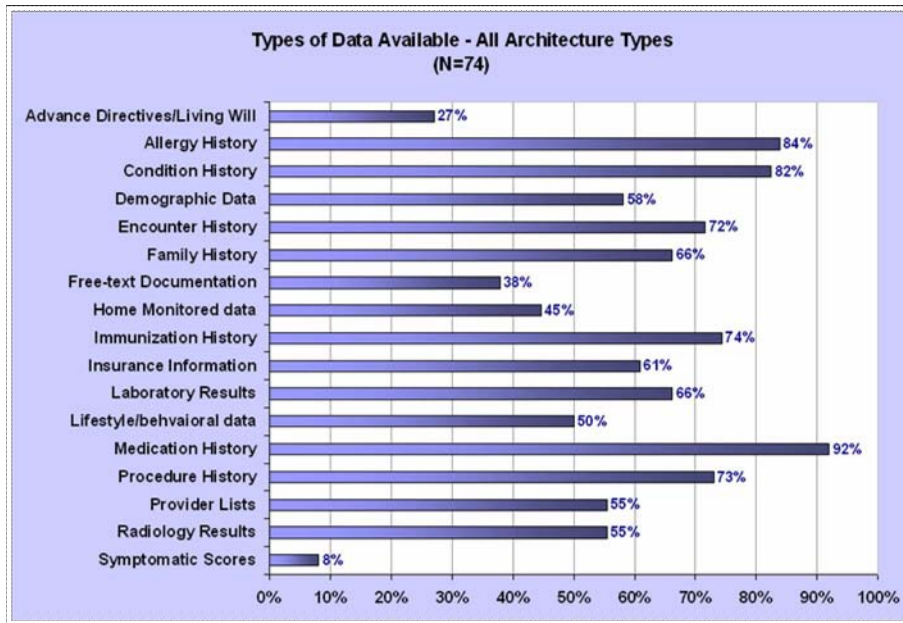
3.3 Data Elements

There is a wide range of information that can be captured potentially in a PHR. After research, we focused on the data elements in Table 4 when analyzing the types of data contained in the PHR:

Table 4: Definition of Data Elements

Data Elements	Definition
Advance Directives/Living Will	Can the PHR store information such as advance directives or living wills?
Allergy History	Can the PHR capture allergy history (e.g., medication, food, environmental, insect)?
Condition History	Can the PHR capture condition history?
Demographic Data	Can the PHR capture demographic data (e.g., age, sex, date of birth)
Encounter History	Can the PHR capture encounter history (e.g., office visits, ER visits)?
Family History	Can the PHR store family medical history?
Free-text Documentation	Does the PHR allow consumers to store free-text writing (e.g., medical journal/diary)?
Home Monitored data	Can the PHR capture consumer self-reported home monitored information (e.g., blood pressure, glucose monitoring)
Immunization History	Can the PHR capture immunization history?
Insurance Information	Can the PHR store insurance information (e.g., contract numbers, contact number, type of insurance)?
Laboratory Results	Can the PHR store the results from laboratory tests?
Lifestyle/behavioral data	Can the PHR capture consumer self-reported lifestyle/behavioral information (e.g., exercise, diet)?
Medication History	Can the PHR capture the consumer's medication history (e.g., date and dose)?
Procedure History	Can the PHR capture the types and dates of the consumer's procedures (e.g., surgical)?

Exhibit 12: All Architecture Data Elements

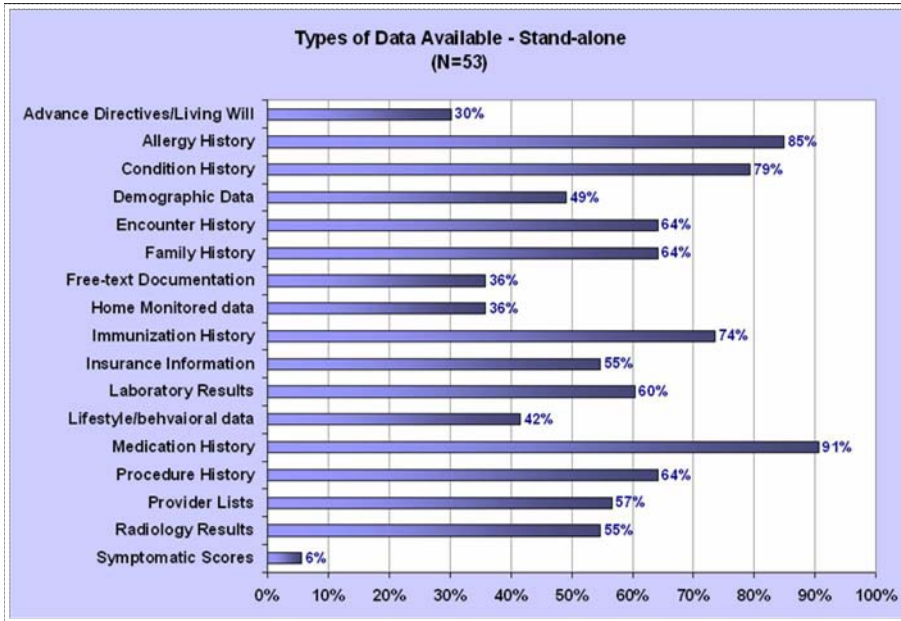


The data elements were first reviewed for all architectures (Exhibit 12). The majority of PHRs captured the consumer's medication history (92%) followed by allergy data (84%) and condition history (82%). Only 8% of the PHRs allowed consumers to input symptomatic scores and only 27% contained advance directives or living will documentation. Only a little over 50% of the PHRs captured demographic data. A number of the standalone PHRs are desktop software which did not contain much in the way of demographic information and some of the Web-based PHRs were designed to keep the PHR as anonymous as possible.

A large number of the PHRs also contained emergency contact information and even "emergency wallet" cards to be carried on the individual. In case of emergencies, the card contains an ID and password that emergency providers could use to obtain needed health information.

Only slightly over one-third of PHRs allowed free-text documentation where the consumer can write about their health experiences or conversations with providers.

Exhibit 13: Stand Alone Data Elements

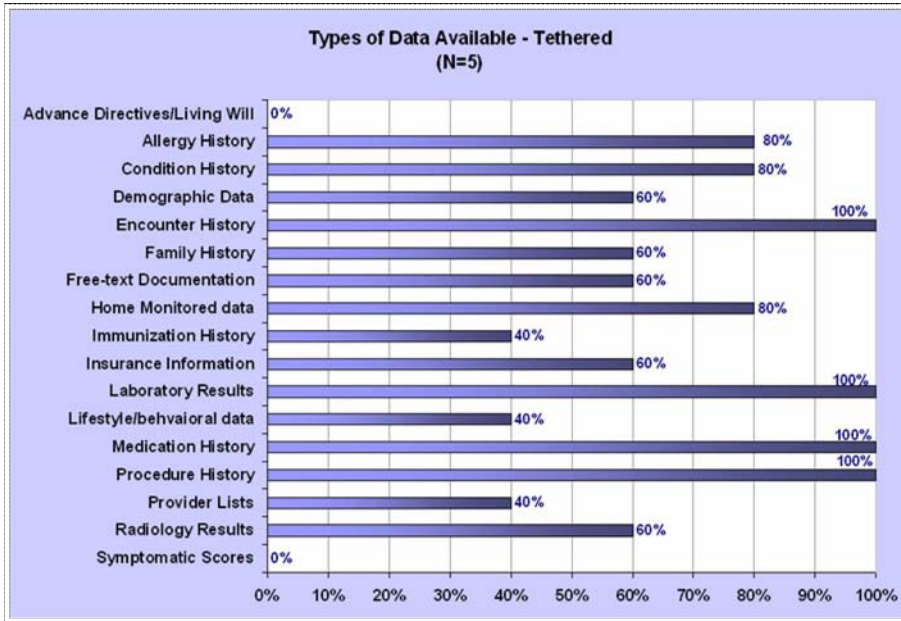


Standalone PHRs rely more on patient-provided data than tethered or integrated offerings. This explains why the typical standalone PHRs do not encompass as much data.

