



Department of Health & Human Services
Office of the National Coordinator for
Health Information Technology

American Health Information Community

Connecting for Health

**Common Framework for Networked
Personal Health Information**

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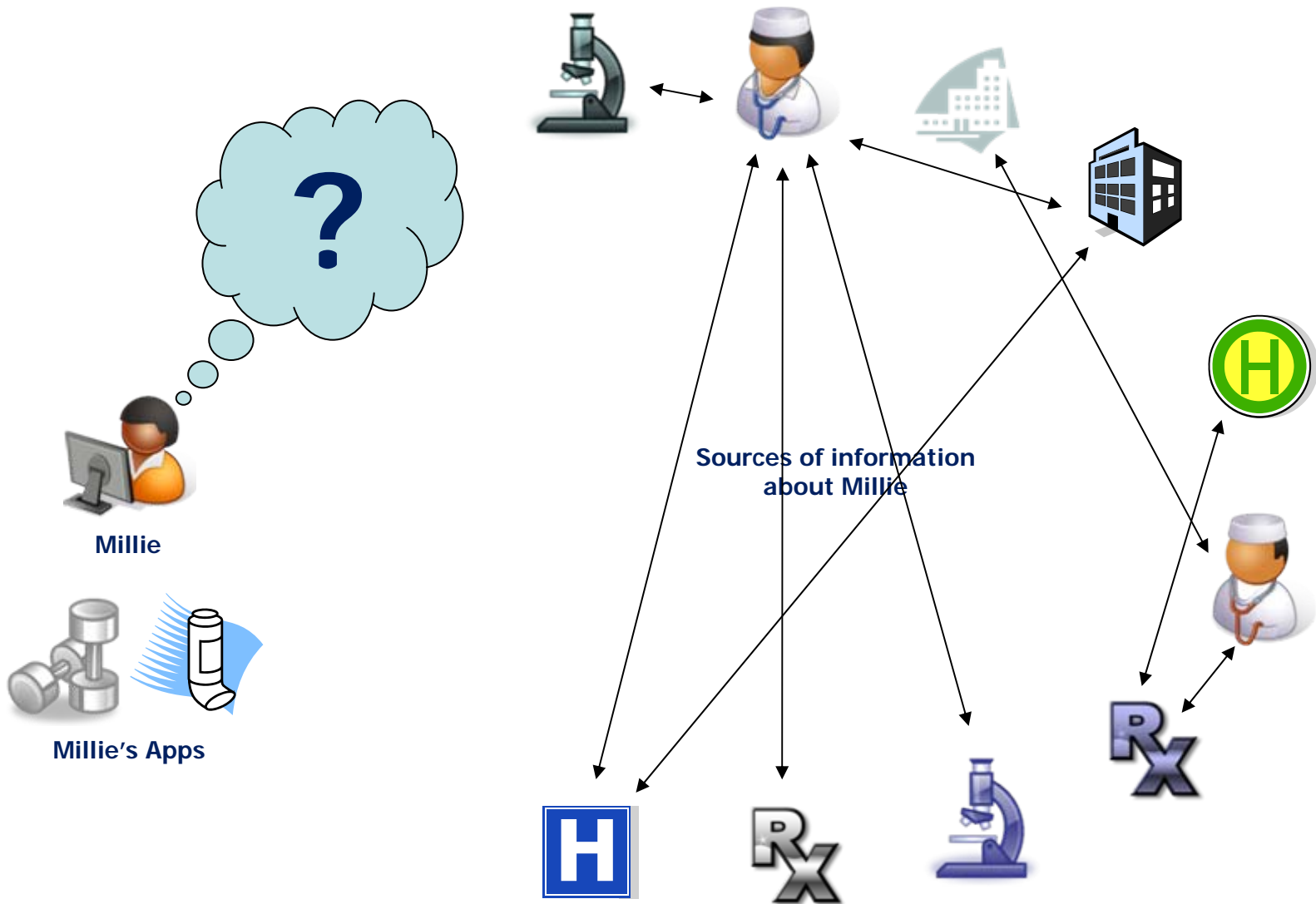
Markle Foundation

July 29, 2008

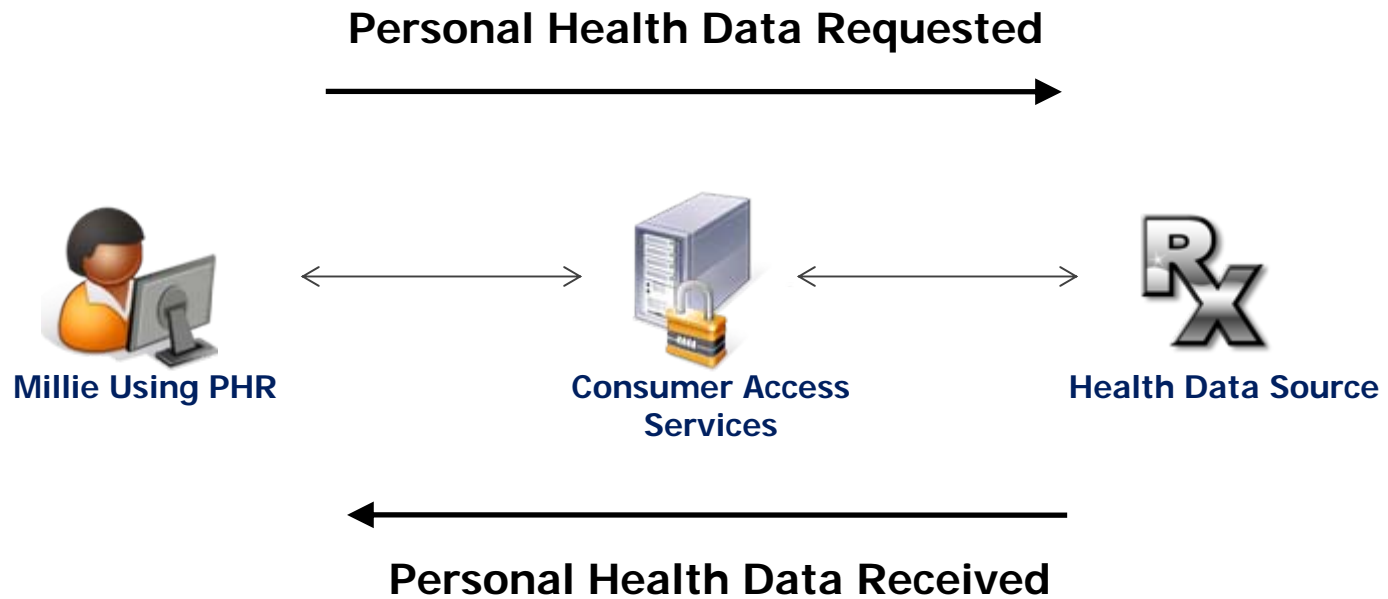
Connecting for Health Common Framework

- The landscape for new internet services that help consumers track and improve their health has shifted dramatically the past several years.
- The public appreciates the potential value of these services but at the same time expresses significant concern about the privacy of personal health information.

