



## CONNECTING FOR HEALTH COMMON FRAMEWORK

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Resources for Implementing Private and  
Secure Health Information Exchange

**CYBER TRUST and INNOVATION in HEALTH CARE:  
Where Code, HIPAA and Fear meet ...**

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# Establishing TRUST and INNOVATION in HEALTHCARE

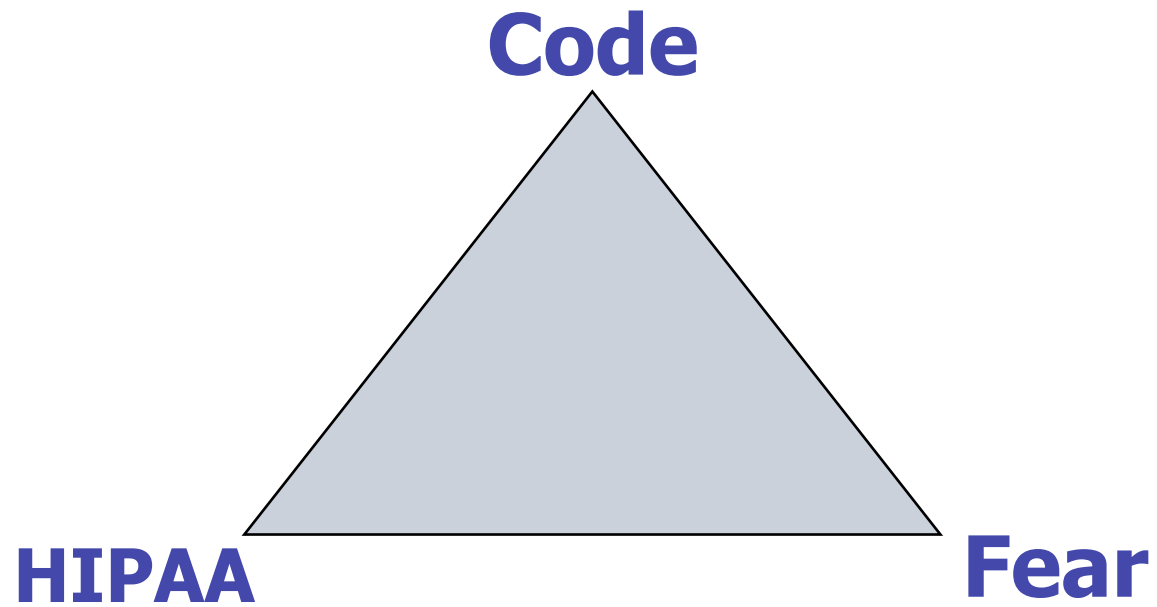
Code, HIPAA and Fear

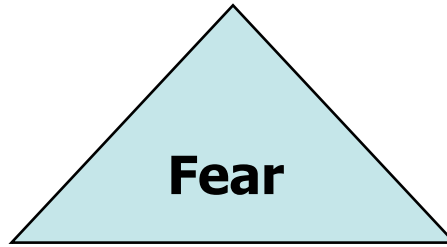


*Need for Paradigm Shift*

21<sup>st</sup> Century Attributes of Trust

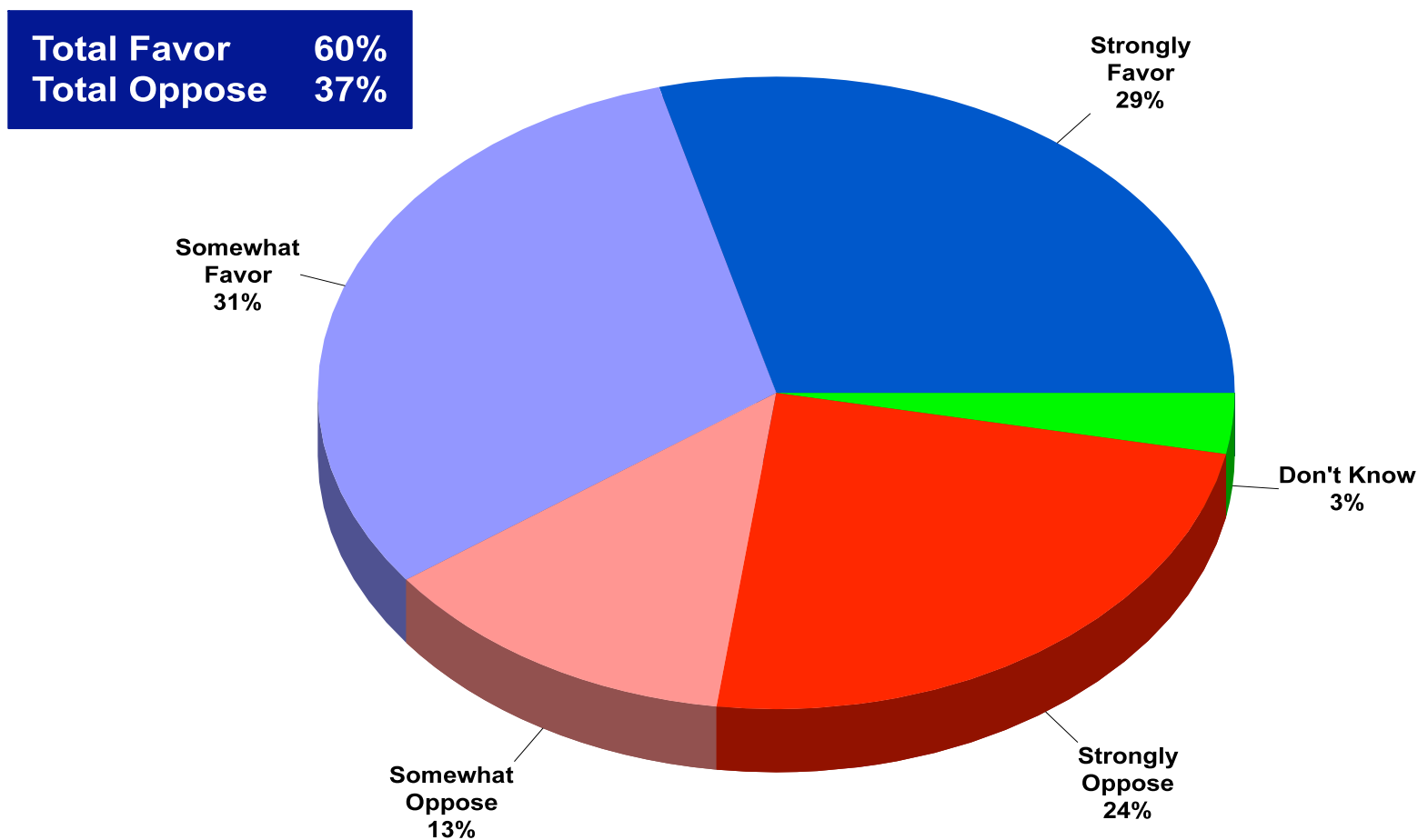
# The Current Paradigm





What do we know from public opinion surveys and focus groups?

**Overall six out of ten Americans say they would favor the creation of a secure online “personal health record” service for their own use.**



*Now, overall, would you favor or oppose the creation of this type of secure online "personal health record" service?*

**There is also a strong interest among consumers in using health information technology to more fully participate in their own health care.**

Statement	% Yes
Check for mistakes in your medical record.	<b>69%</b>
Check and fill prescriptions.	<b>68%</b>
Get results over the Internet.	<b>58%</b>
Conduct secure and private email communication with your doctor or doctors.	<b>57%</b>

Now let's imagine that a new secure online service was made available to you allowing you to locate your medical records and view them through your own secure online "personal health record" account. Now I am going to read you some things this secure online "personal health record" service would allow you to do after I read each item, please tell me, yes or no, whether or not you would use this secure online "personal health record" service for each activity.

