



Connecting Americans To Their Health Care:

A Common Framework for Networked Personal Health Information

CONNECTING FOR HEALTHSM

MARKLE FOUNDATION *A Public-Private Collaborative*

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The collaborators of the Connecting for Health Personal Health Technology Council are pleased to release *Connecting Americans to Their Health Care: A Common Framework for Networked Personal Health Information*.

This document is intended to contribute to an expanding national discussion on the use of information technology to meet the critical needs of consumers, patients and their families.

Many efforts are underway to offer individuals electronic applications to manage their personal health information. This paper explores the possibilities and requirements of networking such applications across the fragmented landscape of health care data and services.

To better manage her family's health, an individual may wish to download copies of her medication history, check her current deductible, exchange secure e-mail with her doctor, read her hospital discharge summary, update her drug allergy information at a clinic, check her son's immunization records, etc. For most Americans, such services if offered at all, are typically provided by several different organizations. There is no convenient way for the consumer to tie them together.

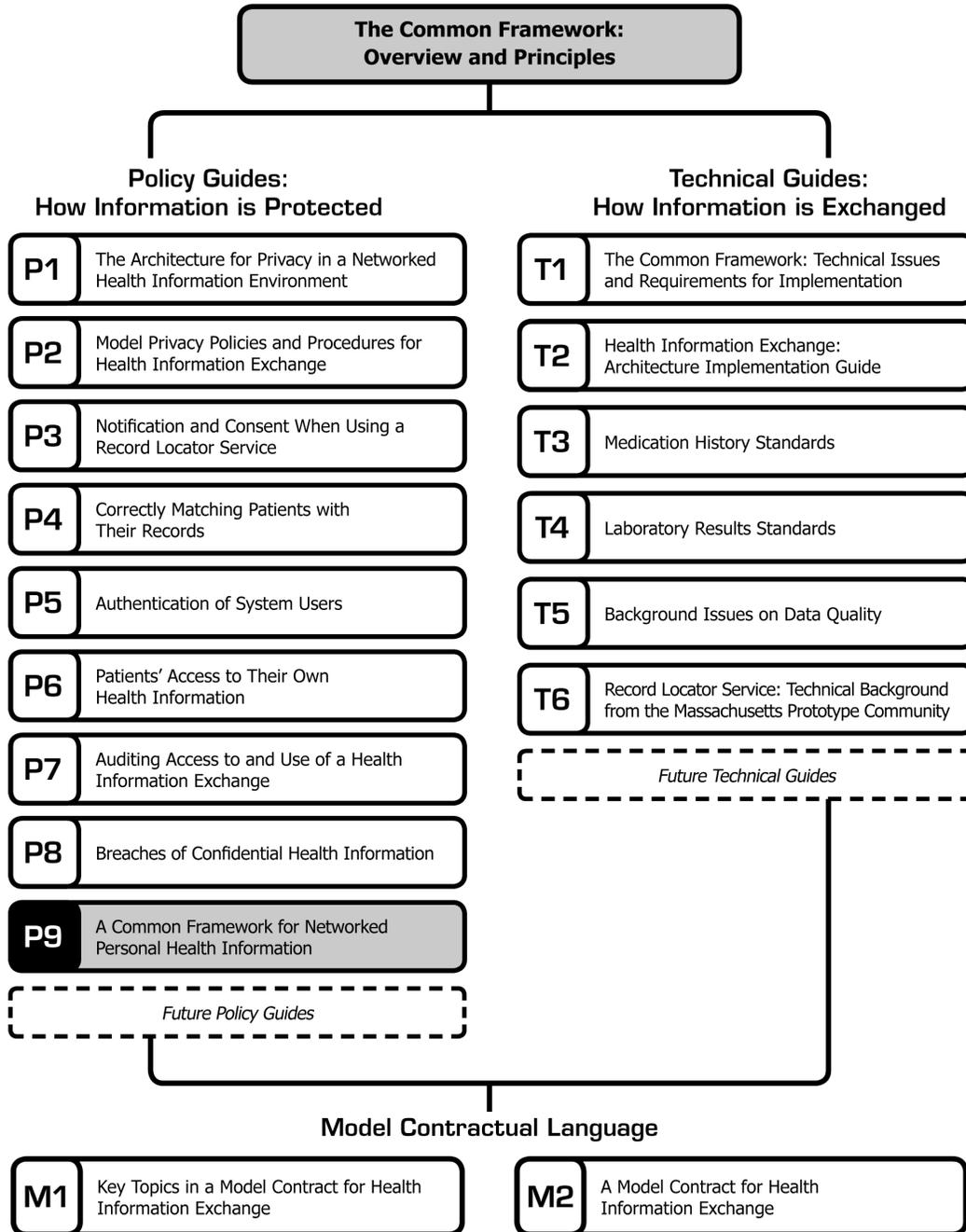
This paper describes a networked environment in which individuals could establish secure connections with multiple entities that hold personal health information about them. It begins with a brief discussion of how consumer participation in networked environments has transformed other sectors, such as travel and finance. It contends that in the health care sector both individuals and organizations (existing health care entities as well as new entrants) could benefit from a properly designed network that enables consumer participation.

This report also raises key policy questions, such as how individual users should be authenticated and what are the necessary safeguards for maintaining the confidentiality of personal health information across a network? The development and implementation of commonly accepted solutions to such questions will be critical to the success of any network.

This document marks the beginning of a new round of Collecting for Health multi-stakeholder work groups to develop consensus recommendations to help improve health and quality of life by connecting Americans to their health care.

Connecting Americans to Their Health Care: A Common Framework for Networked Personal Health Information

The document you are reading is part of *The **Connecting for Health** Common Framework*, which is available in full and in its most current version at: <http://www.connectingforhealth.org/>. The Common Framework will be revised and expanded over time. As of October 2006, the Common Framework included the following published components:



Connecting Americans to Their Health Care: A Common Framework for Networked Personal Health Information *

Section 1: Introduction

Rapid Consumer Adoption of Transformative Technologies

The average person's ability to access data and communicate electronically is proliferating exponentially. Consumer adoption of digitally networked services has transformed the culture of many industries — often in ways unimaginable barely a decade ago.

Consider these examples of rapid consumer adoption of web-based technologies:

- **Communications:** E-mail is now an indispensable tool of communication for hundreds of millions of people worldwide. Instant messaging and Voice over Internet Protocol (VoIP), such as skype.com, are increasingly accepted alternatives to traditional telephones.
- **Search:** The indexing of online information places enormous research power in the hands of individuals. People now "Google" or "MapQuest" without thinking of picking up a phone book or going to a library. Search engines are exposing ever more granular information, such as full-text searches of vast libraries of books, or the estimated value of your home, or the presence of a registered sex offender next door. Collective

¹ **Connecting for Health** thanks Josh Lemieux, Daren Nicholson, MD, Clay Shirky, and David Lansky, PhD for drafting this paper. See Acknowledgements on page 36.

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contributions by customers add value to search engine results, as demonstrated by the niche "layers" that individuals can add to Google maps.

- **E-commerce:** Web sites such as Amazon, eBay, and Craigslist create ever-expanding communities of buyers and sellers, which in turn create ever-expanding content, inventory, and transactions. Opening up online access to previously proprietary networks, such as real estate listings and flight schedules, has precipitated dramatic new conveniences for consumers and efficiencies for industry.
- **Personal finance:** Consumers embrace ATMs, debit cards, personal finance and tax software, and online banking and investment brokerage services. Such online transactions and self-management tools replace mail, phone, and retail encounters with financial institutions.
- **Entertainment:** The explosive popularity of Apple Computer's iPod represents a progression toward individual manipulation and portability of entertainment media and other data. No longer passive consumers of radio program director decisions, individuals increasingly create and share their own "playlists" and "podcasts." In another example, fantasy sports create networks of enthusiasts more deeply engaged than mere spectators of events.
- **Content:** Perhaps the most interesting techno-social trend is how newly networked consumers generate whole new bodies of content. Bloggers, who use software that makes it easy to self-publish on the web, are directly challenging political and journalistic institutions, among others. People are now pouring their innermost thoughts and images into the worldwide digital stream through

online communities, such as MySpace.com and YouTube.com. Wikipedia represents a related and equally powerful trend: online collaborative publishing that derives its authority through the self-regulating nature of open communities. MySpace and Wikipedia in particular illustrate a phenomenal expansiveness of online community content creation. By most accounts,^{1,2} both have emerged in about 18 months to join the 20 most popular sites on the web. Wikipedia is now the most frequently visited reference site on the Internet.³

Consumer-Based Transformation Is Slower in Health Care

A key ingredient to the successes cited above is a fresh openness toward consumer access to, and contribution of, information. By contrast, the health care industry is moving more slowly toward providing consumers with online access to data and services, as evidenced by a still-modest distribution of electronic personal health records (PHRs) with significant bi-directional capabilities.

PHRs encompass a wide variety of applications that enable people to collect, view, manage, or share copies of their health information or transactions electronically. Although there are many variants, PHRs are based on the fundamental concept of facilitating an individual's access to and creation of personal health information in a usable computer application that the individual (or a designee) controls. We do not envision PHRs as a substitute for the professional and legal obligation for recordkeeping by health care professionals and entities. However, they do portend a beneficial trend toward greater engagement of consumers in their own health and health care. (See **Appendix A** for a more detailed discussion of PHR platforms, data suppliers, data integrations, business models, and target audiences.)

A Markle Foundation survey indicates low consumer awareness about PHRs; many people simply have not been exposed to or even thought about the technology. When presented with the concept, however, consumers indicate a high level of receptiveness to the types of services a PHR might provide.⁴ Sixty percent of

Americans favor the creation of secure, online PHR systems that would support their ability to view and refill prescriptions, get lab results over the Internet, check for mistakes in their medical records, and communicate with clinicians via secure e-mail.⁵

Over the past few years, more than 100 PHRs and related technologies have proliferated in the United States and abroad. Despite the increasing availability of these technologies, only a small proportion of the population uses PHRs.⁶ Indeed, some observers express concern that PHRs will fail to ever catch on with the general public.⁷

The low penetration of PHRs to date raises the question: Can PHRs be designed to contribute substantially to transforming health care in the way that other innovations have remodeled their sectors? This paper does not attempt a comprehensive analysis of such successful innovations in sectors other than health care, but we observe that they share a few basic traits:

1. **They are highly useful.** All of the examples cited above provide rapid utility and convenience by taking available digital data, making it digestible, and providing immediate value to consumers.
2. **They are easy to use.** Web applications that have diffused broadly typically deliver not only high utility, but also a simple user interface that does not limit or burden the consumer.⁸
3. **They are free or inexpensive.** Whether supported through advertisements or not-for-profit foundations, dramatic-growth applications generally collect small or no fees from consumers.