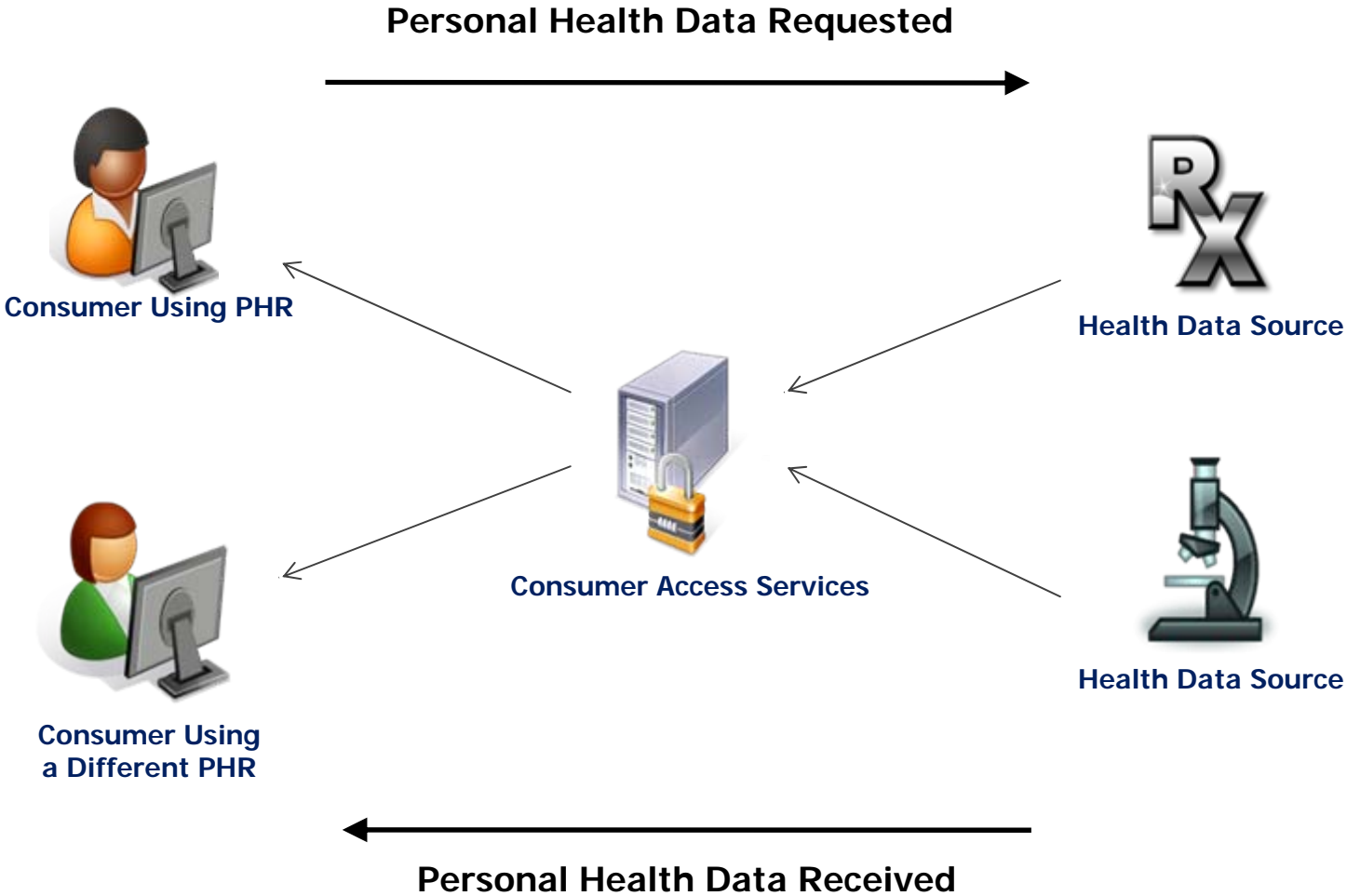
Business data streams of Millie's information