A higher number of standalone PHRs captured advance directive or living will information as compared to the other types of PHRs. A number of the standalone PHRs were marketed for emergency purposes, which would make them more likely to contain this type of information.

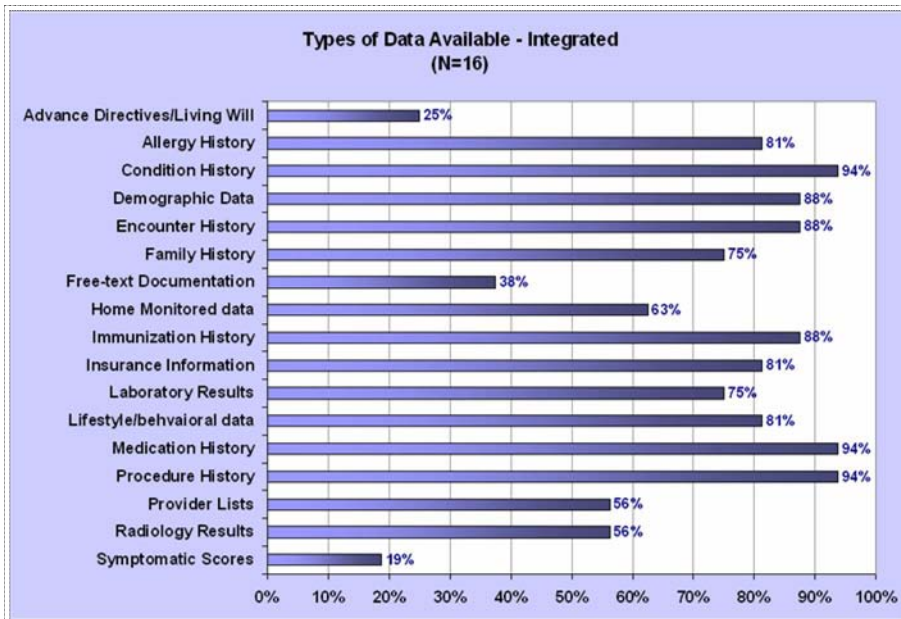
When analyzing the types of data collected in the PHR by architecture type, more integrated PHRs better captured condition, procedure, and medication history as information is drawn in from other systems (e.g., EHRs). In addition, significantly more integrated and tethered PHRs captured encounter data. This can also be explained by data sharing between the PHR and claims systems. For those connected to a claims system, claims information submitted from the provider can be pushed onto the PHR showing dates of visits and procedures.

Exhibit 14: Tethered Data Elements



As shown in Exhibit 14, while the number of tethered PHRs were lower, the amount of information (with the exception of advance directives/living will data) captured was relatively comprehensive. Over 80% of the PHRs captured allergy, condition, encounter, home monitored, lab, medication, and procedure data.

Exhibit 15: Integrated Data Elements



While integrated and tethered PHRs capture more laboratory results, only 55–60% of all three types of architectures have the ability to capture and display radiology results. As digital radiographs become more common, and bandwidth/storage issues are resolved, we would expect this to change.

PHRs allow consumers to capture a significant amount of information that would normally not be in one place. As the PHR market matures, additional functionality and data elements will most likely be added and the usage of integrated and tethered PHRs should increase. Some additional functionality that vendors reported in the Web-based panels include: patient interactive Web cams, remote monitoring of home monitored data, and financial tools to manage health savings accounts. A concern raised was the observation that consumers do not pay attention to maintaining a comprehensive PHR or “to think about their health” until they encounter a significant health problem, which adds to concerns about PHR data accuracy and completeness. One statement from the panel summarizes this concept: “consumers, although well meaning, do not take the time or exert the effort to get prepared. When mother breaks her hip they realize they needed to be better prepared. But, after the crisis resolves, the motivation fades again.”¹⁰ The issues of consumer motivation, accuracy and data completeness will continue to resonate with providers and will need to be addressed in innovative ways to facilitate the successful use of PHRs.

4.0 Privacy, Confidentiality and Security

Privacy is a central tenet of a Personal Health Record. The trust that a consumer must have in their PHR provider is a foundation for their use of the PHR and for realizing any benefit from it. – PHR Vendor

The focus of the privacy, confidentiality, and security aspect of this study was cataloging how current PHR vendors address the following:

- *Limitations on who can access data available through a PHR;*
- *What authentication processes are used to provide access to data available through a PHR;*
- *To what extent vendors have sought to ensure the confidentiality of PHR data through security mechanisms (e.g., encryption) and the type of security mechanisms if any being used; and*
- *Existing privacy policies used by vendors and whether they are available to consumers.*

The current PHR market presents a wide variety of ownership, custody models and issues. For example, a PHR may be in the physical custody of the individual patient (e.g., CapMed’s memory stick, Siemen’s secure card), on an insurer’s Web site (e.g., various Blue Cross Blue Shield portals), or on a third party’s Website (e.g., Health eTracks). Perceived control and risk of loss or disclosure effect acceptance by patients, the provider community, and the insurance community.

It is important to distinguish among "privacy," "confidentiality," and "security"—terms that are often used interchangeably and imprecisely.

- *Privacy* refers to an individual's right to control the acquisition, uses, or disclosures of his or her identifiable health data.
- *Confidentiality*, which is closely related, refers to the obligations of those who receive information to respect the privacy interests of those to whom the data relate.
- *Security* refers to physical, technological, or administrative safeguards or tools used to protect identifiable health data from unwarranted access or disclosure.