These observations relate to the applications themselves and their business models. They are each clearly essential and deserve further evaluation. Our focus with this paper, however, is on a fourth characteristic of web-based technologies that have transformed culture in other sectors:

4. **They rapidly proliferate due to the power of networks.** Consumers connect to various networks via their credit cards, cell phones,

e-mail accounts, affinity club memberships, and so on. Search engines point to information residing across a vast number of sources, all tied together by the Internet (which itself is a network of networks). Point-to-point communication tools like e-mail and cell phones work because they can slice across competing networks. Credit cards work across competing banks because there are worldwide networks that tie them together.

People trust strangers on eBay because there is a trusted payment network, PayPal, as well as a network of buyers and sellers who provide accountability by collectively and publicly rating each other. Sites like Wikipedia, Craigslist, and MySpace have created arrays of communities of people with similar interests.

Network-Enabled, Consumer-Led Transformation: A Case Study

For decades, making flight reservations was a time-consuming task. Airline representatives kept passenger reservation data on handwritten index cards.

First big leap

In 1953, a chance meeting between then-president of American Airlines, C. R. Smith, and a sales representative for IBM, R. Blair Smith, led to the first electronic reservations system, called "Sabre."ⁱ

Second big leap

The success of Sabre motivated other airlines to create their own reservations systems. For example, United Airlines (UA) in the 1970s created the "Apollo" reservations network, which allowed travel agents to book tickets on UA flights as well as its competitors. United felt that the marketing power it gained from offering the reservations network outweighed the losses it might incur from travel booked on other airlines. In these early years, airlines attempted to gain competitive advantage by providing controlled access to their booking service and by various display and presentation approaches to the available flight options. Ultimately, four reservations networks emerged to serve the U.S. market.ⁱⁱ

Third big leap

For years only travel agents and airline reservations representatives used the airline reservations networks. However, following the emergence of Internet travel sites, consumers suddenly gained direct access to these systems. Consumers shifted to self-service for online comparative shopping. Two consequences of this consumer-driven change are the drastic contraction of the travel agent industry and the rapid ascendancy of low-price carriers. Today, travel reservation sites increasingly compete with each other based on other services, such as booking restaurants and selling event tickets.ⁱⁱⁱ

Lesson

By providing consumers with direct access to networked data from multiple competing services, the electronic reservations systems enabled efficiencies and transformed the sector far beyond their original purpose. Similarly, online consumer access to the real estate industry's Multiple Listing Service (MLS) has shifted greater autonomy to homebuyers and sellers, and online banking services have streamlined transactions and services for both consumers and financial institutions.

ⁱ History - Sabre Airline Solutions [homepage on the Internet]. Southlake, TX: Sabre Airline Solutions; [cited 22 May 2006]. Available from: <http://www.sabreairlinesolutions.com/about/history.htm>.

ⁱⁱ Wikipedia [homepage on the Internet]. St. Petersburg, FL: Wikimedia Foundation; 2006 [cited 23 May 2006]. Computer Reservations System; [about 7 screens]. Available from: http://en.wikipedia.org/wiki/Computer_reservations_system.

ⁱⁱⁱ Flying From the Computer - The Travel Industry. *The Economist*, October 1, 2005, U.S. Edition, SPECIAL REPORT (2).

In contrast, today's PHRs are "un-networked." They generally require the consumer to enter data manually or get a view of information from a single entity such as one health plan, one pharmacy, or perhaps one health care provider's electronic health record (EHR). Yet most people have relationships with many different doctors and health care entities; particularly those Americans with multiple chronic conditions — more than 60 million today and estimated to reach 81 million by 2020⁹ — must coordinate their care across several providers and entities. If the PHR is "tethered" to one particular relationship, say with one provider or one pharmacy service, it may not meet the long-term needs of those who need it most. Some people in a stable relationship with one integrated delivery system may today have their information adequately accessible through an application from that institution. However, for most people, over time, PHRs would be much more useful if they were networked to aggregate the consumer's health information across multiple sources (e.g., the consumer's insurance eligibility and claims, her records from all of her doctors, her lab results, her pharmacy services, her diagnostic imaging, etc.).

'Networked' PHRs as Tools for Transformation

The mere aggregation of the consumer's data, however, should not be an end in itself. The true test is whether the network makes it easier for ordinary people to coordinate and engage more actively in their own health and health care. We see a networked environment for PHRs as a foundation for Americans to improve the quality and safety of the care they receive, to communicate better with their doctors, to manage their own health, and to take care of loved ones.

This paper argues that consumers can help accelerate transformative change, particularly in a networked information environment. However, we emphasize that clinicians also have a critical role in realizing the full potential of networked PHRs. Consumers continue to see doctors and other health professionals as the key agents of their care and the most trusted hosts of their personal health information. To take advantage of networked personal health information, both consumers and clinicians must be open to changes in their relationships, responsibilities, and workflows. The network-enabled efficiencies and safety improvements discussed in Section 3 are more likely to occur if consumers and health care professionals act as partners who share access to and responsibility for updating personal health information. The status quo — in which most personal health data are stored in silos controlled by providers, payers, and other entities — makes it more difficult for consumers to gather their data from multiple sources, more difficult to choose freely among providers, and thus more difficult to manage their health.

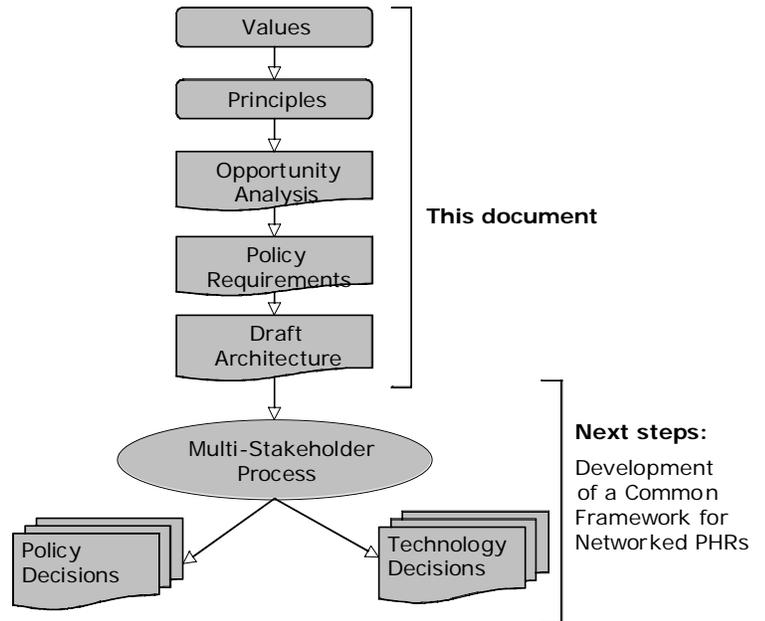
Designing a policy framework and architecture for networked PHRs does not guarantee that consumers or health professionals will widely adopt the technology. This paper does not attempt to overcome every barrier. Our intent here is to recommend a basic architectural approach for networked PHRs consistent with the goals of improving the consumer's access to and confidentiality of personal health information.

Addressing Key Policy Concerns Will Be Core to the Transformation Process

Although a networked PHR would provide significant benefits to consumers, the exchange of health data over an electronic network poses serious concerns. Confidentiality of personal health information is a core American value.¹⁰ There is evidence that Americans support a network for health information exchange — if security and confidentiality safeguards are sufficient.¹¹

Thus, before encouraging the ubiquitous networking of PHRs to other health information systems, we must establish a common understanding and an adequate set of shared rules. We need a technical approach that allows access controls to keep information flowing among people authorized to see it — and protected from unauthorized access or use. The selection and implementation of technical elements are themselves aids or obstacles to confidentiality and security.

Policy principles derived from shared American values must precede, and in fact determine, the design of the network. Consumer representatives must therefore be equal partners with other stakeholders in policy-making bodies. Consistent with the Connecting for Health Common Framework model (see Section 4), we propose that efforts to network PHRs with other information systems be guided by the following path:



This paper recommends a course toward developing networked PHRs. It covers the first five stages of the above diagram. Its purpose is to begin a discussion of the technical architecture and policies necessary to enable consumers to use personal health technologies to connect to their health data and services.

Section 2: Values and Principles

Although there is great heterogeneity in the American population, as a nation we do embrace certain common values. Two of those values, privacy and autonomy, are deeply rooted in American history and remain relevant to many national discussions today, such as free speech and national security. The reach of these values extends to nearly every aspect of the American experience, particularly in health care.

Based on these core values, the **Personal Health Technology Council**[†] has offered a set of consumer- and patient-focused principles for the handling of electronic personal health information. The principles have been endorsed by many consumer groups¹² and recommended to the American Health Information Community, an advisory body on health IT issues for the U.S. Department of Health and Human Services.^{13,14}

The principles are:

1. Individuals should be guaranteed access to their own health information.
2. Individuals should be able to access their personally identifiable health information conveniently and affordably.
3. Individuals should know how their personally identifiable health information may be used and who has access to it.
4. Individuals should have control over whether and how their personally identifiable health information is shared.
5. Systems for health information exchange must protect the integrity, security, and confidentiality of an individual's information.

[†] The **Personal Health Technology Council** is a collaborative body convened by the Markle Foundation and includes representatives who work in government, industry, health care, consumer advocacy organizations, and the professions. See the Acknowledgements for a description of the process we used to develop this paper. For more information about the Council, see <http://www.connectingforhealth.org/phti/index.html>.

6. The governance and administration of health information exchange networks should be transparent and publicly accountable.

Many PHRs today may aspire to these basic principles. However, it is not plausible to expect any current PHR offering on its own to fulfill all of the principles so long as the average individual's personal health information is scattered across multiple, unconnected entities. Furthermore, there are no clear, consensus-based, overarching policies and practices that would guide PHR suppliers toward fulfillment of these objectives.

We conclude that, with the possible exception of individuals receiving all of their care from a single integrated delivery system, only a "networked PHR" has the potential to offer consumers an electronic health information environment that lives up to the principles. To create a trusted network that fulfills these principles, the companies and institutions that hold consumer health data must embrace the values underlying these principles. Fundamentally, personal health data custodians must not attempt to gain or retain market share by forcing consumers into exclusively proprietary mechanisms to access their personal data. Rather, entities should compete to serve consumers with services driven by data that the consumer authorizes them to use. Simply put, consumers should choose PHR applications in a free market.