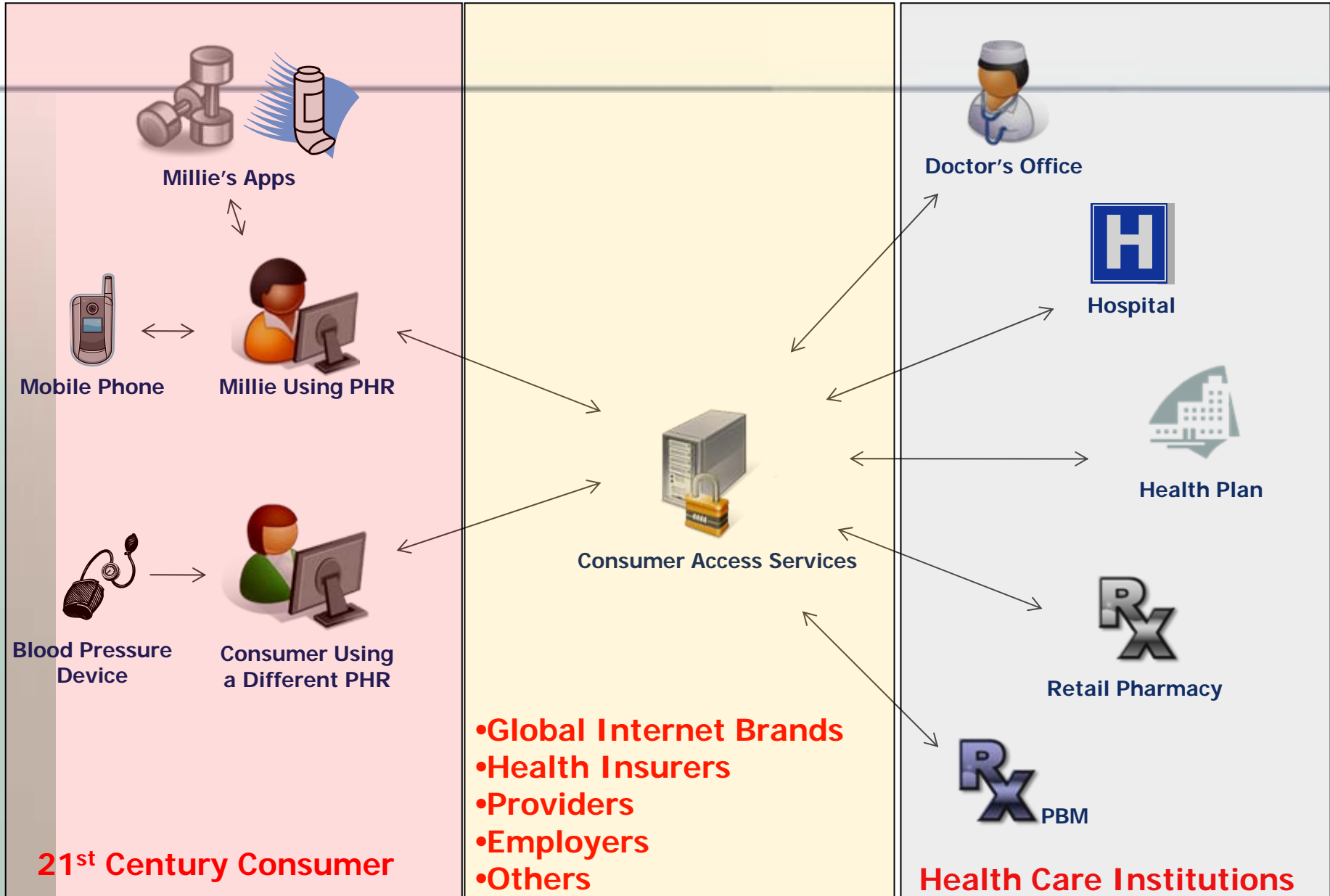


Consumer data streams of Millie's information



Consumer data streams of different consumers' information





- Global Internet Brands
- Health Insurers
- Providers
- Employers
- Others

The Internet enables these connections ...

... but what will be the rules to
facilitate trust on the network?

See: <http://www.connectingforhealth.org/flash/ccframework/>

Americans Overwhelmingly Believe Electronic Personal Health Records Could Improve Their Health

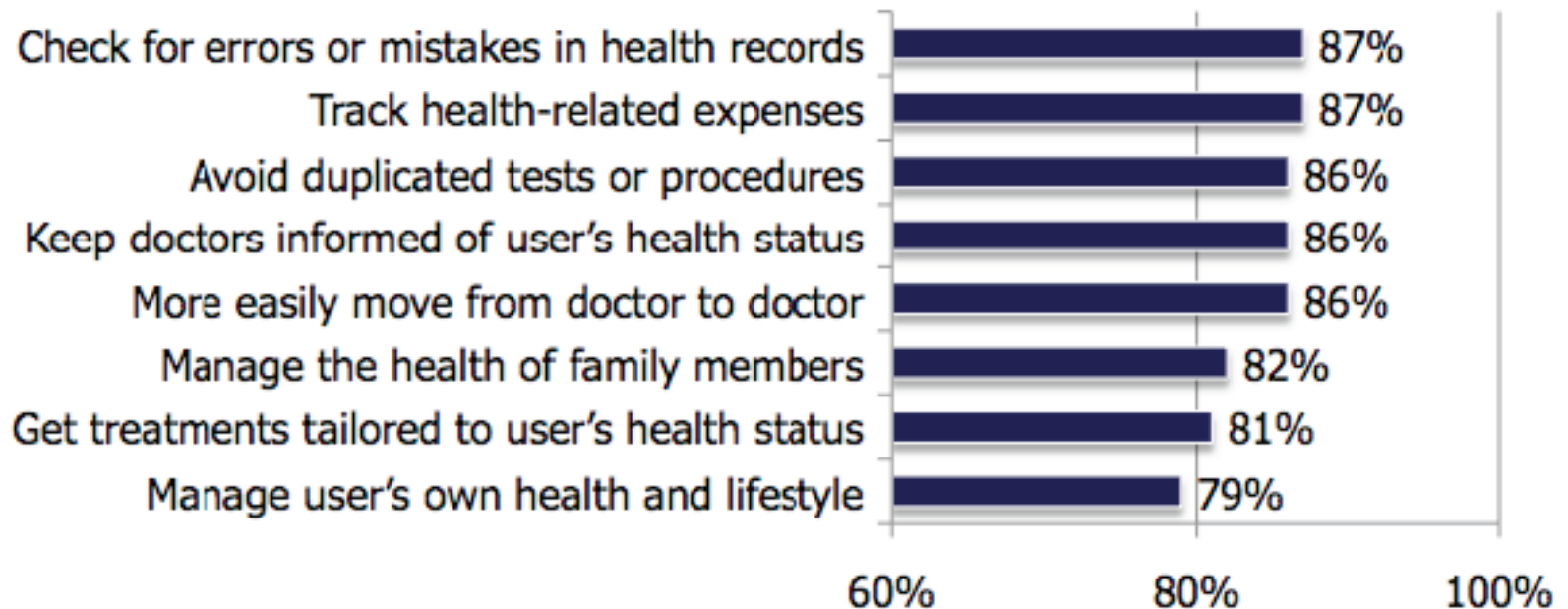
Nearly 9 in 10 Say Privacy Practices Are a Factor In Their Decision to Sign Up for One

- Markle commissioned Professor Alan F. Westin to develop a public opinion survey on the potential and privacy considerations of individually controlled electronic personal health records (PHRs).
- Conducted by Knowledge Networks among 1,580 Americans representative of total adult (18+) population, both on and not on the Net.
- Knowledge Networks places error rate at +/- 2.5%.

High Perception of Value

When the general public was asked how use of an online PHR service would affect individual handling of health and health care, large majorities said such services could improve several activities "a great deal" or "somewhat."

How many believe PHRs would improve their abilities to:



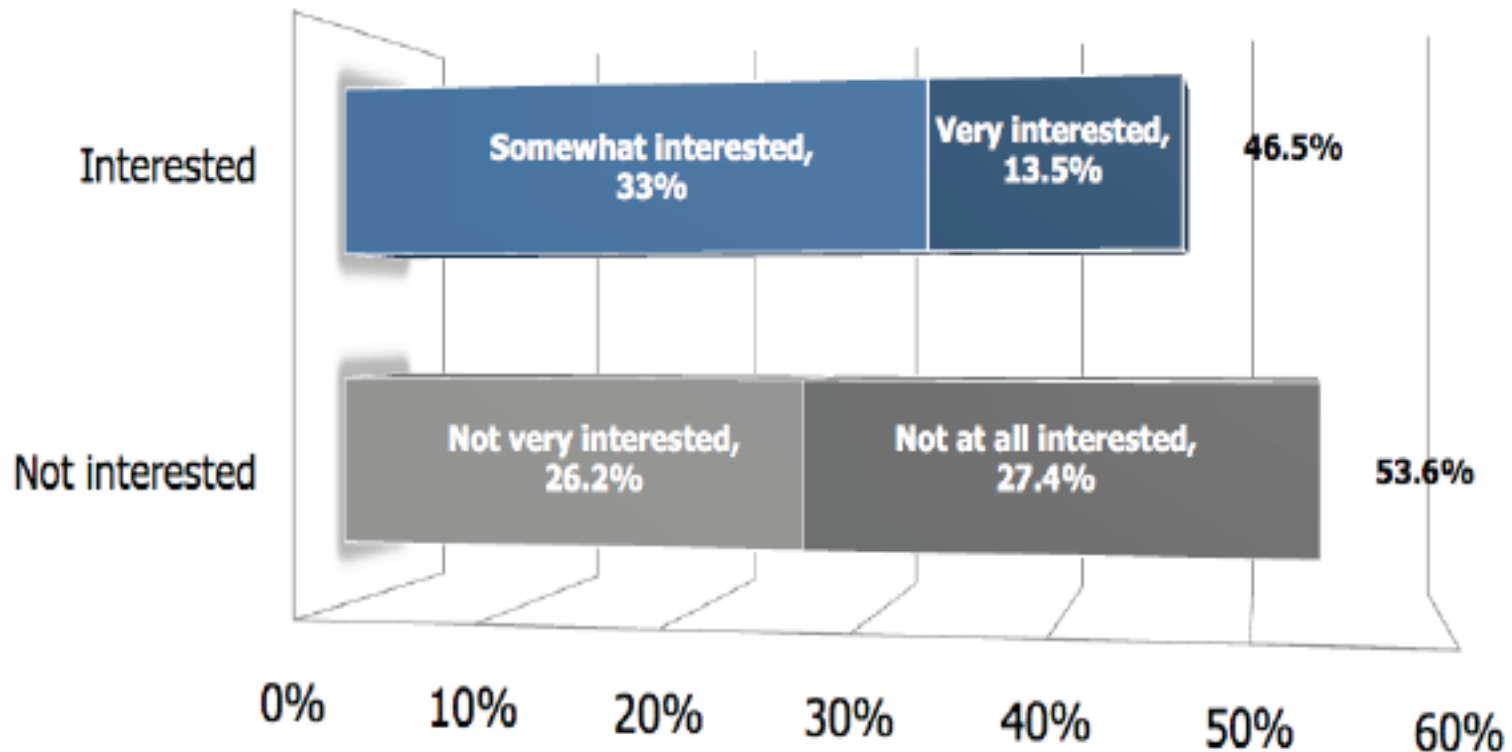
Interest in Joining Online PHR Service

“Some Internet technology companies and health care organizations are inviting individuals to join free online electronic personal health record services. You could obtain, store, and update your health information on a secure web site. You could control which health care providers can see or update your PHR, and you could automatically receive valuable information from the Internet related to the medical and health conditions and interests you indicated in your PHR.”

How interested would you be in joining such a service?

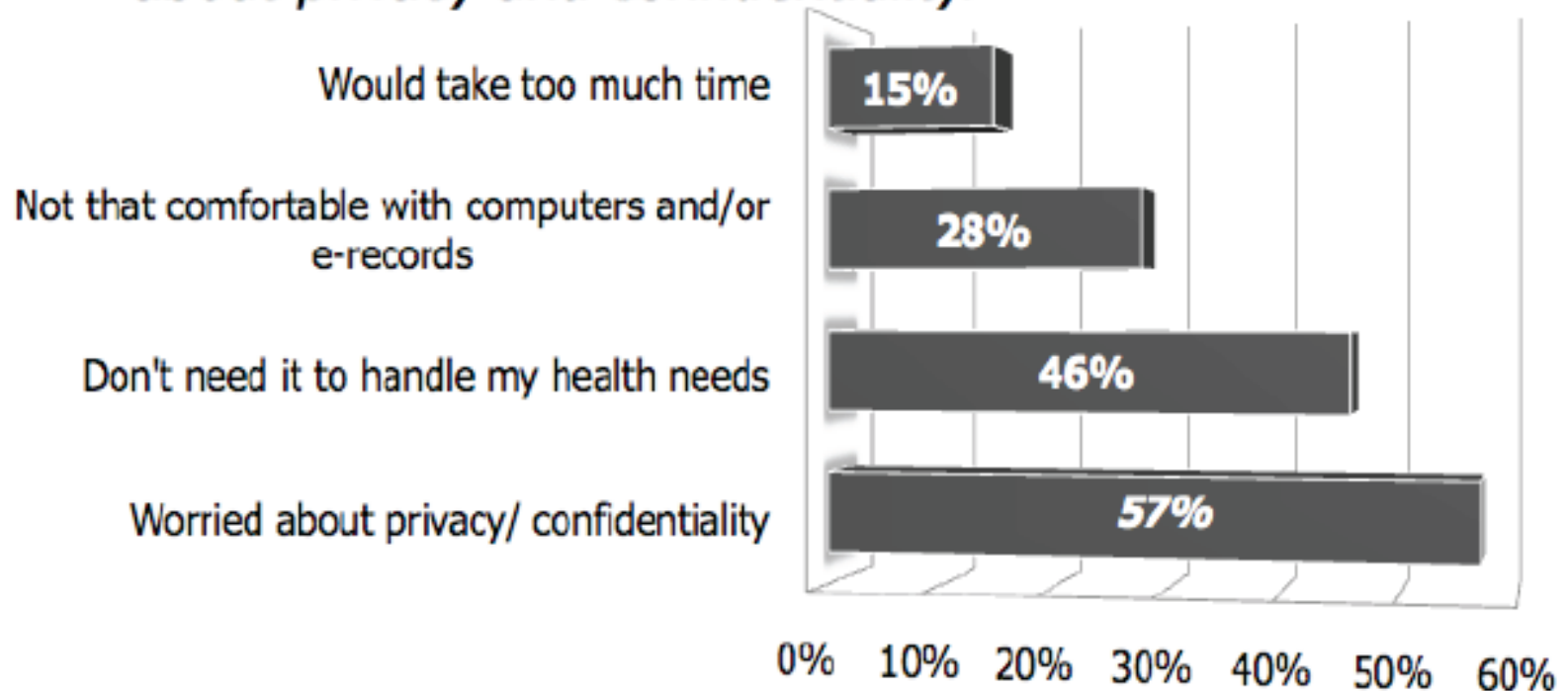
High Interest

Almost half the public say they are interested in joining a free online PHR system, with 13.5% saying they are "very interested."



Privacy Concerns

'Not interested' – Why not? More than half of these respondents not interested in PHRs cited "worries about privacy and confidentiality."