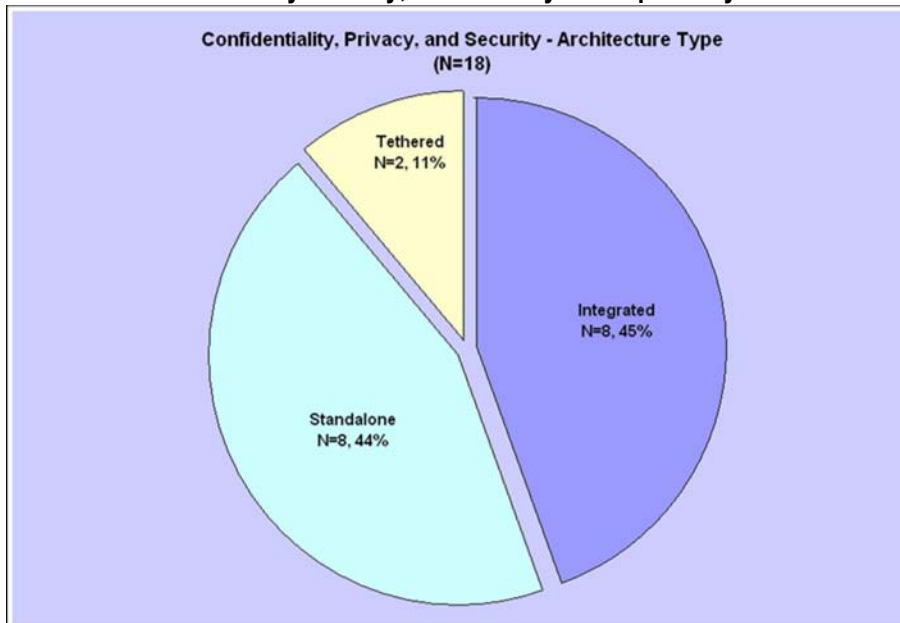
¹⁰ PHR Business Model Web-Based Panel Response, October 2006.

Critical portions of the legal framework with respect to PHRs need further definition. For example, in most states insurance applicants must consent to disclosure of their medical record for underwriting purposes and can be denied coverage if they do not. It is not yet clear whether PHRs are also subject to this disclosure. Another example are the recent changes to the Federal Rules of Civil Procedure (FRCP) that address discovery of electronically stored information. The amendments clarify and codify the existing rules and case law, and recognize issues that litigants and courts have grappled with for the past decade. One specific outcome of the new rules is the explicit definition of e-mail as discoverable. As many PHR offerings include secure e-mail messaging between patients and providers, this may have significant impacts on liability and malpractice lawsuits. It is not clear whether medical or other self-entered information in a PHR is similarly discoverable.

Vendor participants also mentioned that it is not clear whether PHR vendors are covered entities under HIPAA, and therefore constrained (or not) by HIPAA regulations on ownership of data and notification of its release to third parties. Ultimately, legal ownership of the PHR and its data is a core unresolved issue, and will likely require further clarification at the state and federal levels.

Exhibit 16, describes the distribution across architectures for the PHR products we analyzed for this section.

Exhibit 16: Confidentiality, Privacy, and Security Participants by Architecture Type



4.1 Privacy and Confidentiality

Public opinion surveys consistently confirm the value of privacy and confidentiality as critical preconditions to the uptake of electronic health information systems. Consumers have concerns about the privacy and security of their medical records. Surveys of American adults have indicated that between 67% and 91% have strong concerns about the privacy of their personal health records.^{11, 12}

¹¹ California HealthCare Foundation, <http://www.chcf.org/documents/ihealth/ConsumerPrivacy2005ExecSum.pdf> (November 2005).

Individuals consistently state that they do not want to share all their health information with their family members or even their physicians. Similarly, many people distrust employers, insurers, and other third parties with their personal health information.

Individual opinions about privacy and confidentiality differ based on cultural, religious, and other factors. Individuals are also concerned about the disclosure of their confidential personal health information because of possible embarrassment, emotional distress, and stigma. They are also concerned about more tangible harms, such as the inability to obtain employment, mortgages, or various forms of insurance. Measures to protect the security of personal health information from unauthorized access and to protect the confidentiality of disclosures through fair information practices are important to PHR adoption. Nonetheless, these measures will only have a limited effect in addressing the public's primary privacy concern; the use of personal health information to adversely affect individuals' personal, financial and professional rights, interests, and opportunities.

The following table, Table 5, describes the concepts we assessed for privacy and confidentiality.

Table 5: Definitions of Privacy and Confidentiality Concepts

Privacy & Confidentiality Concept	Definition
Access Based on Role	Does the PHR divide users into groups or classes (such as family members, health professionals, etc.) and restrict data visibility based on rules that are specific to each group?
ER Access	Does the PHR provide a means for access in an emergency?
Family Access	Is there a way that family members who participate in the account holder's care can be authorized as a proxy to view or change data?
Individual Access	Can this PHR provide different access levels for different individual providers?
Policy - Privacy	Does your organization have PHR-specific privacy/confidentiality policies in place?
Policy - Privacy Available to Consumer	Can the account holder or other users view or print the privacy policy?
Restrict Certain Data from View? (Block view)	Can the account holder restrict certain data items from view (such as certain meds, or encounters with a certain health professional)?
Sensitive Data Separation	Because data about mental health and substance abuse, reproductive health, etc. are often sensitive, does the PHR sequester this data in its design?

Around 40% of the PHR products analyzed have a mechanism whereby some parts of a health record can be blocked from access. As stated in a June 2006 letter from the Subcommittee on Privacy and Confidentiality of the National Committee on Vital and Health Statistics “Blocking means that the information would still exist, but it will not be seen by health care providers looking at the record unless a provision for overriding blocked information (e.g., in emergencies) or granting certain

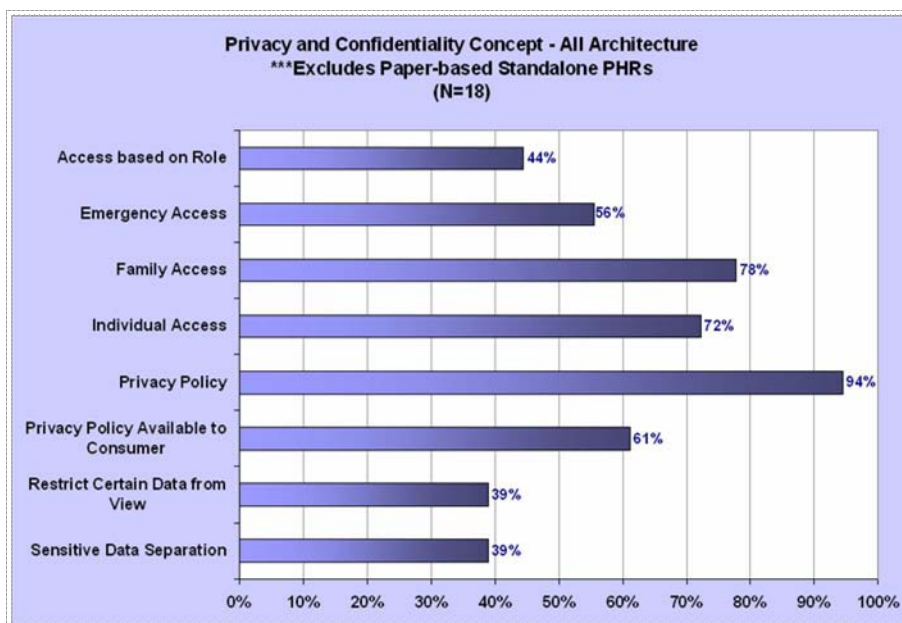
¹² The Markle Foundation's Connecting Healthcare in the Information Age Project “The Personal Health Working Group Final Report” http://www.connectingforhealth.org/resources/final_phwg_report1.pdf (July 2003).

providers access rights (e.g., allowing only mental health providers to see mental health information) is built into the system. Clinical decision support, however, might be programmed to advise health care providers that, for example, the individual had a prior adverse reaction to a certain class of drugs. Blocked information also could be made available for statistical analyses, data aggregation, quality assurance, and other purposes in a de-identified form.”¹³,

Not all of the individuals who need access to personal health information need the same level or kind of information. For example, dieticians and health claims processors do not need access to complete health records whereas primary care physicians generally do. Protecting the confidentiality of personal health information in such settings requires institutions to establish different access rules depending on employees' responsibilities and their need to know the information to carry out their role. Providing different levels of access to healthcare data based on role is one way to address these issues. As noted in Exhibit 17, this functionality is available in close to half of the products evaluated. Another way to address this issue is to allow the account holder to set different levels of access for different providers, 72% of PHRs utilize this approach.

