CP1   CP2   CP3   CP4   CP5   CP6   CP7   CP8   CP9

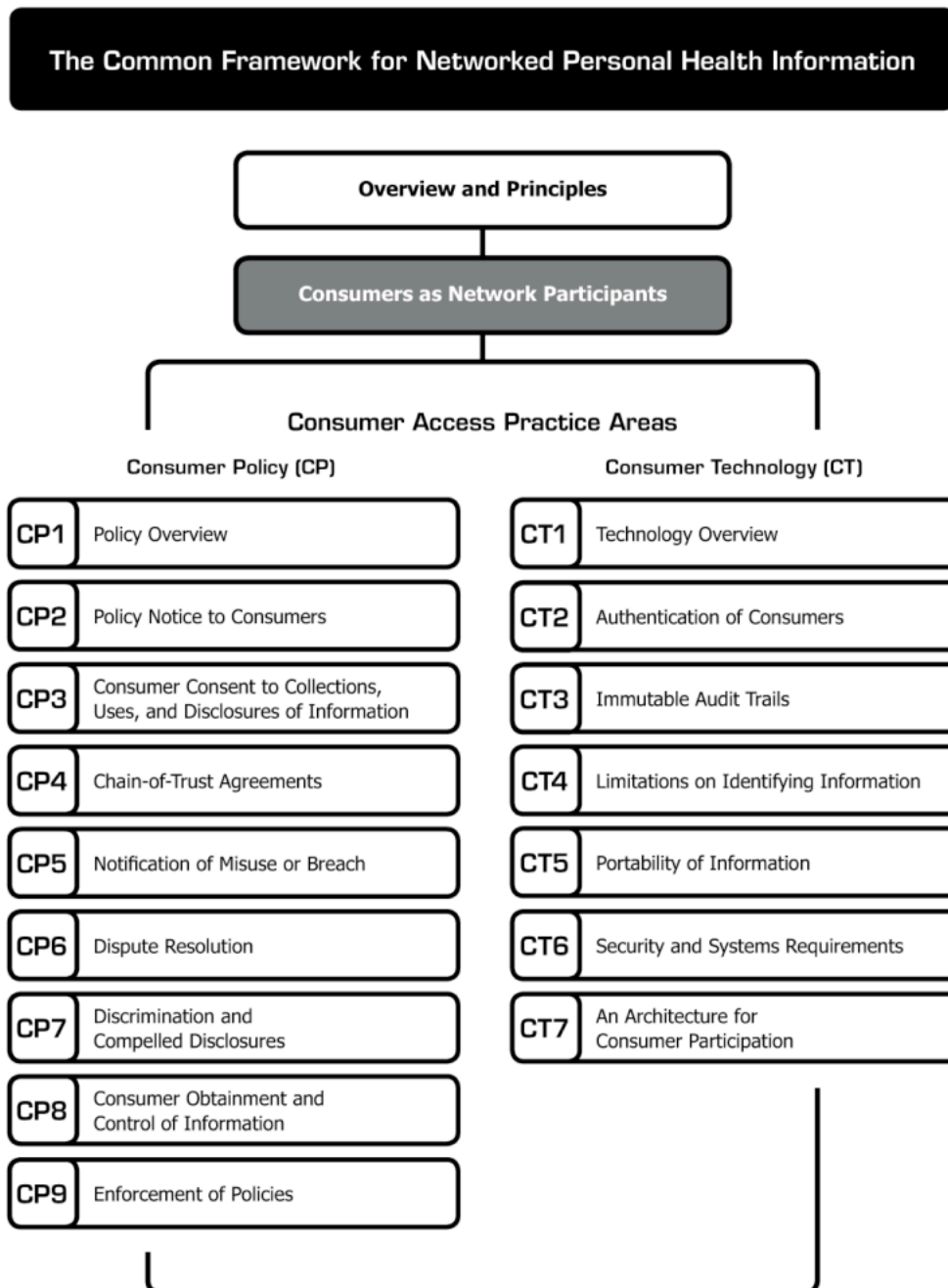CT1   CT2   CT3   CT4   CT5   CT6   CT7

Consumers as Network Participants

Consumers as Network Participants

The document you are reading is part of the **Connecting for Health** *Common Framework for Networked Personal Health Information*, which is available in full and in its most current version at http://www.connectingforhealth.org/.