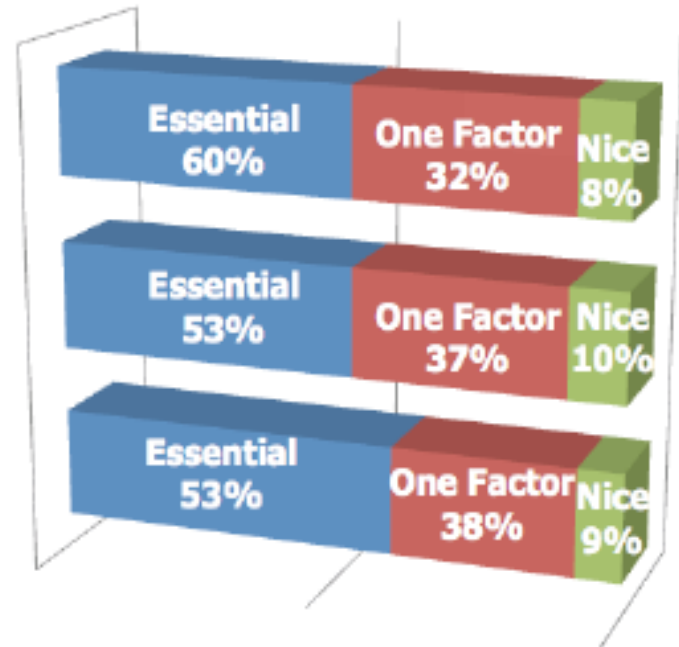
Practices Matter

When asked how important a set of privacy and information practices would be in their decision whether to sign up for an online PHR service, large majorities said each of these would either be "essential" or "a factor in making their decision."

Affected people would be notified if their information falls into unauthorized hands in a way that could compromise their identity or expose their health information.....

An individual would be able to review who has had access to their personal health information.....

Individuals would have a clear process to request corrections or dispute the way their information is handled.....



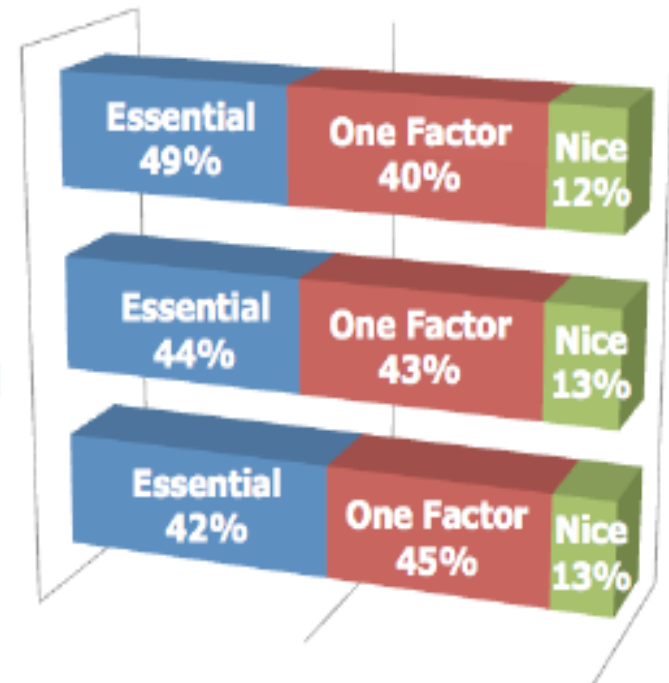
Practices Matter (continued)

When asked how important a set of privacy and information practices would be in their decision whether to sign up for an online PHR service, large majorities said each of these would either be "essential" or "a factor in making their decision."

Individuals would NOT be denied care or penalized financially based on whether they decided to provide certain medical information to an Internet-based service...

Having individuals control what information from their medical records is made available to others. For example, an individual with a sensitive medical condition could decide NOT to include information about treatment for that condition.....

Individuals could make informed choices about how their information is collected and used.....



Variety of Enforcement Tools

“How effective do you believe each of the following would be to ensure that PHR suppliers abide by privacy protections regarding personal health information?”

- Having an independent organization audit the PHR organization and provide a seal of approval to certify it is following good practices **80% believed it would be effective**
- The Federal Trade Commission or state attorneys general enforcing existing consumer protection laws, by finding any PHR that does not follow its own policies is engaging in false and misleading practices... **80% believed it would be effective**
- Market forces – consumers choosing the products and brands they trust and not using others that do not follow good privacy practice **76% believed it would be effective**
- Congress passing a new health privacy law to cover the special features of online PHR services..... **76% believed it would be effective**