Over 50% of the non-paper-based PHRs on the market today include some functionality to support emergency access; 78% allow family member to be given write access; the vast majority of vendors have privacy policies in place; and, close to 40% automatically sequester certain data elements by design.

Exhibit 17: Privacy and Confidentiality Concepts for all Architectures



4.2 Security

Authentication and security concerns differ based on PHR architecture. Portable PHRs need to be protected in case of loss, standalone Web-based PHRs typically utilize 128-bit encryption SSL coupled with password or some other authentication mechanism and before other health information systems share data with integrated or tethered PHRs, they must first verify the identity of the PHR’s

¹³ Subcommittee on Privacy and Confidentiality of the National Committee on Vital and Health Statistics: Letter to the Secretary. <http://www.ncvhs.hhs.gov/060622lt.htm>

...monitoring for the [vendor's] program has shown over 1,000 serious attempts per year to penetrate and no breach has been encountered. Should a breach occur, information is held in separate library look up tables, is double encrypted and not identified by individual. – PHR Vendor

owner. As stated in the NVCHS letter, “In an age in which electronic transactions are increasingly common and security lapses are widely reported, public support ... depends on public confidence and trust that personal

health information is protected. *Any system of personal health information collection, storage, retrieval, use, and dissemination requires the utmost trust of the public.* The health care industry must commit to incorporating privacy and confidentiality protections so that they permeate the entire health records system.”¹⁴ Table 6 describes the concepts we assessed for security.

Table 6: Definitions of Security Concepts

Security Concept	Definition
Encryption	Are the data in the PHR encrypted in some fashion?
Log or Audit Trail - Access	Does the PHR keep an audit trail of all access events? Access events primarily include access (e.g., screen display, printing) and export or data sending.
Log or Audit Trail - Data Update	Does this PHR keep a log or audit trail of all data updates? Data updates include those by a user (e.g., patients, health professionals) as well as data imported from outside sources.
Policy - Security	Does your organization have PHR-specific security policies in place?
Policy - Security Available to Consumer	Can the account holder or other users view or print the security policy?
Separate Physical Data	Is the primary storage for the account holder's PHR data on a device (e.g., PDAs, smart cards, USB, paper) as compared to an Internet or database server?
Synchronize Data/Back-up Mechanisms	Is there a mechanism to synchronize or store a copy of the data to protect against possible loss?
User Authentication	Does this PHR support authentication of specific users? That is, does it have a mechanism to require that a user who tries to sign in gives some evidence that they are indeed that person?

While the utility of personal health information increases as the availability of personal health information spreads to new applications of technology, so do the risks to the privacy, security, and confidentiality of the information. The question of who shall control access—and to what kind of data—is important. Although patients ideally should have the right to give permission to various types of health care personnel access to their record, some argue that patients may not always know what kinds of information a health care provider needs to make health care decisions. By giving patients control of access to their records, PHRs offer more selectivity in sharing of personal health information.

Vendors of integrated PHRs have more mature approaches to security; with interconnected data sources, security risks increase exponentially. Most integrated products have incorporated policies that address many of these key concerns. In addition, the majority of integrated products provide

¹⁴ Subcommittee on Privacy and Confidentiality of the National Committee on Vital and Health Statistics: Letter to the Secretary. <http://www.ncvhs.hhs.gov/060622lt.htm>

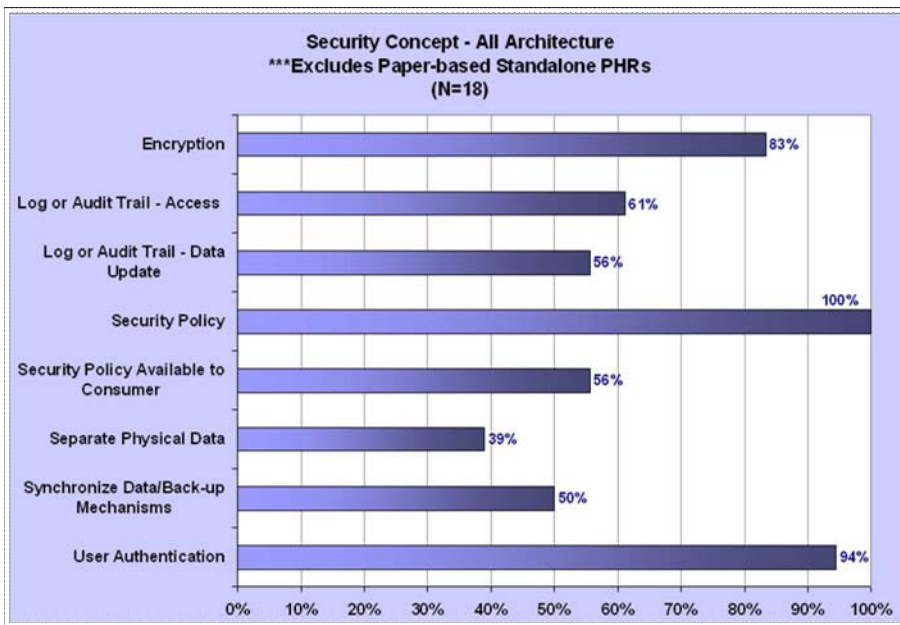
some type of encryption to protect the data from unauthorized parties and report compliance with HIPAA privacy and security requirements (Exhibit 18).

One of the PHR vendors that responded to the Confidentiality, Privacy and Security Web-based panel allowed tailoring of security measures to their clients needs; the “the higher the security, the more the cost.”¹⁵ These additional security measures included biometrics and additional security layers.

Another question that was asked in the Web-based panel was whether or not the PHR required any primary source identification documents before the PHR could be established. Some PHRs required face-to-face contact to set-up an individual’s PHR initially and some required a copy of the consumer’s photo ID. Others required a check against eligibility files or other associated health plan identification.

All vendors of non-paper-based PHRs analyzed had a security policy in place, with more than half making it available to the consumer. More than half the products also included functions to maintain audit trails of access and data updates. Nearly all utilized some user authentication mechanism and the vast majority employ encryption techniques.