Connecting for Health argued this same position when it advised the Centers for Medicare & Medicaid Services to set an example for the health care industry by not providing an exclusive portal for beneficiaries to view their claims data, but instead experimenting with beneficiary data downloads into PHR applications that they select.¹⁵

If PHRs can be authorized to connect securely to multiple data streams on the network, then the competition among PHRs will be based on service, features, and value to the consumer, not mere custody of the consumer's data. To illustrate this argument by analogy, the custodianship of personal health data should be more like that of personal cash. Consumers, not banks, own personal cash. People use banks to store and transfer their cash. The banks

compete based on services that they provide in exchange for those deposits. Of course, this analogy is not perfect. People are much more accustomed to managing cash than personal health information. Furthermore, the information generated by the health care system is vastly less structured, more complex, and more sensitive than financial data. Lastly, financial fraud is a well-understood personal and business risk, with well-established remedies supported by business practices, tax law, FDIC, etc. The improper disclosure of personal health information, on the other hand, can inflict a very different kind of damage, which is hard to prove or fully remedy. This underscores the importance of designing a health information network based on principles that are consistent with American values.

All of the participants within the networked environment — including health care institutions and professionals, insurance companies, labs, pharmacy services, employers, and consumers themselves — must agree to basic principles for providing individuals access to personal health information, and security and confidentiality protections must be “baked in” to the network design.

The overarching principles must be translated into specific policies and authorizations, which may vary depending on the location of a given piece of information at a given point as it flows across a network. For example, imagine two applications: one controlled by a doctor and a networked PHR controlled by a patient. The doctor records a diagnosis, and the patient receives a copy of that diagnosis through the networked PHR system. The patient will now control all access by third parties to the copy of diagnosis data in the patient’s own application. However, just as with paper records, once information has been entered into the physician-maintained medical record, the doctor needs to retain the original data, without alteration. Further, existing regulations under the Health Information Portability and Accountability Act (HIPAA) authorize the doctor to share the data with authorized third parties for purposes of treatment, payment and operations without getting the patient’s explicit permission.

Before exploring these network-design and policy principles and policy questions in greater detail, in the next section we propose how networked PHRs may be helpful in improving our broken health care system.

Section 3: Opportunity Analysis in the Current Health Care Landscape

Entrenched problems in the American health care system are well-documented. Among the oft-cited deficiencies:

- Fragmentation that leads to inefficiency and duplication of efforts and costs.^{16,17}
- Disappointing levels of safety and quality that lead to high rates of medical errors.^{18,19,20}
- Frequent unavailability of vital information at point of care.²¹
- High costs that are growing at an unsustainable rate.^{22,23}
- An overall lack of patient-centeredness.²⁴

Connecting for Health focuses on how health information technology can help transform the industry to reduce these problems and enable new forms of personal health management. We contend that strategic acceleration of the following trends can catalyze the long-awaited transformation:

1. **Widespread use of digital data systems.** If health information remains paper-based, little can be done to leverage data to improve health research, quality, and outcomes.
2. **Adoption of EHRs.** Clinicians need to use EHRs so that the clinical data they generate can be captured for sharing, coordinating care, and quality assessment.
3. **Interoperability of EHRs.** Only a minority of clinicians use EHRs today, and most of these EHR users have implemented proprietary systems that are not interoperable with other systems.
4. **Proliferation of PHRs.** Consumers are a logical point of aggregation for copies of their own health information. PHRs can be essential tools to make the task easier and place individuals at the center of their care.
5. **Distribution of technology to the patient and family.** Other technologies, such as health monitoring devices, can add the home as a key collection point for important personal health data. Such monitoring opens possibilities for more collaborative care and early intervention when monitored values reach certain thresholds.
6. **Reallocation of roles, responsibilities, and money to the patient and family.** PHRs and other new technologies must support a shift from episodic and acute care toward continuous healing relationships between patients and families and the health care professionals who serve them, as envisioned by the Institute of Medicine's landmark report *Crossing the Quality Chasm*.²⁵ Consumers, aided by new technologies, can assume added responsibility for self-care, personal health management, and care-giving. A shift in financial incentives to reward clinical follow-up, outcomes, and quality is a key part of this trend, since current rewards favor fragmented and episodic care. The goal is to reinforce the benefits of improved collaborative relationships among consumers, their families, and their trusted health professionals.

Networked PHRs Would Help Meet IOM Design Rules

In 2001, the Institute of Medicine (IOM) published the landmark *Crossing the Quality Chasm*ⁱ report with six widely cited, broad goals for redesigning health care in the 21st Century. It envisions a health care system that is:

1. **Safe** — By avoiding injuries to patients from the care intended to help them.
2. **Effective** — By providing services based on scientific knowledge to all who could benefit, and refraining from services not likely to benefit (i.e., avoiding underuse and overuse, respectively).
3. **Patient-centered** — By providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
4. **Timely** — By reducing waits and sometimes-harmful delays for both those who receive and those who give care.
5. **Efficient** — By avoiding waste, including waste of equipment, supplies, ideas, and energy.
6. **Equitable** — By providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

There is broad consensus that clinician adoption of electronic health records (EHRs) is critical to progress toward these worthy aims. In the same report, the IOM issued ten design rules that are less frequently cited, but more specific about the need for an advanced role for patients and their families (particularly those with asterisks below):

1. Care based on continuous healing relationships.*
2. Customization based on patient needs and values.*
3. The patient as the source of control.*
4. Shared knowledge and the free flow of information.*
5. Evidence-based decision-making.
6. Safety as a system property.
7. The need for transparency.*
8. Anticipation of needs.*
9. Continuous decrease in waste.
10. Cooperation among clinicians.

Clearly, a strategy that relies on clinicians' adoption of EHRs alone will not achieve all ten of the IOM's design principles. The IOM envisions consumers as full information partners with the health care professionals and institutions that serve them. Thus, a fully formulated strategy for accomplishing these ten goals would also include promotion of networked personal health records (PHRs).

PHRs will be critical to achieving more than half of these design principles (see asterisks above) if they collect, anticipate, and reflect the needs and values of individual health care consumers. PHRs can foster long-term healing relationships between individuals and their health care providers if they are networked to chronicle care longitudinally across multiple points of care. PHRs also have the potential to provide consumers with an unprecedented level of control over their information and health decisions that affect them. Further, PHRs can be vehicles for transparency about treatment options and transactions, ranging from the evidence base for various treatments to the costs of medical services.ⁱⁱ

In summary, we do not believe that the IOM's worthy aims can be attained without PHRs networked to the plurality of institutions through which consumers receive care.

ⁱ Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington: National Academies Press; 2001.

ⁱⁱ Tang PC, Lansky D. The Missing Link: Bridging the Patient-Provider Health Information Gap, *Health Affairs*, Sept.-Oct. 2005, p1290-1295.

We do not view the above trends as perfectly sequential steps of transformation, each one dependent on one prior. Instead, we view them as concurrent processes that will reinforce each other. In evaluating the highest leverage approach to take over the coming years, we offer a best guess assessment of how far along the United States is likely to be in advancing each of these trends by 2008.

1. Widespread use of digital data systems by 2008:

- Nationwide, more than 90 percent of pharmacy claims transactions will be computerized and increasingly available through national clearinghouses, consistent with the National Council for Prescription Drug Programs' (NCPDP) coding.
- As many as half of all laboratory results available electronically will be using Logical Observation Identifiers Names and Codes (LOINC) standards (although it is not as clear how much of the lab information will be available through distributed networks or whether most end-user applications will be ready to receive the data).
- More than 95 percent of clinical claims will be in electronic format.

2. Adoption of EHRs by 2008:

- Only one-third or fewer hospitals and health care practices will have an EHR installed.

3. Interoperability of EHRs by 2008:

- Most EHR installations will continue to be based on proprietary software that is largely non-interoperable.
- No more than ten percent of the public will live in communities where health information can be exchanged among interoperable EHRs.
- Incentives for interoperability will remain very modest.

4. Proliferation of PHRs by 2008:

- Several of the current barriers to PHR adoption (such as concerns about privacy and security, lack of consumer awareness, lack of brand, lack of a sustainable

business model) will likely remain in place and limit growth.

- The continuing stream of news reports about privacy breaches of electronic data in several sectors, including health care, may affect consumer demand for PHRs and even create backlash against EHRs.

5. Distribution of technology to the patient and family by 2008:

- Control over technology and information will remain in the hands of health care organizations.
- Public reporting efforts and information support for health care transparency and quality will be very modest.
- Few incentives will be in place to entice consumers to adopt technology and to take a more active role in their care.

6. Reallocation of roles, responsibilities, and money by 2008:

- Higher co-pays and health savings accounts (HSAs) have been promoted in part to shift greater responsibility for health care decision-making to the consumer. Additionally, there are government, payer, and employer initiatives to "pay-for-performance." However, we predict that these efforts will have little effect on the underlying roles, responsibilities, and financial flows of the health care system as a whole by 2008.

Given the low expectations for EHR penetration and interoperability, health care transformation strategies that rely on EHRs and clinician-based health data sharing networks are not likely to yield substantial near-term impact. We recognize the importance of EHRs and the high value of their integration with PHRs. We support efforts to increase EHR adoption and interoperability. However, we contend that it would be a strategic mistake to wait for full fruition of trends 2 and 3 in order to achieve increased consumer participation through trends 4 and 5.

Rapid consumer adoption of newly networked services has proven to be possible — indeed phenomenal — in other sectors. Consumers can adapt to technology and culture transformation more rapidly than large health

care institutions with long histories of business processes and legacy systems. Furthermore, even as the majority of clinicians continue to keep consumers' data on paper, other important personal health information — namely claims, pharmacy, diagnostic images, and lab data — are available in digital form today. We conclude that the immediate effort to catalyze health care transformation must include a strategy to create a networked environment for PHRs and related technologies that takes advantage of these currently available digital data streams. Providers can gradually form and join networks as their systems increasingly interoperate. In fact, networked connections to PHRs could help accelerate the EHR adoption curve as clinicians see advantages to joining the network.

There are additional strong rationales for involving consumers in a much-needed transformation toward greater information access and transparency. First, the health care consumer has the largest stake in the contents of such information. The consumer's life is put at risk when preventable errors occur due to lack of information. Second, the consumer is the ultimate payer of health care services.