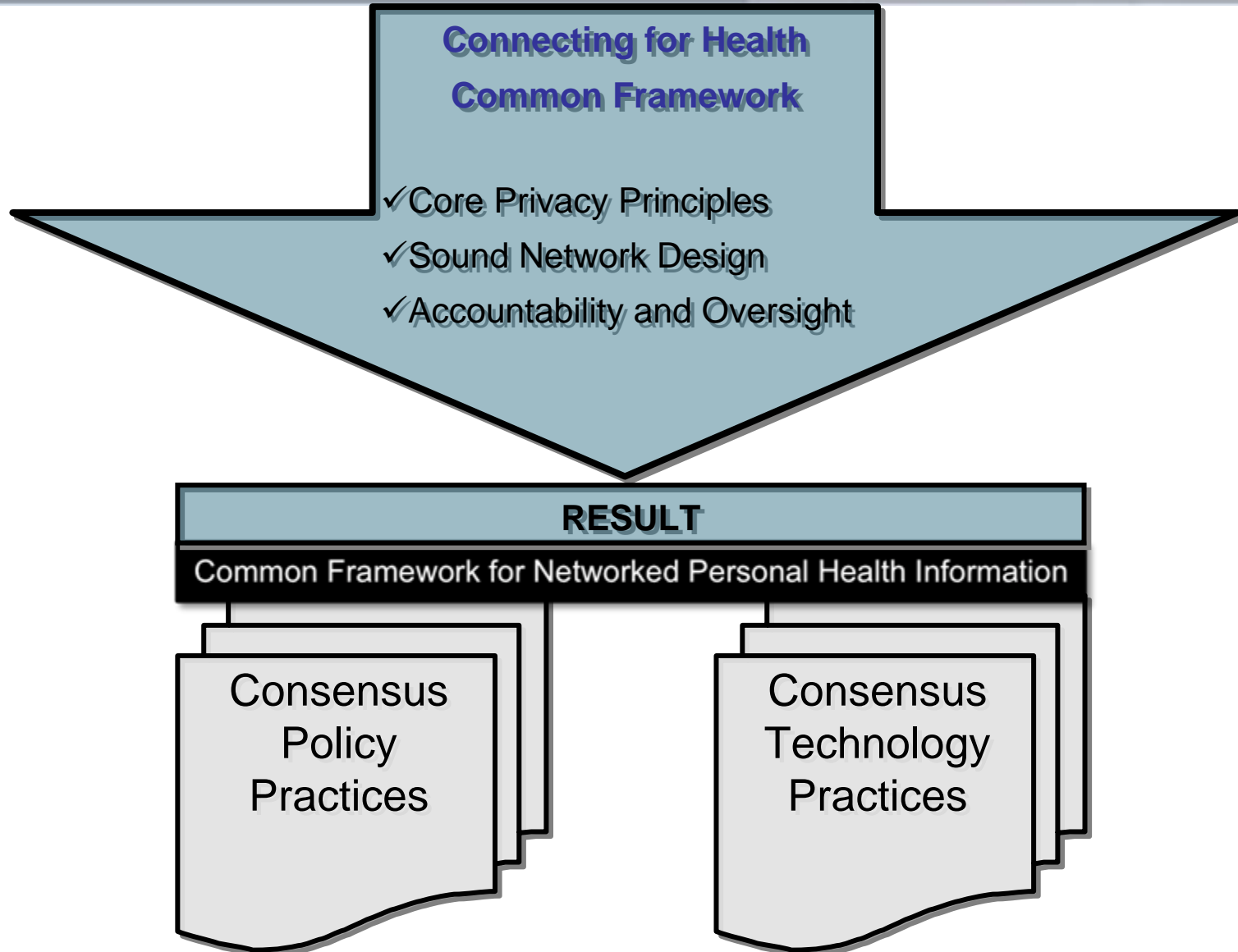
Markle Survey: Key Findings

- Four in 5 believe that online PHRs would be beneficial in managing their health and health care.
- Nearly half the public expresses some interest in using one.
- Among those not interested, concern for privacy is the most frequently cited reason why.
- Majorities of 87 percent to 92 percent say six key privacy practices are factors in their decision to use an online PHR.
- More than 90 percent said their express agreement should be required for each use of their online health information.
- More than 75 percent said each of four possible policy enforcement mechanisms would be effective.

Key Implications

- Among many possible keys to stimulate broader public adoption of online PHRs and related services, a majority of the public sees a comprehensive set of privacy practices to be essential.
- And, they support the effectiveness of a variety of possible mechanisms to enforce these practices.

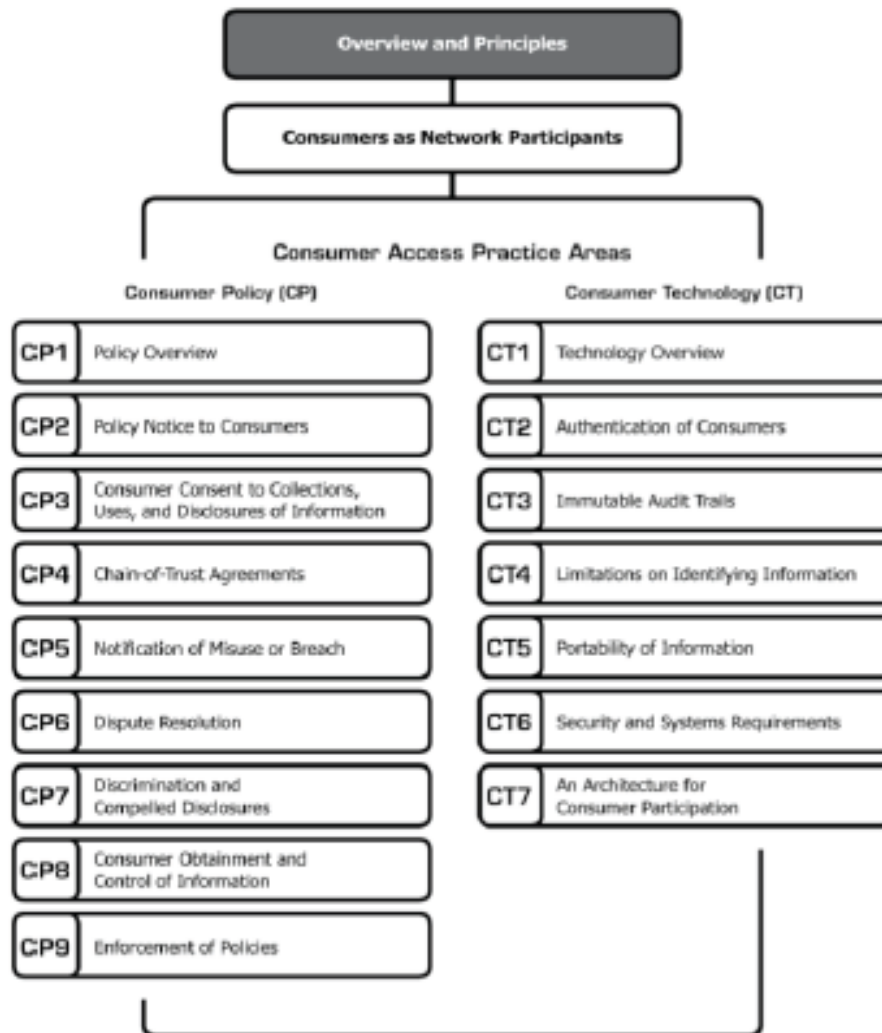
Our Approach



The purpose of the Connecting for Health Common Framework is embodied in “Millie”



The Common Framework for Networked Personal Health Information



Millie illustrates the needs of millions of U.S. adults who could benefit from greater connectivity in health and health care.

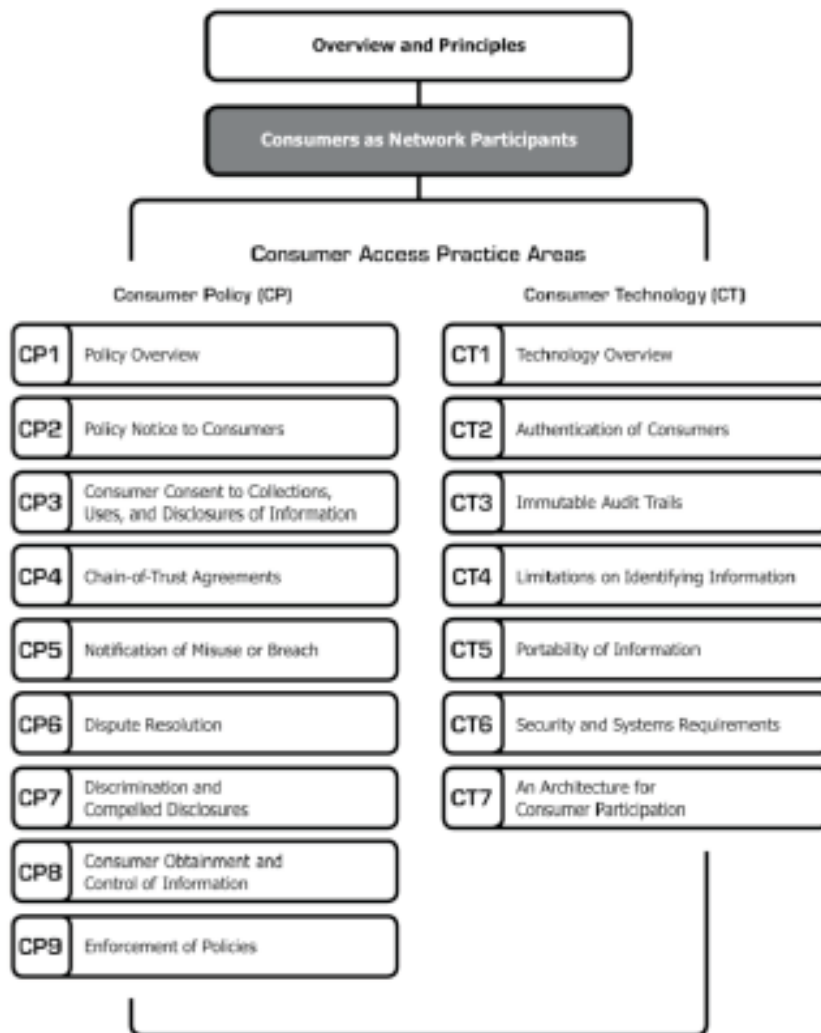
Consumers should be able to collect, store, manage, and share copies of health information.