Exhibit 18: Security Concepts for All Architecture Types



5.0 Business Models

At this point in time, starting a nationwide consumer education program for PHRs would be like promoting seatbelt usage before cars were readily available.
 – PHR Vendor

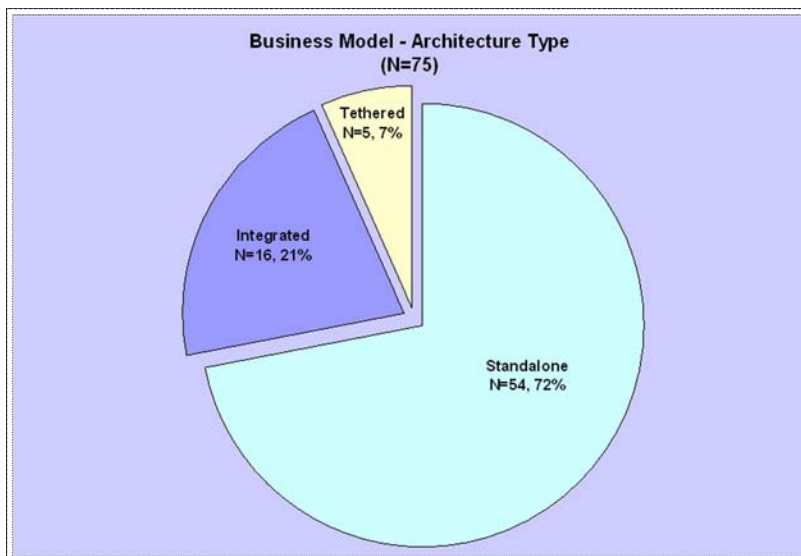
PHRs have the potential to provide a number of benefits to patients, providers, and insurers, including qualitative improvements to patient care and quantitative improvements to financial performance. However, the business case for widespread adoption is still unclear as interoperability/connectivity technologies are still maturing and policies and

¹⁵ PHR Confidentiality, Privacy and Security Web-Based Panel Response, October 2006.

market consolidation have yet to take stable form. Some vendors have not been financially successful and many products and companies are no longer in existence. As technological issues resolve and market leaders emerge, who should pay for PHRs will become clearer as it will be easier to quantify the benefits of PHR adoption. PHR stakeholders range from government payers and other insurers to physician group practices and, of course, patients. However, these stakeholders all have varying vested interests, abilities to pay, and time and material investments required to interact with PHRs.

Potential business models include revenue from subscription fees (monthly or annual) paid by patients, providers, or insurers; cost-sharing across multiple parties; and bundling PHR with EHR capabilities. We were pleased to find that no respondent claimed a business model that incorporated revenue from re-selling PHR data.

Exhibit 19: Business Model Participants by Architecture Type



The data presented in this section is based on 75 PHR products with the mix of architectures shown in Exhibit 19. Of the products for which we obtained business model information, 72% are standalone PHRs, 7% are tethered, and 21% are integrated.

Current PHRs are based in a diverse array of business models. While respondents were largely unwilling to discuss market share and consumer uptake and retention rates, other aspects of the business model were more forthcoming. Consumers are identified overwhelmingly as the target market audience and the architecture is dominated by standalone systems. No similar convergence is found in pricing strategies, where end-user prices are quite variable. The business model panel also identified consumer ease of use as the main critical success factor, in keeping with the earlier finding of consumer-centered marketing. These findings are further discussed in the following section.

The overall size of the PHR market could not be accurately determined using our vendor-based solicitation of responses. Vendors have no reason to voluntarily report uptake and retention data, and most did not. We note only that data received did not appear to invalidate previous estimates of PHR penetration of 1% or less of the population¹⁶; or that 9% of those using a PHR were using an

¹⁶ HarrisInteractive "Health Care News" August 2004 accessed on line at http://www.harrisinteractive.com/news/newsletters/healthnews/Hi_HealthCareNews2004Vol4_Iss13.pdf

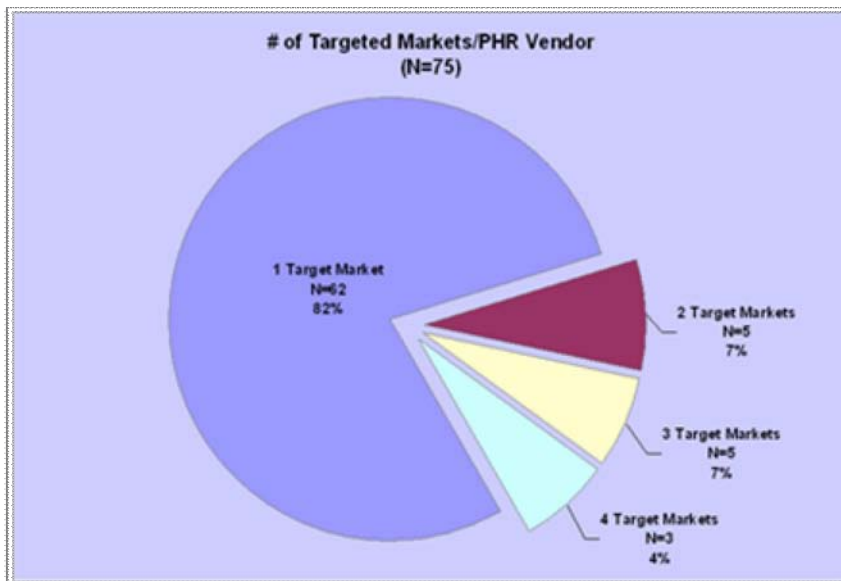
electronic form or Web-based tool¹⁷; or that approximately 2 million or fewer adults actively managing their clinical information in electronic format at any point in time. Anecdotally, uptake counts of 50,000 users were generally considered to be quite large and represent a success, which implies that no single dominant firm has yet emerged.

Note also that the lack of complete market information prevents us from describing market share; in particular, whether the number of respondents in each category is reflective of the number of consumers using products in each category. Uptake and retention rates are therefore not discussed in this report.

5.1 Marketing Practices

Practices vary widely by vendors to retain and engage new customers. We found significant efforts in niche marketing (see Exhibit 20), for example, some products are sold largely under the umbrella of ‘emergency preparation,’ others are marketed through affinity groups of chronically ill patients, expectant mothers, and other “high utilizers.” While supported by only anecdotal evidence, we believe current PHR adoption rates are higher among subpopulations with significant responsibilities for helping to manage the care of others—parents of young children, people caring for elderly family members, and those who help manage care for chronically ill family members. There is often a significant degree of communication internal to such groups, for instance a recommendation from someone who is enthusiastic about a particular offering is likely to recruit additional users among affinity group members.

Exhibit 20: Number of Targeted Markets



¹⁷ IDC 2006 “Health Industry Insights Consumer Survey” May 2006, accessed on line at http://www.idc.com/downloads/HIIConsumersurveyePHRs_Q&A.pdf

Exhibit 21: Targeted PHR Markets



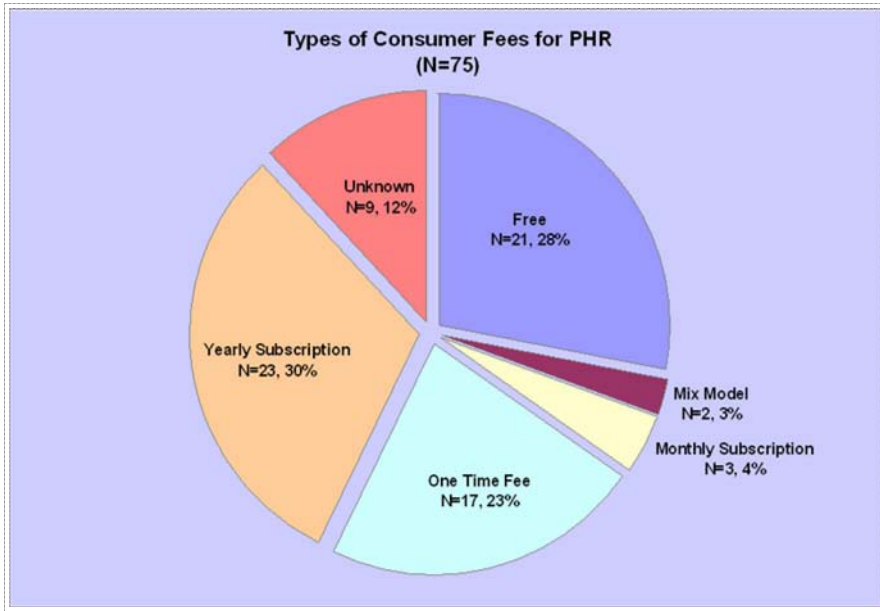
As seen in Exhibit 21, of the PHRs analyzed, direct-to-consumer advertising was the key marketing channel. While these results include vendors that target more than one market, 80% of the vendors analyzed only target one marketing channel. Sixty-five out of 75 are directed primarily to consumers. Only 14 appear to target insurance companies, whereas 12 target providers and 11 target employers.