Consumers are being asked to pay directly for a larger proportion of their care.^{26,27} Third, younger generations expect to use technology in almost all aspects of their lives. Fourth, as the number and complexity of diagnostic and treatment modalities grows at a rapid pace, patients are increasingly required to share the responsibility of decision-making with their health care providers. Furthermore, patients are often in the best position to gather and share information with providers.^{28,29} For example, a physician might know that a medication has been prescribed for a patient. But without asking the patient, the doctor does not know whether the patient actually took the medication, how well it worked, what other remedies she is taking, or whether she had side effects.

Empowering health care consumers by placing information directly in their hands has the potential to radically improve health care.^{30,31} PHRs are still in the early development stages, and a great deal of study is needed to measure the benefits and risks of PHRs. Consumers, patients, and their families vary widely in the responsibilities they each wish to

maintain in their own health. However, as noted in **Connecting for Health's** 2004 report, *Connecting Americans to Their Health Care*, preliminary evidence suggests that PHRs have potential to:

- Empower patients and their families.^{32,33,34,35,36 37,38,39}
- Improve the patient-clinician relationship.^{40,41,42,43,44}
- Increase patient safety.^{45,46,47,48}
- Improve the quality of care.^{49,50,51,52,53}
- Improve efficiency and convenience.^{54,55,56,57,58,59}
- Improve privacy safeguards.^{60,61}
- Save money.^{62,63,64,65,66,67,68}

Lastly, there is general agreement among many stakeholders, including those listed below, that PHRs should be a key part of health care modernization and reform efforts:

- Government bodies, like the National Committee on Vital and Health Statistics⁶⁹ and the American Health Information Community.⁷⁰
- Professional societies, such as the American Medical Association⁷¹ and the American Health Information Management Association.⁷²
- Consumer groups, such as AARP and the American Diabetes Association.⁷³
- Health insurance plan associations, like America's Health Insurance Plans and the Blue Cross Blue Shield Association.⁷⁴
- Bipartisan political leaders.⁷⁵

Stakeholders do not share a consensus view on how to stimulate PHRs (or even what PHRs should ultimately be). We do not know what kinds of applications and functions will be most effective in encouraging the transformation we seek. The mere presentation of health data to consumers is unlikely to be transformative. Applications likely will have to interpret and apply the data in innovative ways that provide specific benefit to specific people, and connect them with their health team and caregivers. Although the next sections of this paper recommend a framework for enabling networked PHRs, we purposely avoid recommendations on what those applications should be or do. Development of a sufficiently flexible network will enable the use of a great variety of personal health technology applications, including many that we cannot imagine today.

Section 4: Background on the Common Framework Architecture

Connecting for Health has created a structure, called the Common Framework,⁵ which is specifically designed to strike an appropriate, consensus-based balance between the need to share personal health information electronically and the need to protect it from inappropriate access or use. Although the Common Framework was originally designed to guide personal health information exchange among health care providers, its underlying principles were developed to support consumer access. Below we briefly discuss these principles.

Common Framework Policy Principles

The Common Framework has endorsed a set of fair information practices to guide systems that support the exchange of personal health information. These principles are fully presented in "*P1: The Architecture for Privacy in a Networked Health Information Environment*."⁷⁶ Here we summarize them:

- **Openness and transparency:** Consumers should be able to know what information exists about them, the purpose of its use, who can access and use it, and where it resides. They should also be informed about policies and laws designed to ensure transparency on how privacy is assured.
- **Purpose specification and minimization:** The purposes for which personal data are collected should be specified at the time of collection, and the subsequent use should be limited to those purposes or others that are specified on each occasion of change of purpose.
- **Collection limitation:** Personal health information should only be collected for

specified purposes and should be obtained by lawful and fair means. Where possible, consumers should have the knowledge of or provide consent for collection of their personal health information.

- **Use limitation:** Personal data should not be disclosed, made available, or otherwise used for purposes other than those specified.
- **Individual participation and control:** Consumers should be able to control access to their personal information. They should know who is storing what information on them, and how that information is being used. They should also be able to review the way their information is being used or stored.
- **Data quality and integrity:** All personal data collected should be relevant to the purposes for which they are to be used and should be accurate, complete, and current.
- **Security safeguards and controls:** Personal data should be protected by reasonable safeguards against such risks as loss or unauthorized access, destruction, use, modification, or disclosure.
- **Accountability and oversight:** Entities in control of personal health information must be held accountable for implementing these principles.
- **Remedies:** Legal and financial remedies must exist to address any security breaches or privacy violations.

⁵ The **Connecting for Health** Common Framework Policy and Technical Resources are available at: <http://www.connectingforhealth.org/commonframework/overview.html>.

Common Framework Technical Principles

The Common Framework also prescribes several technical principles upon which health information exchange networks should be based. We summarize them below:

- **Make it “thin”:** Data exchange networks should impose the minimal requirements for storing and transmitting health data, leaving as much processing as possible to applications at the edges of the network.
- **No requirement of a national health ID:** We argue that a national health identifier is neither likely nor necessary.
- **Avoid “rip and replace”:** The health care industry has already invested heavily in technology. The network should take advantage of the technology currently in use, not require its replacement.
- **Separate applications from the network:** The roles of the network and of applications should be distinct. The purpose of the network is simply to transfer data. All other data-related functions should reside at the application level. This architecture provides for a stable infrastructure upon which application developers may build innovative functions. Because this distinction is critical to our recommendations for networked PHRs, we discuss it further in **Appendix B: How Applications Interact with Networks**.
- **Decentralization:** Data should remain with the originators of that data (e.g., providers, pharmacies, etc.). Consumers already have trusted relationships with these entities.
- **Federation:** A federation of network members based on mutual agreements is necessary given the complexities of a decentralized network.
- **Flexibility:** The network should be designed such that it can scale and adapt over time and allow participation by a wide variety of network members.

- **Security and privacy:** Privacy protection and security should be top priorities that guide the design and development of the network.
- **Accuracy:** There should be a low tolerance for errors with regard to identifying people and their data records. There should also be a means to correct data errors that are discovered.

Connecting for Health put these principles into practice in a three-region prototype documented in previous Common Framework technical and policy papers. This paper adds to a compendium of policy resources for interoperable electronic health information exchanges. Those resources consist of:

- An overarching “architecture” for privacy based on nine interdependent principles.
- Model privacy policies and procedures.
- Notification and consent policies.
- Policies for correctly matching patients with their records.
- Policies for authentication of system users.
- Patient information access rights summary based on the Health Information Portability and Accountability Act (HIPAA).
- Policies for audit logs.
- Policies for breaches of confidential health information.[§]

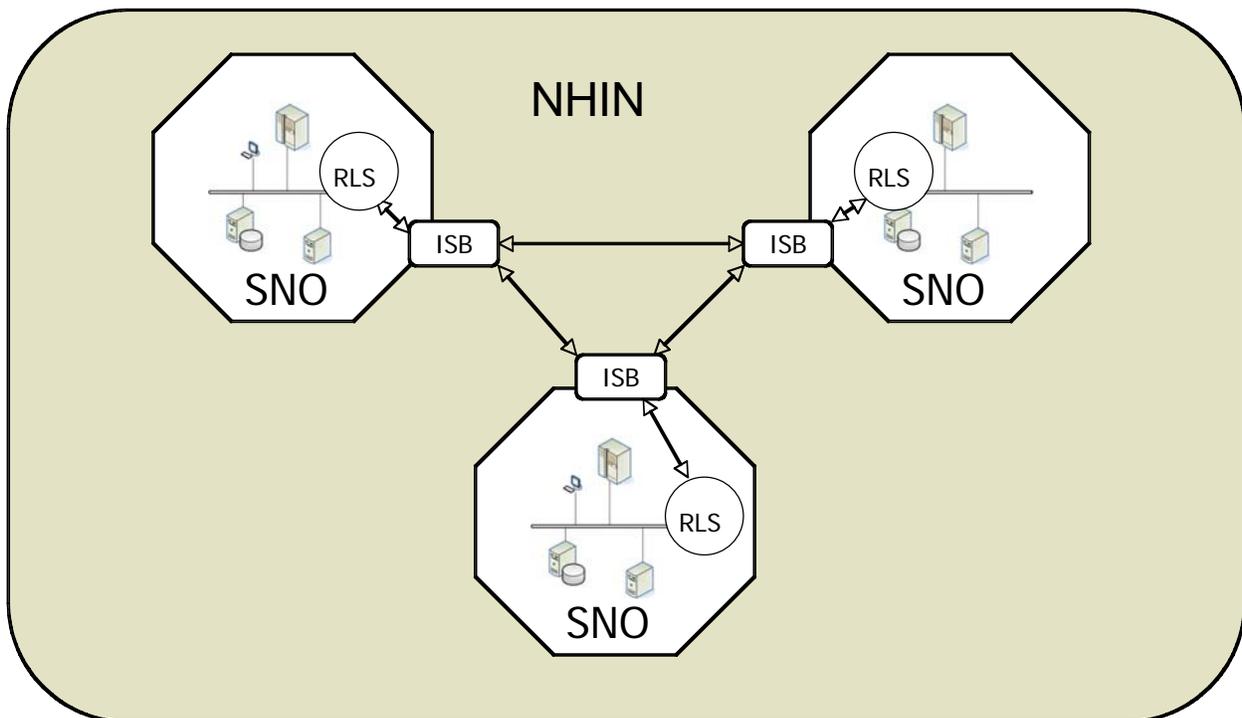
[§] The **Connecting for Health** Common Framework Policy and Technical Resources are available at: <http://www.connectingforhealth.org/commonframework/overview.html>.

The Common Framework as an Architecture for Networked PHRs

To date, the **Connecting for Health** policies have been designed to enable interoperable exchange of patient data *among clinicians*. It is a substantial challenge to add consumers to the exchange. From the policy standpoint, these principles must be translated into an adequate set of information-sharing policies to which both consumers and institutional data custodians can agree. On the technical side, a network architecture must be developed that is consistent with the above principles, yet scalable and adaptable to the many combinations of relationships that consumers have with various health care entities. These technical and policy challenges must be addressed in tandem.

Definitions in the Connecting for Health Common Framework Architecture

Previously released Common Framework documents described **Connecting for Health's** vision of a nationwide network for health information exchange. The fundamental design elements of that network architecture would not be changed by granting consumers access to the network. In fact, consumer access has always been a design principle of the work. Below we review some of the key architectural concepts described more fully in prior Common Framework reports.