This framework proposes a set of practices that, <u>when taken together</u>, encourage appropriate handling of personal health information as it flows to and from personal health records (PHRs) and similar applications or supporting services.

As of June 2008, the Common Framework included the following published components:

The Common Framework for Networked Personal Health Information

Overview and Principles

Consumers as Network Participants

Consumer Access Practice Areas

Consumer Policy (CP)	Consumer Technology (CT)
CP1 Policy Overview	**CT1** Technology Overview
CP2 Policy Notice to Consumers	**CT2** Authentication of Consumers
CP3 Consumer Consent to Collections, Uses, and Disclosures of Information	**CT3** Immutable Audit Trails
CP4 Chain-of-Trust Agreements	**CT4** Limitations on Identifying Information
CP5 Notification of Misuse or Breach	**CT5** Portability of Information
CP6 Dispute Resolution	**CT6** Security and Systems Requirements
CP7 Discrimination and Compelled Disclosures	**CT7** An Architecture for Consumer Participation
CP8 Consumer Obtainment and Control of Information	
CP9 Enforcement of Policies	

Consumers as Network Participants*

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 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]

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.[4]
3. **They are free or inexpensive for consumers to use.** Whether supported through advertisements or not-for-profit foundations, dramatic-growth applications generally collect small or no fees from consumers.
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.

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 has moved more slowly toward providing consumers with online access to health data and interactive services. Personal health information is different — often more complex, scattered, sensitive, less structured — than the other types of information cited above. However, electronic personal health records (PHRs) represent an emerging vehicle to increase consumer participation in the health sector.

Personal Health Records (PHRs)

PHRs encompass a wide variety of applications that enable people to collect, view, manage, or share copies of their health information or transactions electronically. Many PHR applications in existence today facilitate the viewing of health information. A new generation of PHRs promotes the development of multiple and diverse applications that act on personal health information to help users with specific tasks. 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.

Today's PHRs are generally "un-networked." They typically 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 2020[5] — must coordinate their care across several providers and entities. If the PHR is limited to one particular relationship, it may not meet the long-term needs of many whose information is dispersed

across organizations. 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. Network-enabled efficiencies and safety improvements 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 information under the custodianship of providers, payers, and other entities is largely "un-networked" — 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.

The Rationale for Networking Consumers

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.[6,7]
- Disappointing levels of safety and quality that lead to high rates of medical errors.[8,9,10]
- Frequent unavailability of vital information at point of care.[11]
- High costs that are growing at an unsustainable rate.[12,13]
- An overall lack of patient-centeredness.[14]

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.[15,16] 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.[17,18] 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.[19,20] 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. [21,22,23,24,25,26,27,28]
- Improve the patient-clinician relationship.[29,30,31,32,33]
- Increase patient safety.[34,35,36,37]
- Improve the quality of care.[38,39,40,41,42]
- Improve efficiency and convenience.[43,44,45,46,47,48]
- Improve privacy safeguards.[49,50]
- Save money.[51,52,53,54,55,56,57]

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 Statistics[58] and the American Health Information Community.[59]
- Professional societies, such as the American Medical Association[60] and the American Health Information Management Association.[61]

- Consumer groups, such as AARP and the American Diabetes Association.[62]
- Health insurance plan associations, like America's Health Insurance Plans and the Blue Cross Blue Shield Association.[63]
- Bipartisan political leaders.[64]

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.[65] There is evidence that Americans support a network for health information exchange — if security and confidentiality safeguards are sufficient.[66]

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.

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. 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 the ability to obtain personal health information about them, and security and confidentiality protections must be "baked in" to the network design.

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 not as likely to be transformative as new applications 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 Common Framework for Networked Personal Health Information recommends 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.

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*Note: State and Federal employees participate in the Personal Health Technology Council but make no endorsement

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