The Common Framework is based on fair information practices and focuses on network rules, not application standards.



Consumers as Networked Participants

The Common Framework for Networked Personal Health Information



Millie could manage her health using a wide variety of networked tools and services

Consumers can help transform the health sector, as they have in other areas.

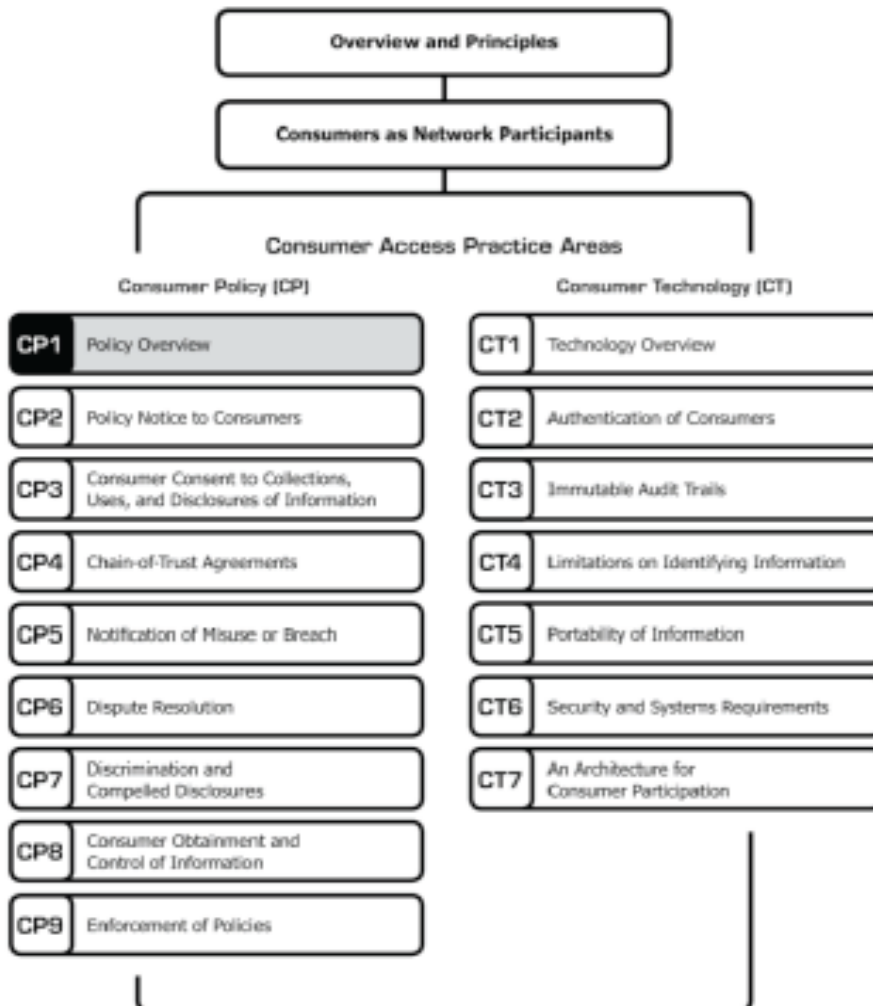
“Networked PHRs” are an important tool for consumer empowerment.

But to have an environment of trust, some basic rules should guide the emerging industry.



CP1: Policy Overview

The Common Framework for Networked Personal Health Information



Millie would know that there are rules for how her information will be collected, used, and shared.

New services present potential benefits and risks for consumers. Many are not covered by HIPAA.

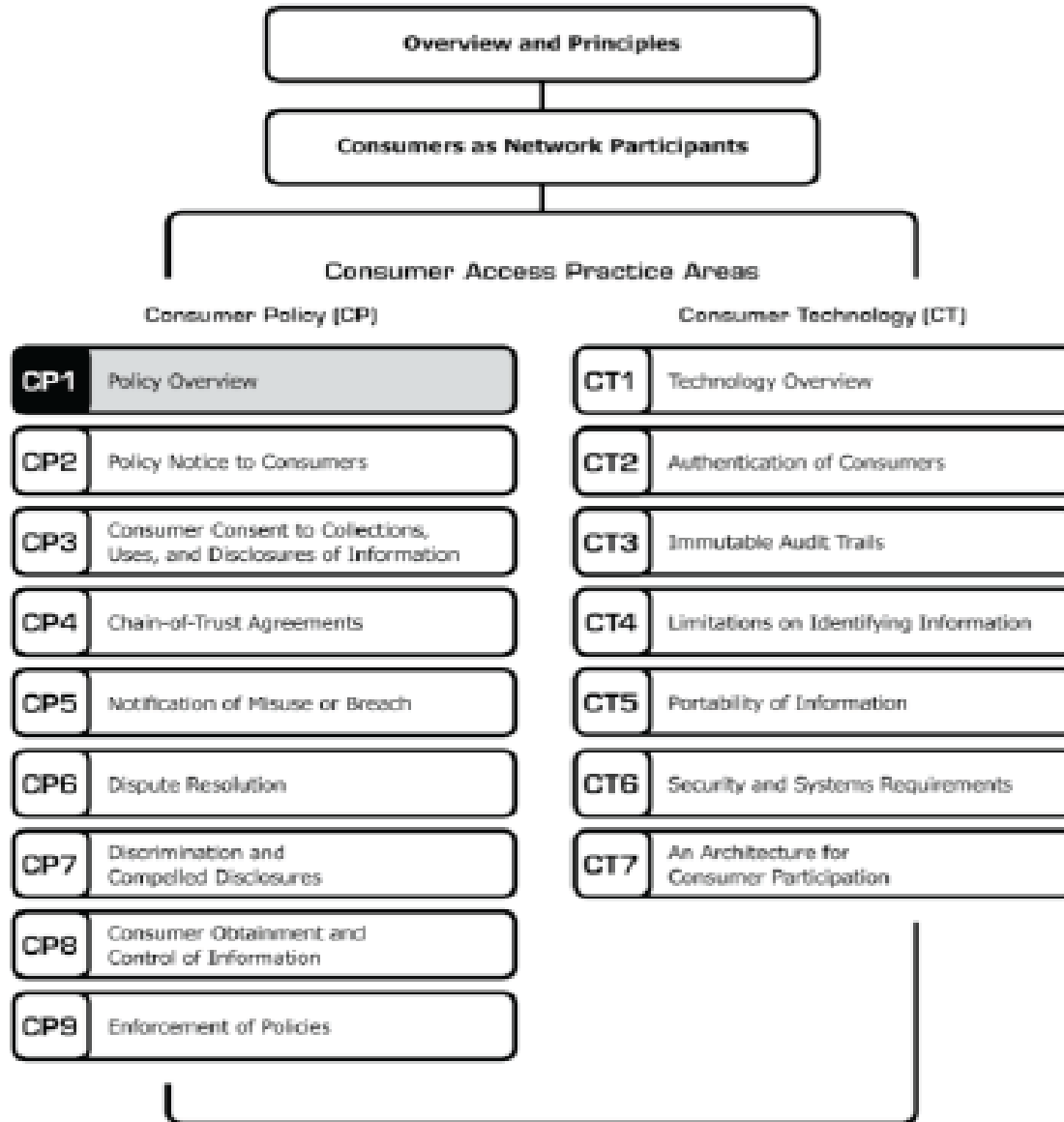
This emerging, innovative new space is evolving without a common set of information practices and expectations.