- **Nationwide Health Information Network (NHIN):** As its name implies, the NHIN is an overarching network that connects exchange networks within the nation. Thus, it is envisioned as a network-of-networks.
- **Regional Health Information Organization (RHIO):** The current trend in health information exchange is to build provider-centric, regionalized networks. These networks are usually referred to as RHIOs. A functioning RHIO would connect multiple provider institutions in a region, such as a state or county.
- **Sub-Network Organization (SNO):** A Sub-Network Organization is a business structure comprised of entities that agree to share personal health information in accordance with a minimum set of technical and policy requirements embodied in the Common Framework. A SNO may be organized on a geographic basis (i.e., a RHIO) or in support of other business relationships that are not determined by location. For instance, the Veterans Administration (VA) has a network of hospitals and clinics that exchange health information on a nationwide level. Both RHIOs and non-regional networks like the VA would be sub-networks of the NHIN. Thus, we prefer the term "SNO" because it is a more inclusive term than RHIO.
- **Record Locator Service (RLS):** As its name implies, the RLS is a service that queries the locations of patient records within a SNO. Each SNO has its own RLS. The purpose of an RLS is best described by an example. A physician or other health care professional may wish to retrieve data on a patient from other institutions that the patient has visited. The physician would send a query to the RLS, which returns a list of record locations, but not the data itself. Thus, the RLS might inform the doctor that her patient has medical records at institutions X, Y, and Z. The contents of those records are not revealed by the RLS. Retrieval of data contained in an identified record is a separate process that occurs directly between the requesting physician and the institution that stores the record.
- **Inter-SNO Bridge (ISB):** A physician might want to search for records outside his SNO. Thus, he would send a query to the RLS of another SNO. The ISB is the conduit through which these queries and responses flow. Each SNO would have an ISB, which would be its single gateway for channeling all requests and responses from other SNOs.

In summary, the Common Framework architectural vision is a network of networks (one NHIN made up of many SNOs). Each SNO uses an RLS to locate the consumer's records and an ISB to talk to other SNOs. Institutions that want to share information across the network must be members of a SNO, comply with Common Framework policies, maintain an RLS or equivalent service, and build an ISB.

As noted in Section 3, many important pieces of the consumer's record are already held in digital format. The custodians of this information include:

- Health insurance plans (both private and public).
- Pharmacy services and clearinghouses.
- Nationwide laboratory services.
- Self-insured employers' data warehouse services.
- Large, integrated delivery networks.
- And, to a lesser extent, some small hospitals and smaller-practice EHRs.

The next section discusses how PHRs could become part of this network, connecting consumers to their own unique slice of data and enabling them to drive health care transformation.

Section 5: How Consumers Could Be Networked Via the Common Framework

Currently available PHRs either rely on existing data silos (i.e., patient portals offering access to non-interoperable health records) or create new silos (i.e., consumer-populated, non-interoperable records). Potential large-scale benefits of PHRs are unlikely to materialize if these applications remain dependent on limited data sources.⁷⁷ For PHRs to become more universally useful to consumers, they must provide a convenient and secure means of connecting to personal data and interactive services from multiple sources, *and* they must provide a convenient and secure means of moving the data out of the PHR as well, in whole or in part.

A number of architectural approaches could permit consumers to deliver information from disparate data sources into a PHR and vice versa. At one end of the spectrum, the PHR could rely entirely on a **centralized database of personal health information**. A master database at the center of the network would aggregate data from other health information systems before the information becomes accessible in the PHR. Theoretically, the consumer could then have access via one interface to the central data repository, with potentially greater efficiencies than could be provided by queries across a distributed network. The primary problems with this centralized approach are:

1. **Data management:** Copying all personal health data to a single database, and keeping it all up to date, is impractical at population scale given the vast amounts of data that exist across systems.
2. **Data quality:** Sending all data to a central database may magnify data quality problems (although such an effort may also reveal data problems). The centralized repository model would make error checking and data reconciliation difficult compared to a model that keeps personal health information close to the entity that creates it and knows the

patient. Organizations closest to the consumer are in the best position to validate, adjudicate, or update the consumer's data.

3. **Business case:** It is implausible that any one entity can emerge to garner the trust of all health care systems and all consumers in the fragmented U.S. health care environment. A single, central database would raise questions central to trust such as who controls the data, who governs the process, what secondary uses and resale of data will be allowed, etc. A single source of control for the database would risk the shortcomings of monopolies in general: low innovation, poor customer service, and higher prices. It also limits the power of the network to grow organically and incrementally.
4. **Security and privacy:** While breaches are a concern for all information holders, a centralized model poses significant risk to privacy since a single security breach could lead to a catastrophic data leak.

Centralized systems can provide valuable efficiencies and controls, and may be very appropriate at various network nodes, which should have flexibility with regard to data-storage solutions for the information that they each hold. If centralization is the only model by which health information can be shared across disparate entities, however, there is a high risk that many entities will not participate.

The polar opposite of the centralized architecture is an **entirely peer-to-peer network**. Under this model, a consumer would have to create and manage separate data streams between her PHR and each system that holds her data. The primary problems with the completely decentralized approach are in many ways the mirror image of the problems of absolute centralization:

1. **Data management:** If each consumer is expected to aggregate her data, she will become both her own registrar and her own system administrator. This burden will be too much for the majority of consumers.

2. **Data quality:** Clinical data comes in both highly structured and very unstructured forms. The consumer would be responsible for managing these disparate forms of data — again, a task too challenging for most consumers.
3. **Business case:** Each person would pay for (or choose a sponsorship model for) a PHR, but the system would be highly fragmented and create few economies of scale.
4. **Security and privacy:** The security risk would be multiplied across many servers with varying levels of technical support and policy compliance. However, the breach of any given source of data would be more limited, reducing the potential for catastrophic data disclosures.

The pure point-to-point approach would place too much burden on the consumer to establish electronic transaction relationships with all of her health care services. It also would be cumbersome and pose high risks for each of the consumer's data sources, given the current lack of standards for clinical information or of a trusted mechanism to authenticate each consumer. Further, providers would be less likely to access and use the consumer's data if they were confronted with a hodgepodge of information aggregated from a series of unstructured point-to-point transactions.

How Could Consumers Aggregate Their Data?

Creation of centralized data repositories should not be an architectural requirement for data sharing, however, data aggregation at the level of the consumer could be very beneficial, for all of the reasons cited in Section 3 of this paper. How, then, can the individual aggregate her health data without relying upon a single repository at the center of the network or learning to manage a completely peer-to-peer model?

Any practical strategy for networking PHRs must avoid the negative consequences of these two extremes while satisfying the consumer-

and patient-focused principles discussed in Section 2.

The Common Framework vision of a federated, decentralized network of SNOs was created to meet this core requirement. Under the Common Framework, authorized clinicians are able to query the network (e.g., request an index of the locations of a patient's records) on the basis of their organization's membership in a SNO. To establish a chain of trust, the participating SNOs must have common understandings and expectations, such as how to authenticate and authorize clinicians to use the network and how to log their actions.

Consumers also need a chain of trust to interconnect across networks. Yet they represent a greater challenge than clinicians for authentication, authorization, liability, and security. There is no commonly accepted set of practices today to provide credentials to consumers for health information exchange across different systems and data repositories. It is reasonable to expect that consumer applications could become more easily "networked" if such a set of common practices existed — that is, if some type of enforceable arrangement required all participants to operate under a common set of policies and agreements to mitigate risks such as misidentification or identity theft.

In the **Connecting for Health** model, a network of interconnected SNOs is viewed as the most flexible and practical means to untether applications from data silos, as well as to enforce a common set of rules among participants. To integrate PHRs into the NHIN, we assume that the same model for connecting users — a chain of trust, brokered by an ISB that can talk to other entities in the system — must be available to patients and consumers. This paper considers the functions and requirements of an entity that provides consumers with access to the nationwide network of SNOs.

Consumer Access Services Could Act as Intermediaries

We start with three assumptions about how consumers could gain access to their data in the future. The first is that there will be services acting on the consumers' behalf as aggregators of personal health information. Other kinds of networked services with many sources of data, from e-mail to online bill paying to airline booking sites, aggregate data on behalf of the user. It may become technically possible for the consumer to access her health data (via a personal computer) directly from the hospitals, labs, and other organizations that hold it. However, even in such a scenario, many services will arise to hold and manage the data on the consumer's behalf. Issues of backup, remote access, and economies of scale are in fact already driving the creation of these sorts of services. (Some models may offer storage services of all of the consumer's data; others may emerge simply as gateways for access without actually storing the data. Ideally, consumers would choose which aggregation model best serves them.)

The second assumption is that there will be services that issue identity and authentication credentials to the consumer and pass those credentials or proof of authentication to other organizations in the NHIN, on the consumer's behalf. Today, we have no generally accepted methods or policies for initially proving the identity of each individual for the issuance of online credentials based on that identification, nor for the initial and repeated authentication of that individual's identity in an online environment. In a nationwide health information network, those who hold personal health data will need to be confident that the person to whom they transmit data is indeed who she claims to be. Common, reliable policies for initial proofing and repeated verification of identity will be essential functions of these intermediary services. (Although a complex set of issues surround identity, authentication, and authorization, we will group all of these issues under the label "authentication" for the rest of this document.)

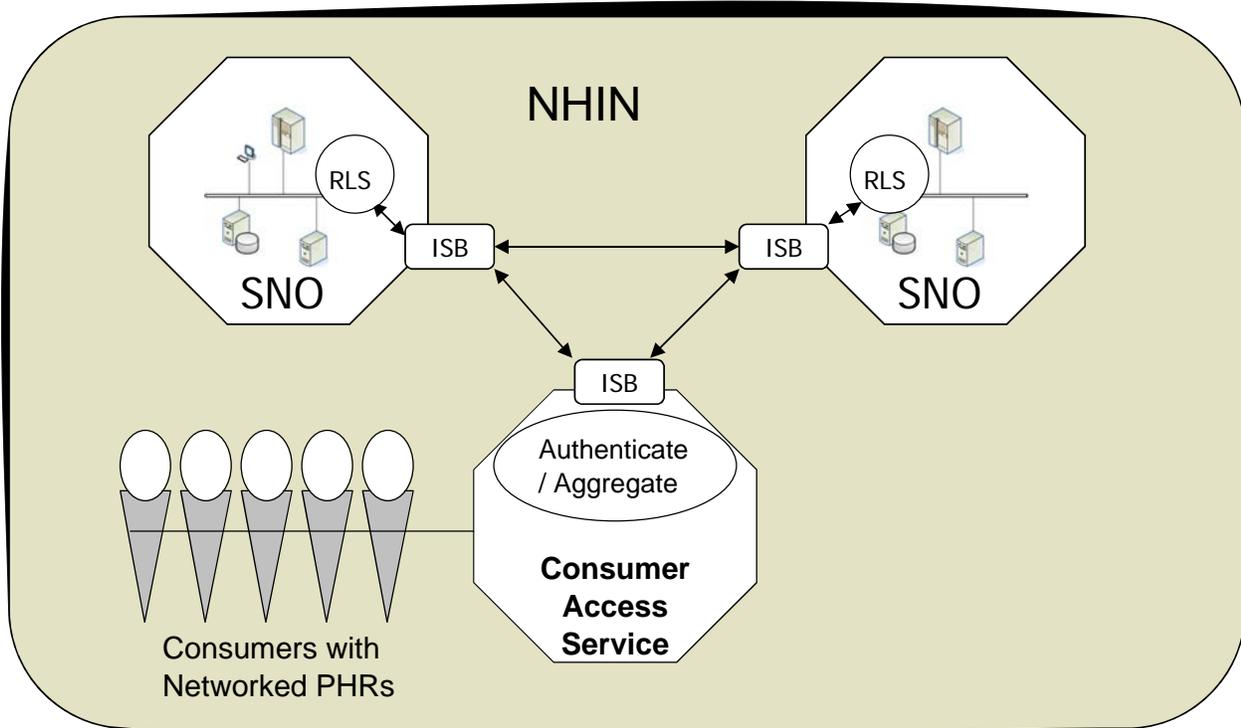
Given the high cost of the initial consumer identification and the low cost of the subsequent authentications, economies of scale will drive