These results may indicate that PHR vendors perceive that benefits to consumers outweigh benefits to providers, insurers, and employers, thus making them more likely to pay for such products/services. Another interesting note is that some very large vendors are offering their PHR products for free to consumers in the hopes of gaining enough market power to entice physicians and insurers later. In some respects, this approach is analogous to direct-to-consumer pharmaceutical advertising resulting in patients demanding certain brand name drugs from their providers.

5.2 Pricing

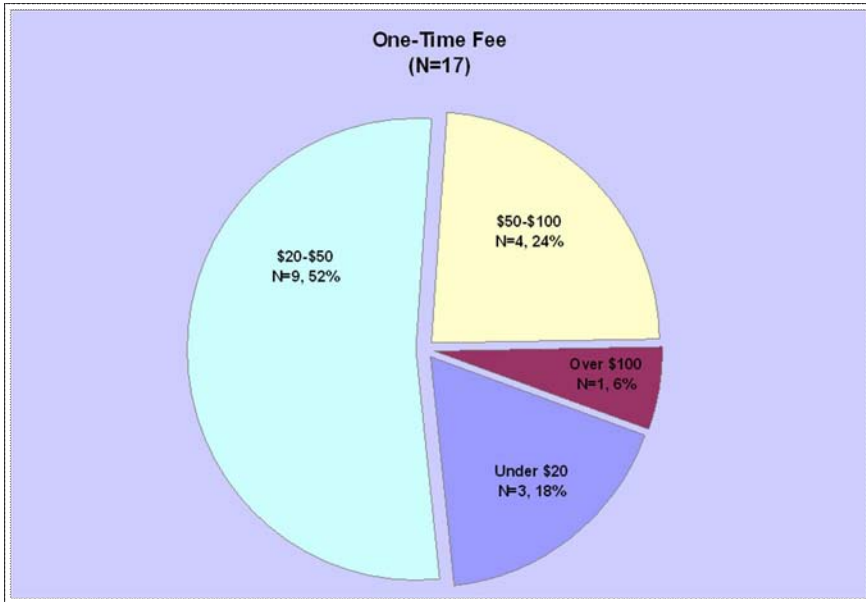
For the PHRs analyzed, no single pricing model dominates. The diversity of this market is strongly reflected in the diversity of pricing strategies. We noted a significant variation among PHRs in terms of how well consumer prices reflected our subjective assessment of the range of value different products offer the consumer. While this report doesn't address the cost-value tradeoff, we do report on the range of pricing models in the market today. As shown in Exhibit 22, 23 (30%) products have a yearly subscription fee, 21 (28%) are free to the end user and 17 (23%) have a one-time fee. The balance are unknown or are mixed cost-sharing models.

Exhibit 22: Pricing Strategies



For PHRs that are provided free to end users, the exact source of revenue generation is not always clear. In some cases the PHR is free to the consumer, but a fee may have been paid by an insurer, provider group, employer or hospital to provide this service. In other cases the PHR is funded through grants or advertising dollars. Pricing also varied for certain vendors depending on whether optional services were purchased like Web-based back-up storage or different amounts of available memory for portable storage offerings.

Exhibit 23: Dollar Amount of One Time Free



For respondents indicating a one-time fee, half indicated a range of \$20 to \$50 (see Exhibit 23). A small number had a rate below that, and the balance were above.

Exhibit 24: Dollar Amount of Yearly Subscription Fee

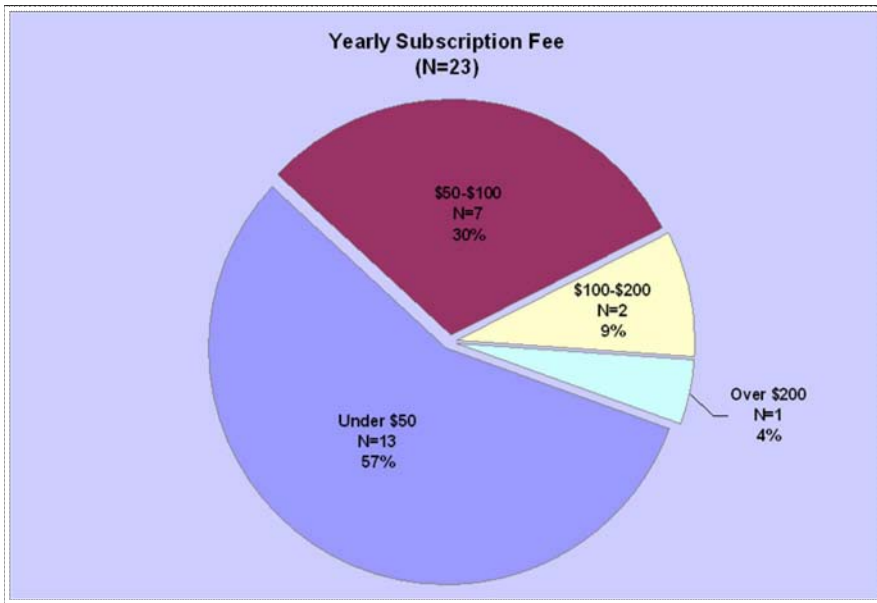


Exhibit 24 illustrates those vendors indicating a yearly fee. The range was comparable to that of the one time fee, with slightly more than half indicating a range of \$50 or less, with the balance above \$50 and ranging upwards of \$200 per year. This price comparison at least suggests that retention rates are not very high or else the price differential would be larger between one-time and annual fees.