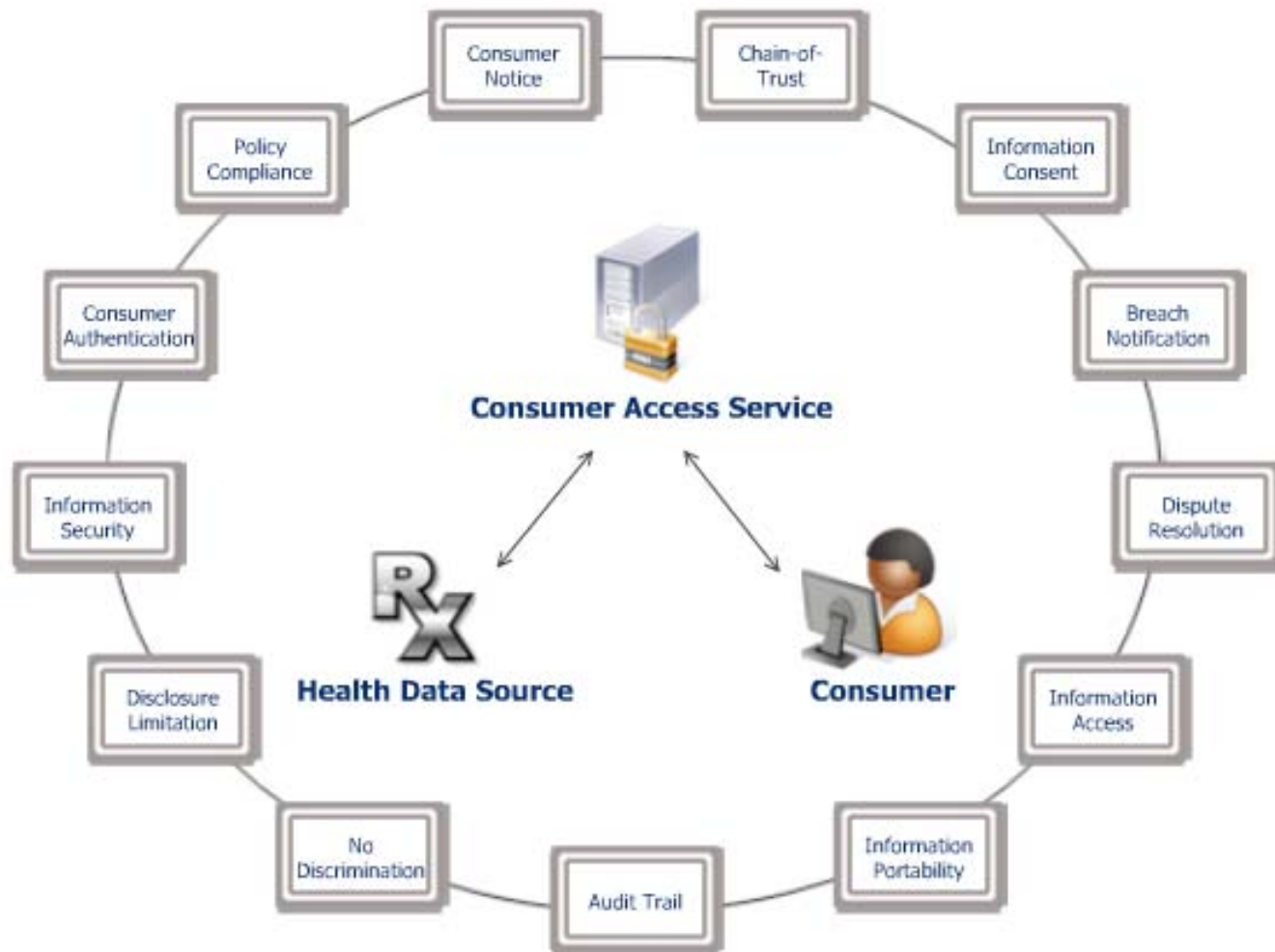
CP1: Policy Overview

- This Connecting for Health Common Framework for Networked Personal Health Information is a positive step that industry can take now toward increasing trust.
- All PHRs and supporting services, whether they are covered by HIPAA or not, should address each element of the Common Framework.

The Common Framework for Networked Personal Health Information



When taken together, the practices enhance participation and protect personal health information



Endorsers of the First Detailed, Consensus-Based Framework for Networking Personal Health Records

AARP	Cisco Systems Inc.	National Partnership for Women and Families
Aetna	Consumers Union	NewYork-Presbyterian Hospital
American Academy of Family Physicians	Dossia	Pacific Business Group on Health
Association of Online Cancer Resources (ACOR.org)	FollowMe	Palo Alto Medical Foundation
America's Health Insurance Plans	Geisinger Health System	Partners Healthcare System
BlueCross BlueShield Association	Health Care For All	RxHub
CapMed	InterComponentWare Inc.	SureScripts
Center for Democracy and Technology	Intuit Inc.	U.S. Department of Veterans Affairs
Center on Medical Record Rights and Privacy	MedicAlert	Vanderbilt Center for Better Health
	Microsoft Corp.	WebMD
	National Breast Cancer Coalition	

Key Points

- Consensus practices among health sectors and technology innovators can help internet health information products flourish.
- A stable set of principles and practices will foster innovation and improve consumer choice for these emerging services.
- This collaboration lays out specific practices that all PHRs and related services can use, whether they are covered by federal privacy rules or not, so they can enhance public trust.
- See <http://www.connectingforhealth.org/phti/>