the creation and growth of these functions. These intermediary services would be contractually obligated to comply with the rules governing participation in the network. Likewise, they would be expected to enforce those rules in the event of any violation by one of their authorized users (and to successfully exclude unauthorized users). By the same logic, the entities that issue identity credentials to individual consumers must have the organizational standing to enforce nationwide policies within their network.

Third, we assume that the aggregation and authentication functions will be combined. While aggregation and authentication could be offered separately, the economic logic driving the creation of the services will also drive their combination. As a result, competing services would act as proxies for many consumers, potentially millions at a time, holding both their authentication tokens and their data. These authentication/aggregation service providers would not necessarily be covered entities under HIPAA. For the rest of this document, we will assume that authentication and aggregation functions will be offered in tandem by entities we will call "**Consumer Access Services.**" We will also assume that the interaction between Consumer Access Services and other entities in the NHIN will use the service-oriented architecture of the Common Framework, including both SOAP messages and message brokering by Inter-SNO Bridges.

Following the diagram below, such a combined authenticating and aggregating service would perform key NHIN functions including, at a minimum, authenticating individual users, providing an ISB interface to bridge between those users and the rest of the NHIN, and aggregating information into PHRs on those users' behalf.

- **Pharmacy services** (i.e., pharmacy benefit managers, retail pharmacies, clearinghouses) could offer new services to attract consumers.
- **Application vendors** could benefit from a more efficient marketing and distribution environment by offering their products to a range of Consumer Access Service suppliers with large populations of consumers.



A number of entities may be interested in offering these combined services to enable consumer access to the NHIN, including the following examples:

- **Provider organizations** could strengthen their role as primary care providers and care coordinators by accessing all of a patient's data when authorized and playing the role of interpreter and coach.
- **Health insurance plans and government programs** (e.g., Medicare, Medicaid, VA) could apply their data analytic- and decision support-capabilities to the clinically rich patient data available across the network and compete on their ability to deploy beneficial interventions based on that analytic intelligence.
- **Affinity and patient advocacy groups** could create their own intermediary services to help members select and use appropriate products, while using aggregate data as a platform for improving health and advocating for shared concerns.
- **Employers** could steer employees toward consumer access services that allow secure access to personal health information and other benefits.
- **Web portals and other non-traditional health care players** could enter the health care space, both leveraging their brand credibility and gaining appropriate access to data that the consumer wants them to have without negotiating separate access agreements with each trading partner.

- **Regional Health Information Organizations (RHIOs)** could offer services to connect consumers.

Connecting for Health wishes to enable consumers to aggregate and manage their health care data while protecting them against "silo-ization" (the difficulty or inability to move their personal data easily from one source to another, especially data they may have added to their own records) and against the misuse or loss of personal data. Two key questions will need to be addressed:

1. What qualifications must a Consumer Access Service possess?

One broad answer could be: "Only current participants in the health care system would be allowed to offer consumers access to their data." This restriction would assure that all those offering consumer access are already covered entities under HIPAA. An alternative answer could be: "Any organization that ensures accurate authentication and accountable handling of consumer data would be allowed to act as a Consumer Access Service." One possible middle ground would be to insist contractually that all Consumer Access Services abide by HIPAA regulations, regardless of their status as a covered entity.

2. What policies, contracts, and other governing mechanisms should be applied to these services?

Consumer Access Services must be trusted partners of every other SNO and NHIN participant. These organizational partners must be confident that the entity to which they pass personal health information will handle it properly, and only share it with the intended and authenticated user. What sorts of contracts, standards support, and other mechanisms of governance would constitute a sufficient chain of trust to enable Consumer Access Services to participate fully in the NHIN?

One set of issues involves identification and authorization of the patient, including, but not limited to:

- Minimum standards of original proofing.

- Minimum procedures for authentication.
- "Levels of sensitivity" authentication methods (stronger authentication for more sensitive data) and how those levels are established.
- Bonded access to ensure some sort of penalty for misuse by third parties.
- Co-issuance of credentials across the network.
- Contracts that specify responsibilities and liabilities.

Another set of issues is related to access, including, but not limited to:

- Whether the consumer must be offered a store-and-forward capability (like e-mail).
- Whether the consumer must be offered an encrypted cache (to secure the data on the server).
- Whether the consumer must be asked for consent for secondary uses of the data, and what constitutes "consent."
- Whether the consumer must have access to an audit trail that tracks every time her data is viewed or used by someone else.
- Whether the consumer must have the right to get a full copy of her data in an appropriate format.

These issues should be resolved by a process that maximizes the value of these intermediary services for the consumer while limiting the risk of misuse of that data by other parties (including the Consumer Access Services themselves.)

Public policy must make it possible for each person to access personal health information regardless of where it was originally acquired and where it is now maintained. In solving a problem like authentication, the NHIN needs to make sure that every American has an opportunity to gain the necessary credentials and take advantage of the information channels that exist, without being subservient to any particular gatekeeper.

Section 6: Charting a Path Toward Fully Networked PHRs

A number of significant projects to deploy PHRs are now underway. With this document, we have offered a vision of how these multiple approaches to the PHR might coexist and even support each other. We began by presenting a set of values and principles that assert the right of the individual to control personal health information and eventually to share that information with a variety of innovative health care services. We then outlined a strategy to put those principles into practice by developing a networked PHR. The first step toward achieving our goal is to develop policies that will enable consumers to participate in health information exchange.

Connecting consumers to a health information exchange network raises a number of policy questions:

- How will individual consumers be authenticated?
 - How will authorized users of an individual's PHR be authenticated and allowed access?
 - How does the consumer know she is communicating with who she thinks she is through the network? How does she verify the source and accuracy of data received?
 - What consent procedures will be followed before granting consumers access to the network?
 - Which secondary uses of the data, if any, are to be sanctioned?
 - How will unauthorized uses of data be handled?
 - How will personal health applications be certified to access data sources?
 - Will standards for patient-sourced data be defined?
 - Will patient-entered data (e.g., errors, changes in medication use, etc.) be propagated back to data suppliers?
- How will the consumer's ability to control the sharing of her data be ensured?
 - By what procedures will consumers grant access to other users such as providers and caregivers?
 - How will relationships among consumers, Consumer Access Services, and other NHIN participants be formalized?
 - What mechanisms will assure accountability?

All of the policy issues above cannot be solved at once. Therefore, we have chosen to focus on a few priority problems in 2006 and 2007. These significant policy issues can be grouped into the following categories:

- **Authentication:** How does a network participant know that a consumer user is really who she says she is? The discussion of this issue should include a thorough exploration of private sector and federal sector roles in determining adequate policy.
- **Consumer Access Service policy requirements:**
 - What are the key principles and characteristics of a Consumer Access Service?
 - What specific capabilities and liabilities must a Consumer Access Service assume to maintain a chain of trust with the participants of other SNOs?

Connecting for Health will convene multi-stakeholder Working Groups that will formulate policy recommendations for each of these challenges. We recognize that each stakeholder has its own set of interests. To successfully develop an open market of networked PHRs, each stakeholder must make a commitment to enable portability of personal health data with the consumer in control.

Organizations should make the data that they hold available — at the consumer's request — to applications offered by other entities, as long as those entities comply with a Common Framework of rules and practices for information stewardship.

This approach would allow consumers to access their information through applications of their choosing, as opposed to having access exclusively through the application offered by each entity that captured their data. The networked model opens up possibilities for existing entities and new entrants to compete on innovation, value, and service to consumers. This model holds more promise than proprietary silos, because no one organization holds all of the data valuable to most consumers. We therefore recommend that organizations aim to exploit the power of networks by developing and adopting a Common Framework for networked PHRs.

A networked PHR environment cannot be achieved without collaborative efforts and consensus agreements among all stakeholders. To achieve our national vision of networked PHRs for every American who wants one, we need to agree on the characteristics of the network and the means by which personal health information will be shared and managed. We must create an environment of trust and confidence. Without a Common Framework of policies for information stewardship, even a thousand interesting projects and product offerings are not likely to produce a trustworthy, interoperable PHR.

This paper provides a vision of a plurality of organizations that offer opportunities for consumers to connect to networks of personal health information and services. An individual could connect via a Consumer Access Service offered by a provider group, a RHIO, a retail chain, a payer, an affinity group, a web portal, a bank, etc. We seek a free and fair competitive environment in which all players agree to a minimum set of common rules. The precise path toward this vision is not completely knowable now. However, we envision several steps over the next five years:

1. Collaboration among multiple stakeholders to recommend policies, beginning with the key areas cited above.
2. Development of one or more prototype Consumer Access Services with multiple PHR connections.
3. Broad dissemination of the prototype findings and requirements.
4. Contractual agreements to abide by a Common Framework among a critical mass of health care actors.
5. Evaluation of potential methods to validate and enforce rules for Consumer Access Services and the applications that connect to them.

As we have witnessed in the short history of the Internet, market demand and the power of networks can combine to make consumers a driving force for change. This paper outlines a framework aimed at allowing a similar phenomenon to happen in the particularly complex and sensitive area of personal health information.

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Appendix A: Definitions of PHRs

"Personal health record" (PHR) is a widely used but loosely defined term for a variety of emerging technologies that enable people to manage their health information and health care transactions electronically. The following brief discussion outlines key characteristics of PHRs.