Exhibit 25: Architecture and Consumer Fee Type

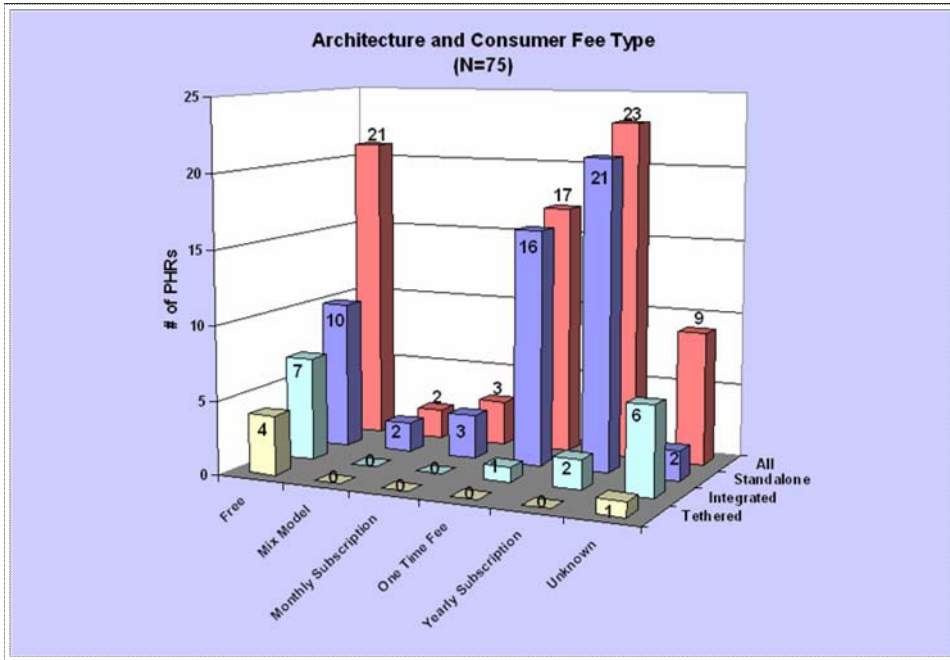
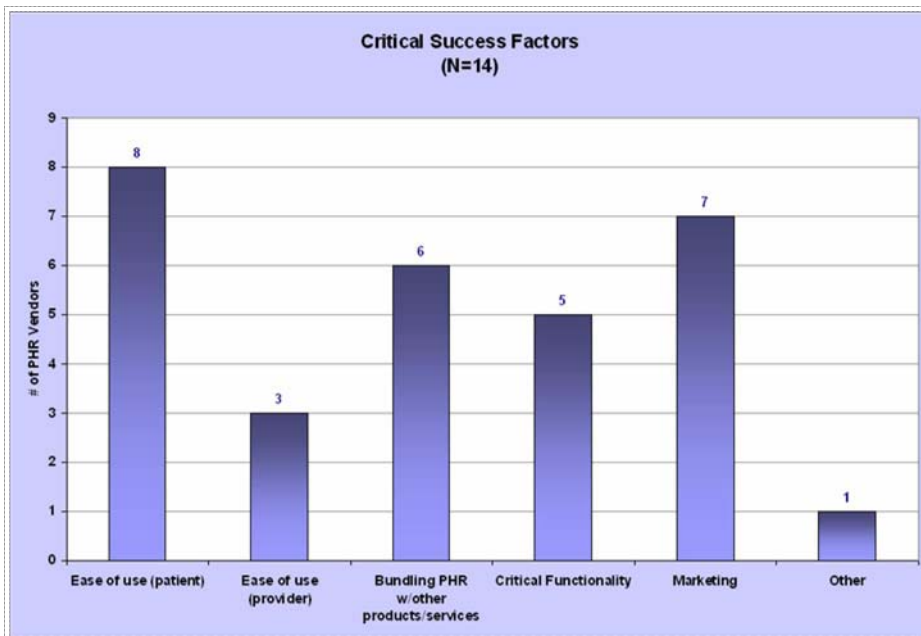


Exhibit 25 demonstrates that the consumer aspect of pricing models do not differ across the previously defined architectural categories as might be expected. Free-to-consumer offerings are available across all architectural types. This is interesting because consumer benefits likely are quite different across these types of offerings.

5.3 Critical Success Factors

Exhibit 26: Critical Success Factors



For participating vendors we attempted to evaluate opinions of critical success factors: the factors considered to most likely affect the PHR adoption rates (Exhibit 26). Some of the dimensions include: ease of use (either for the patient or provider), bundling of PHR with other services or products, critical elements of functionality, and marketing efforts to increase public knowledge of PHR benefits. While we were only able to obtain the views of 14 vendors to this question, ease of use by consumers is most widely cited success factor, with eight reporting it as critical. In response to a follow-up question, “ease of use” was typically characterized as ease of data entry including both automated and manual approaches. Seven identified “marketing efforts” as important, and six identified “bundling PHR with other products/services”. Critical functionality was identified by only five respondents, and only three identified ease of use by providers as critical to their success.

6.0 Final Conclusion and Recommendations

Our experience has shown that there is virtually no public awareness of the need for a PHR. There seems to be a “disconnect” between the government’s rhetoric about the need and the individual citizen’s perception.
– PHR Vendor

Consumer empowerment can be facilitated through widespread PHR adoption and that would likely have a transformative impact on the US healthcare system. PHR use can improve care continuity, provide patients the ability to verify the information in their medical record, improve communication between providers and patients, and enhance the documentation and utility of physician interactions. Widespread use may also have notable impacts on emergency care, patient safety, efficiency and patient satisfaction. However, the most notable impact of widespread use may be much needed improvements in coordination.

Delivering high quality, efficient care requires having access to the right information at the right time. Both patients and providers need to make fully informed decisions and the fragmented nature of the US healthcare system often prevents them from doing so. Widespread PHR adoption can address this need, particularly for patients (and their families) who are faced with conditions that require significant coordination across multiple physician, hospital, clinic, and pharmacy interactions.

Though personal health records have substantial transformative potential, this report demonstrates that currently the PHR market is newly emergent and lacks an obvious technological or market leader. Vendors are pursuing a variety of business models and products show an enormous diversity in approach, architecture functionality, data, and privacy and security protections. PHR adoption is, in some respects, also reliant on advances in larger public policy issues such as data standards and interoperability. Interconnectivity with external data feeds, and potential interfaces to provider-based electronic health records are still in initial formative stages and should be a focus of future research and policy development.

This report presents an initial description of the state of the PHR market. Additional research should be conducted in the following areas to inform policy development:

1. *Market Definition:* The price elasticity of PHR offerings and the utility of different architectures. Market definition of total potential PHR user population across US; likely PHR users; current PHR users, forecasts of adoption rates and attributes of likely users.
2. *Consumer Views:* Consumer opinions, expectations, perceived value and demand for PHR products. Positive and negative experiences of current PHR users. Views on most desired attributes/features and most prevalent concerns. Differences among types of users and types of architectures.

3. *Provider Views:* Provider opinions, expectations, perceived value and demand for PHR products. Provider confidence in PHR data and opinions about utilizing PHR data in their practices. Views on liability issues associated with using (or ignoring) PHR data.
4. *Data Issues:* Approaches to, and maturity of, interconnectivity and data mobility among PHR products and between PHR products and other electronic record systems. Application of data standards, role of certification bodies, consistency with standards setting activities. Estimating the true costs of populating and maintaining PHRs (consumer and provider time requirements; interface costs, and; likely third party costs).
5. *Confidentiality, Privacy and Security Issues:* HIPAA applicability. Maturity of current confidentiality and privacy policies in place. Discoverability of PHR data. Impact of vendor dissolution and transferable rights and responsibilities.