PHRs Are Distinct from EHRs

It is important to distinguish PHRs from electronic health records (EHRs). EHRs are electronic systems used by health care providers to record and manage information about their patients. EHRs are designed to replace the paper "patient chart" that clinicians have a legal and professional obligation to maintain throughout the course of each patient's care and for many years afterward. In contrast, PHRs are optional tools for consumers, who do not have similar legal and professional obligations for health record-keeping.

Attributes of a PHR

The Connecting for Health Personal Health Working Group described the PHR as an electronic tool that "...enables individuals or their authorized representatives to control personal health information, supports them in managing their health and well-being, and enhances their interactions with health care professionals."¹

Connecting for Health has put forward the following as seven attributes of an ideal PHR:

1. Each person controls his or her own PHR.
2. PHRs contain information from one's entire lifetime.

3. PHRs contain information from all health care providers.
4. PHRs are accessible from any place at any time.
5. PHRs are private and secure.
6. PHRs are transparent. Individuals can see who entered each piece of data, where it was transferred from, and who has viewed it.
7. PHRs permit easy exchange of information across health care systems.²

The American Health Information Management Association has a similar definition: "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 health care providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider."³

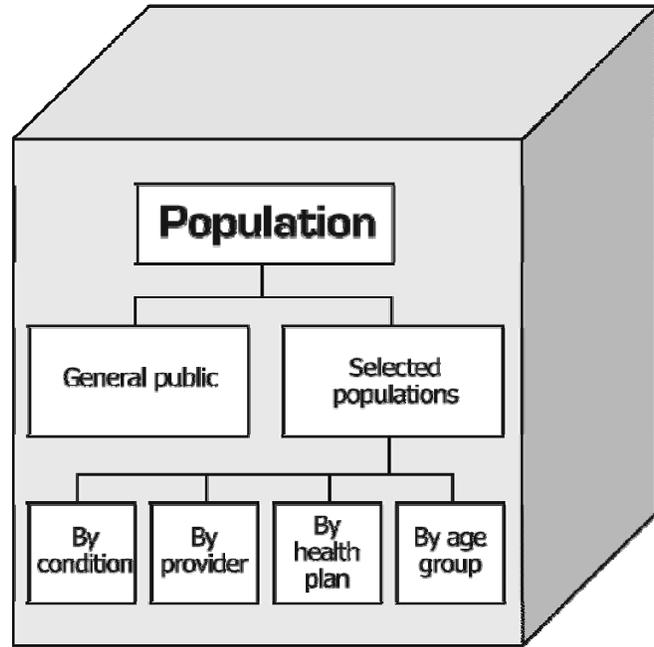
As noted in Section 2 of this paper, few if any current PHRs provide an easy means to reach the full ideals of all seven **Connecting for Health** attributes. Attributes three and seven are particularly difficult to achieve in today's health information technology environment.

Dimensions of PHRs

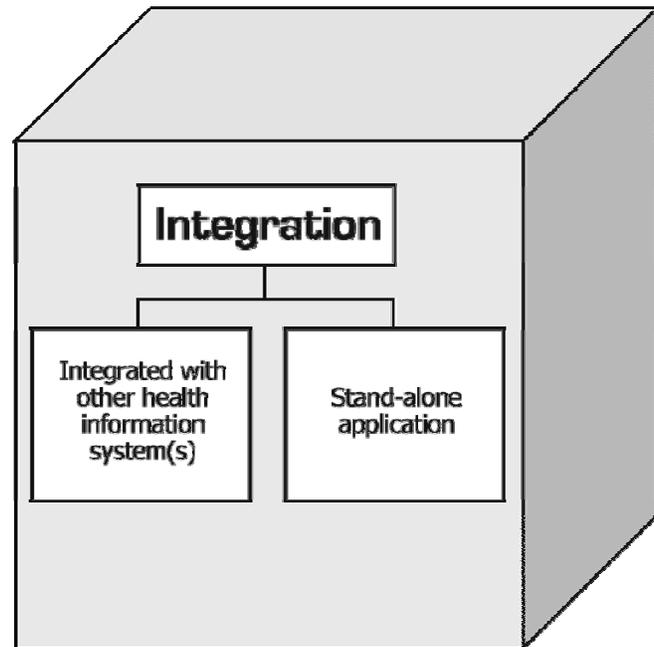
There is a heterogeneous group of applications that describe themselves as PHRs. Below we describe a set of six dimensions to classify the many PHRs on the market today. As a visual aid, we illustrate these dimensions as sides of a cube. Each side of the cube has a taxonomy to help understand the diversity of offerings.

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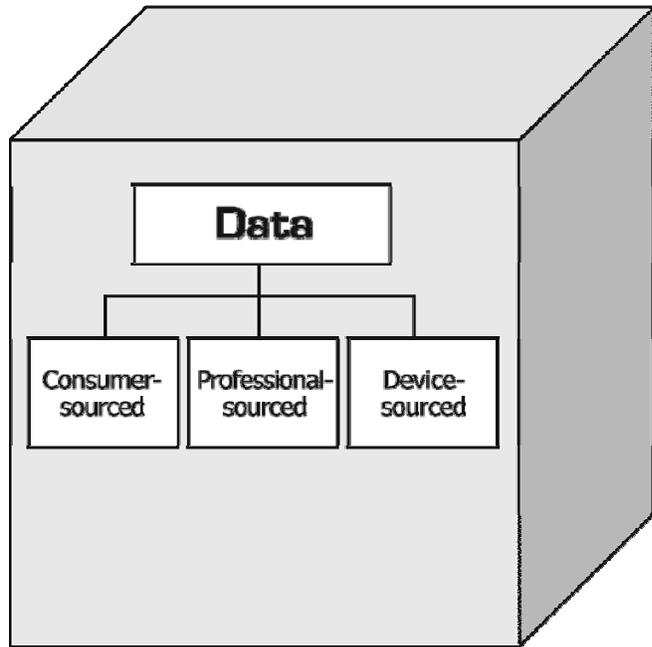
Many PHRs are intended to serve the general public. Others are offered to selected populations, such as employees of a certain company or members of a health plan. The size of these population segments ranges from small (e.g., parents of children with hydrocephalus) to very large (e.g., people who have diabetes).



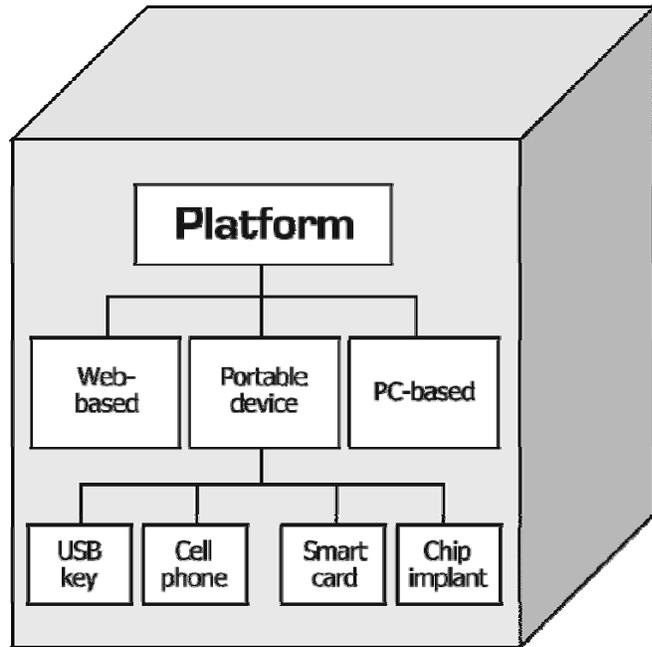
Perhaps the most recognizable characteristic of a PHR system is its relationship to other health information systems. A PHR may be integrated (or sometimes said to be "tethered") to an EHR. This type of PHR is often called a patient portal, because the PHR provides the patient's view into an extract of the provider's EHR. Other PHRs are integrated with non-EHR systems. For instance, a PHR may have a relationship with an insurance company's claims system, a pharmacy's information system, or a health-monitoring device. The other type of PHR is called independent or "stand-alone" (i.e., not integrated with another information system, and typically reliant on patient-input data).



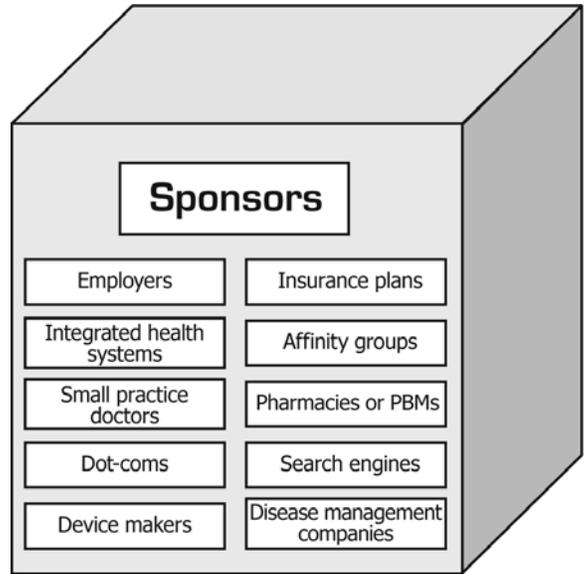
The third dimension relates to the source of data that PHRs capture and store. This is closely related to the type of integration with other health information systems that the PHR offers. There are three main types of PHR data: consumer-sourced, professionally sourced, and device-sourced data. Consumer-sourced data are captured, typically via manual entry, from the individual or individual's authorized proxy. Professionally sourced data are from clinicians and other health care entities (e.g., payers, pharmacies, labs, etc.). Device-sourced data are generated via uploads of information from monitoring tools, such as blood glucometers or blood pressure cuffs. Of course, PHRs can implement any combination of these data sources.



PHRs may also be categorized based on the type of platform on which the application runs. Most PHRs are web-based. However, some PHRs may run on the user's PC or a portable device. These portable devices include USB keys, mobile phones, smart cards, and even implantable devices. PHRs may evolve to interoperate across several platforms.

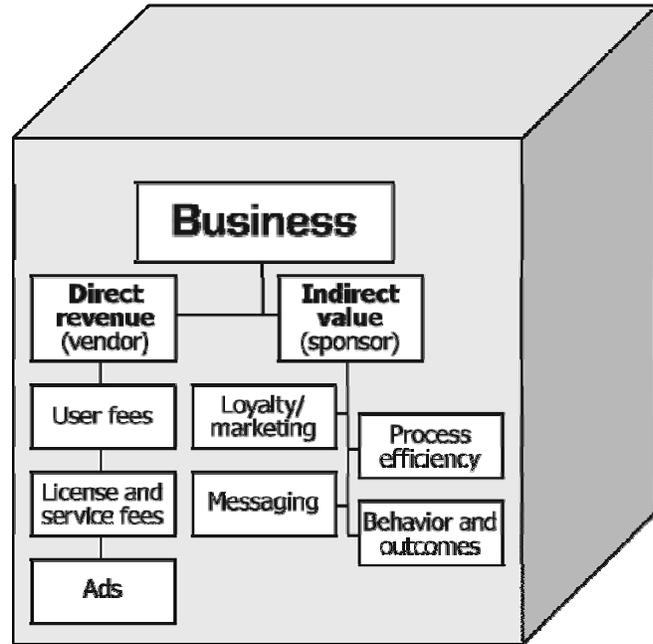


PHRs may also be differentiated by the entity that sponsors the product, and there are a wide variety of such entities. Employers, large and small health care providers, insurance plans, pharmacy services, affinity groups, dot-coms, device makers, and disease management companies are among those sponsoring PHR applications. **Note:** A PHR sponsor often does not directly supply a PHR product to its target population, but rather contracts with a PHR vendor for the service.



Closely related to sponsorship is the final dimension: the business model or value proposition. PHRs' applications differ according to the value proposition that they promise their vendors and sponsors. PHR vendors generally rely on revenue from some combination of licensing fees, services or transaction fees, advertisements, and subscription fees. PHR sponsors are generally seeking to derive value from one or more of the following:

- **Loyalty and marketing:** For example, a health plan or integrated delivery network may offer the PHR as a means to differentiate its service from competitors and build loyalty and/or dependence among its membership.
- **Process efficiency:** For example, an integrated delivery network may offer a PHR with online appointment scheduling or online prescription refills to reduce the number of telephone calls from patients to its physicians.
- **Messaging:** For example, an employer may offer a PHR to communicate health and health benefits information to its employees, including the availability of disease management programs for people with certain conditions.
- **Behavior and outcomes:** For example, some PHRs may offer functionality to improve adherence to prescription regimens or exercise programs with the goals of improving behavior and outcomes.



An important note about all of these diagrams is that the categories within each dimension are not mutually exclusive. Many existing models are blended. For example, a PHR can have all three types of data sources or have several different business objectives.

More Than Merely a Repository

In its 2004 report, *Connecting Americans to Their Health Care*, **Connecting for Health** emphasized the importance of integrating services into PHRs beyond the mere storage of health data.

Similarly, the National Committee on Vital and Health Statistics concluded: "The term 'record' in 'personal health record' may itself be limiting, as it suggests a singular status repository of personal data. The Committee found that a critical success factor for PHRs is the provision of software tools that help consumers and patients participate in the management of their own health conditions. A 'personal health record system' provides these additional software tools."⁴

A Symposium of the American Medical Informatics Association's College of Medical Informatics reported: "Personal health record systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become more active participants in their own care."⁵

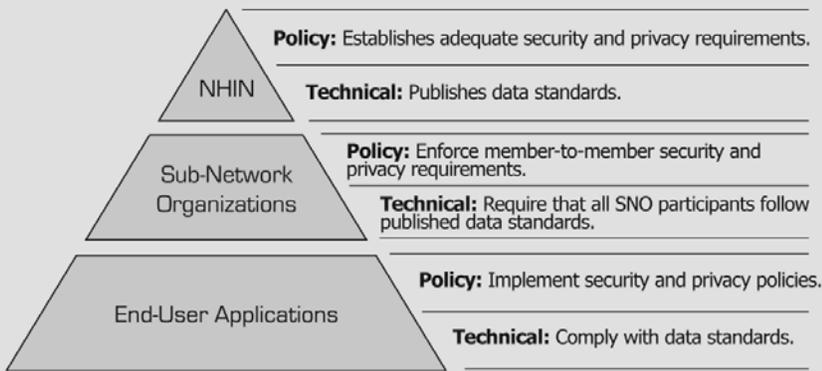
At this early stage of development, we believe that it is important not to restrict innovation by defining PHRs too narrowly. Different populations of consumers are likely to embrace various types of personal health applications. Thus, health information exchange networks should be designed to support a broad diversity of personal health applications and technologies.

- ¹ The Personal Health Working Group Final Report. Connecting for Health, Markle Foundation, July 2003, p 16. Access on May 19, 2006 from URL: http://www.connectingforhealth.org/resources/final_phw_g_report1.pdf.
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Appendix B: How Applications Interact with Networks

How Applications Interact with Networks

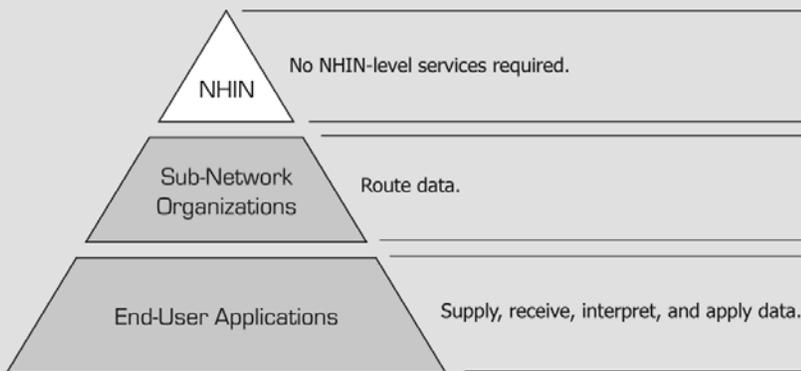
As previously discussed, there should be a clear distinction between the role of the network and that of the end-user application. Application vendors and their clients are in a much better position to determine what sorts of data integration, manipulation interactivity, and display are required for different users. The optimal network specifies only the minimum necessary network configuration to permit flexible data access and effective protections of privacy and security. This minimalist approach will allow a great variety of personal health technology applications to connect to the network, including those applications that exist today and others yet to be developed. The diagrams below illustrate the respective roles of the network and applications:



Data Standards, Security, and Privacy

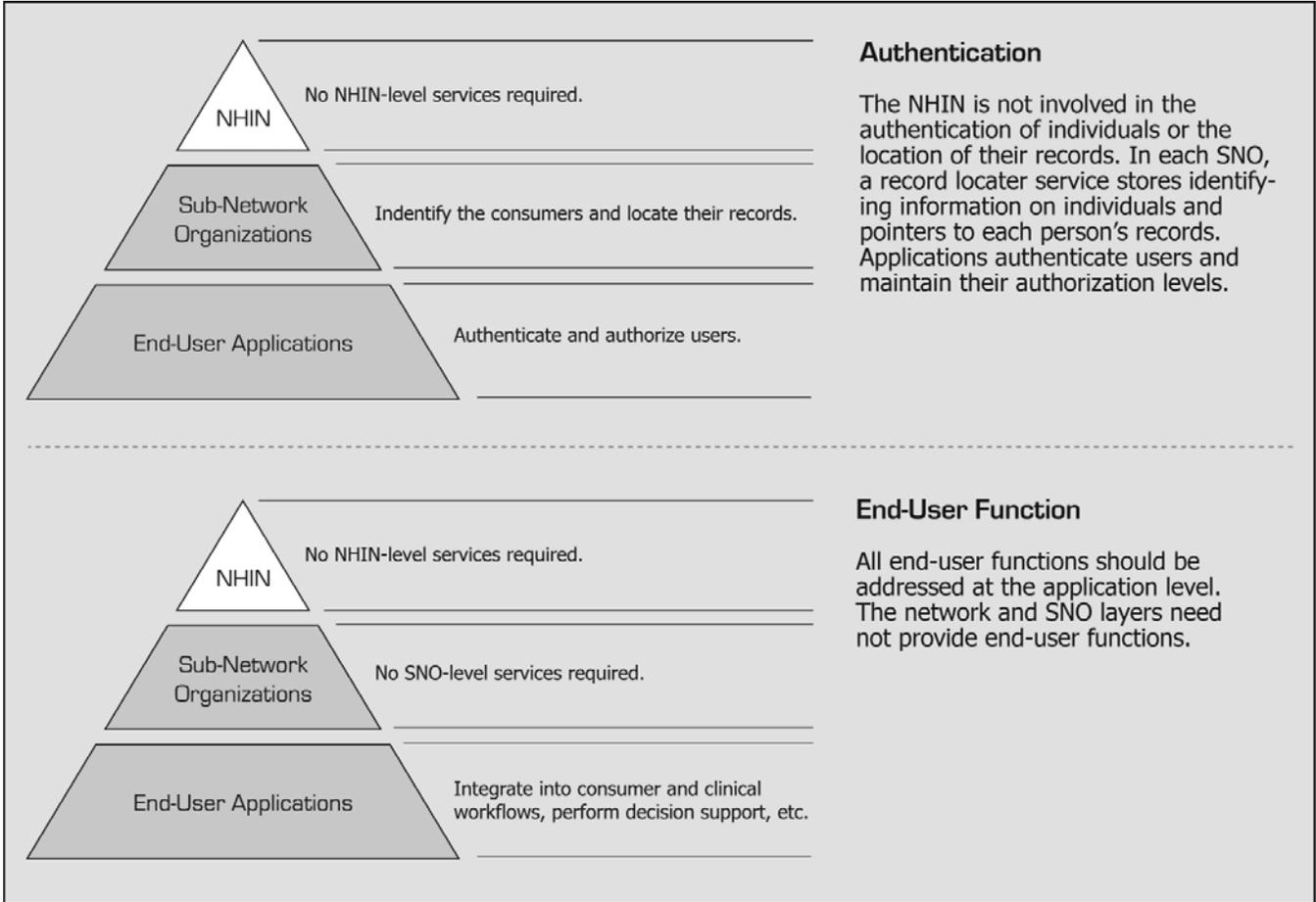
Policy: The network defines the minimum security and privacy requirements necessary to participate in the network. The sub-network organizations (SNOs) enforce these requirements among the SNO members. Actual implementation of these policies occurs at the application level.

Technology: Similarly, the network establishes which technical data standards are acceptable. Ensuring compliance with these standards is the responsibility of the SNO. The main burden, however, falls on the applications, which must be capable of sending and receiving data in a specified format.



Data Routing

The NHIN connects the SNOs, but does not touch the data shared among them. It merely allows them to connect and transport the data. SNOs route the data. Again, the main burden is on applications to supply, receive, interpret, and apply the data for end-users.



Acknowledgements

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