Appendix A – Functionality Questionnaire

1. Please enter the ID included in the e-mail you received *
2. What types of data does your PHR contain?
 - Provider List
 - Condition History
 - Encounter History
 - Medication History
 - Procedure History
 - Lab Results
 - Radiology/Imaging Results
 - Immunization History
 - Allergy History (e.g., medication, food, inhalant, environmental)
 - Family History
 - Lifestyle/Behavioral Health Data (e.g., diet, sleep pattern, exercise)
 - Home-Monitored Data (e.g., blood pressure, weight, glucose)
 - Symptomatic Scores (e.g., pain scores)
 - Advance Directives/Living Wills
 - Discharge Instructions
 - Free Text Documentation
 - Demographic Data (e.g., age, ethnicity, race, geographic)
 - Insurance Information (e.g., eligibility info, claims)
 - Copay/Deductible Paid YTD
 - Specify your own value:
3. Does your PHR support multiple views of the data it contains (e.g., does it present information differently to providers than it does to patients)?
 - Yes
 - No
4. Can other types of patient information be shown on your PHR - e.g., educational materials, information on OTC drugs and alternative medicine/therapy, or links to healthcare information on the Internet?
 - Yes
 - No
5. If you answered "yes" to question #4 - please list additional types of information.
6. Does your PHR support online communication between the patient and the provider (secure messaging/email)?
 - Yes
 - No
7. Can your PHR give patient reminders for wellness checkups (annual exams, mammograms, immunizations)?
 - Yes
 - No
8. Does your PHR include the ability to order pharmacy refills?

Yes
No

9. Does your PHR allow/support appointment scheduling?

Yes
No

10. Can your PHR capture patient self-reported outcomes (e.g., reaction to drugs, whether or not a condition is improving)?

Yes
No

11. Does your PHR support any non-English languages (Spanish, French, Japanese)?

Yes
No

12. Please provide any additional comments on your PHR's functionality or planned functionality.

13. Please select the range that most accurately describes the number of current users of your product.

Under 100
100-499
500-999
1,000-4,999
5,000-9,999
10,000-24,999
25,000-49,999
50,000-99,999
100,000 - 499,999
500,000 - 999,999
over 1,000,000

14. Which best describes your PHR's architecture?

Stand-alone (e.g., USB, Smartcard, paper)
Tethered (an EHR-viewer connected to one or more data sources)
Interconnected (more complex than tethered - includes data inflow/outflow to other systems)

15. If you answered "tethered" or "interconnected" to question #14, please list what the PHR is attached to and how.

16. If you answered interconnected to question #14, can it be interconnected to more than one system?

Yes
No

17. If you answered yes to question #16, please list what systems the PHR can be interconnected to.

18. Is the PHR a "viewer" providing read-only access to an EHR or other data source?

Yes

No

19. Please provide any additional comments/information about functionality/architecture issues.

* indicates a required field

Appendix B – Confidentiality, Privacy & Security Questionnaire

1. Please enter the ID included in the e-mail you received *
2. Does the PHR account holder have primary control over access to data contained in the PHR?
Yes
No
3. Can the account holder restrict certain data items from view (such as certain meds, or encounters with a certain health professional)?
Yes
No
4. Does the PHR provide a means for access in an emergency?
Yes
No
5. Because data about mental health and substance abuse, reproductive health, etc. are often sensitive, does the PHR sequester this data in its design?
Yes
No
6. Does the PHR divide users into groups or classes (such as family members, health professionals, etc.) and restrict data visibility based on rules that are specific to each group? That is, does the PHR support role-based access?
Yes
No
7. Can this PHR provide different access levels for different individual providers? For example, is there a way that one health professional (Dr. A) has different ability to view or change data compared to another health professional (Dr. B)?
Yes
No
8. Is there a way that family members who participate in the account holder's care can be authorized to view or change data?
Yes
No
9. Does this PHR support authentication of specific users? That is, does it have a mechanism to require that a user who tries to sign in gives some evidence that they are indeed that person?
Yes
No
10. If you answered Yes to Question #9 please describe the authentication mechanism used.
11. Is the primary storage for the account holder's PHR data on a device (including PDAs, smart cards, USB, paper, etc.) as compared to, an Internet or database server?
Yes
No

12. Are the data in the PHR encrypted in some fashion?
Yes
No
13. Are there any other mechanisms used to protect the PHR data (for example, physical lock and key)?
Yes
No
14. If you answered Yes to Question #13 please describe.
15. Is there a mechanism to synchronize or store a copy of the data to protect against possible loss?
Yes
No
16. If you answered Yes to Question #15 please describe.
17. Does your organization have PHR-specific security policies in place?
Yes
No
18. Can the account holder or other users view or print the security policy?
Yes
No
19. Does your organization have PHR-specific privacy/confidentiality policies in place?
Yes
No
20. Can the account holder or other users view or print the privacy policy?
Yes
No
21. Does this PHR keep a log or audit trail of all data updates? Data updates include those by a user (e.g., patients, health professionals) as well as data imported from outside sources.
Yes
No
22. Does the PHR keep an audit trail of all access events? Access events primarily include access (screen display or printing) and export or data sending.
Yes
No
23. Do you require any primary source identification documents (e.g., driver license) before a PHR can be established? If yes, please explain. (How do you ensure the identity of the PHR user?)

24. Please provide any additional comments/information about confidentiality, privacy and security issues and how your product addresses them.

* indicates a required field

Appendix C – Business Model Questionnaire

1. Please enter the ID included in the e-mail you received *
2. Who are the customers that you target for PHR sales?
 - Physician/Physician Practices
 - Hospital/Health Systems
 - Insurance Companies
 - Disease/Case Management Companies
 - Employers
 - Patients/Consumers
 - Specify your own value:
3. Who typically pays for the use of the PHR?
 - Patients/Consumers
 - Employers
 - Health Plans
 - Specify your own value:
4. How do you generate revenue from the PHR? For example, is it a monthly fee/subscription, a one-time fee?
 - One-time fee
 - Monthly subscription
 - Advertising
 - Free/Public good
 - Specify your own value:
5. Does your business model include any cost-sharing arrangements? (e.g., both physician and patient pay a portion of the cost)
 - Yes
 - No
6. If you answered yes to question #5, who is involved in the cost-sharing?
7. Do you or any of your partners provide any incentives to use your product?
 - Yes
 - No
8. If you answered yes to question #7, what types of incentives are typically offered?
9. If you answered yes to question #7, who is the target of the incentives?
 - Physician/Physician Practice
 - Hospital/Health System
 - Insurance Company
 - Disease/Case Management Company
 - Employers
 - Patients/Consumers
 - Specify your own value:

10. Do you target a certain segment of the PHR market? If yes, please explain.
11. Do you work through providers, insurance companies, employers or affinity groups to market your product?
Yes
No
12. Have you identified any factors that are critical to the success of your product? (e.g., ease of use, bundling of PHR with other services or products, critical functionality, marketing and related factors).
Yes
No
13. If you answered yes to question #12, what types of critical success factors have you identified?
Ease of use for the patient/consumer
Ease of use for the provider (e.g., implementation)
Bundling of PHR to other products/services
Critical functionality
Marketing Approach
Specify your own value:
14. What are you doing to address critical success factors?
15. Do you use surveys to track customer feedback?
Yes
No
16. Do you track complaints to determine customer feedback?
Yes
No
17. What types of strategies do you use to engage current customers? To attract new customers?
18. Please provide any additional comments about your business model or any marketing hurdles and how your product addresses them.

* indicates a required field