*But...*

*California Health Care Foundation (2005)*

- **67% of Americans are concerned about the privacy** of their personal medical records--recent privacy breaches have raised their level of concern
- **1 in 8 Americans have put their health at risk** by engaging in privacy-protective behavior:
  - *Avoiding their regular doctor*
  - *Asking a doctor to alter a diagnosis*
  - *Paying privately for a test*
  - *Avoiding tests altogether*

*Harris/Westin poll on EHRs and Privacy (2006)*

- **42% of Americans feel that “privacy risks outweigh expected benefits” from health IT.**

## Keeping electronic medical information private and secure remains chief among consumer concerns.

Statement	% Absolute Top Priority
The identity of anyone using the system would be carefully confirmed to prevent any unauthorized access or any cases of mistaken identity.	91%
An individual would be able to review who has had access to their personal health information.	81%
Only with an individual's permission could their medical information be shared through this network.	79%
Employers would NOT have access to the secure health information exchange networks.	68%

*I am going to read you different attributes that could be part of this exchange or network and I would like you to rate the importance of each. As you respond, please keep in mind that not every attribute can be a top priority.*



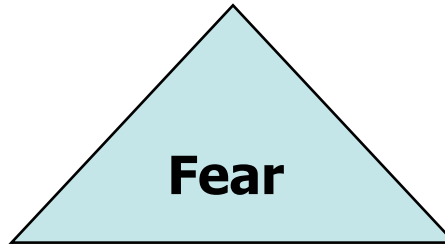
# Americans recognize the “upside”... and the “downside”...

- Fear of misuses
  - 52% believe employer uses medical info to affect personnel or insurance benefits (CHCF Survey 2005)
  - 85% believe if genetic test results known to insurers, would refuse policies or charge more (Genetics and Public Policy Center Survey 2007)
- Three-quarters of Americans are willing to share their personal information to help public officials look for disease outbreaks and research ways to improve the quality of health care if they have safeguards to protect their identity (Markle Survey 2006).

# Markle Survey

## November 2006

- *3/4 want the government to set rules to protect the privacy and confidentiality of electronic health information*
- *2/3 want the government to set rules controlling the secondary uses of information*



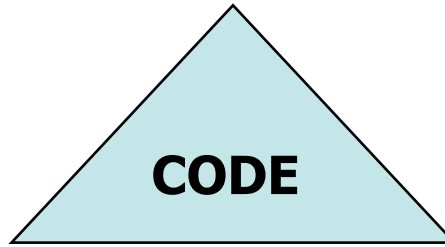
# Organizational Impact

What do we know about variation  
in compliance?

# **HISPC: Sources of Variations in Business Practices**

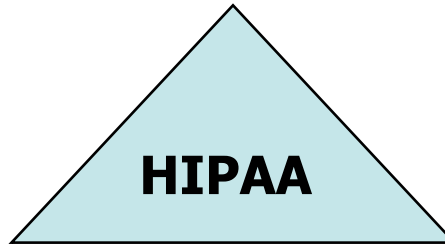
1. Variation related to misunderstandings and differing applications of HIPAA
2. Variation related to state privacy laws, scattered and often conflicting and antiquated
3. Lack of trust in applied information security
4. Cultural and business issues, concern about liability for incidental or inappropriate disclosures and general resistance to change

***Variations due to uncertainty and doubt***



- Federal efforts have been dominated by standards and certification
- Technical design choices have profound policy effects (Code is Law, Architecture is Policy)
- Privacy debates and policy making have been reactive instead of pro-active (guiding technical design)
- Lack of policy guidance has the potential to undermine trust

Paradigm Shift: *Technology and policy need to be developed together*



HIPAA (Health Insurance Portability and Accountability Act 1996) –

## **Solving 20<sup>th</sup> Century Challenges...**

- Disclosure, consent
- “Covered entity” paradigm
- De-identification (18 identifiers)



## HIPAA

### Challenge

- Disclosure vs. Collection and Use of Personal Health Information
- Consent paradigms do not alone provide for protection of the consumer, rather it can burden them unfairly (consent to what? and what are the protections when consented?)
- What is “personally identifiable” is blurring, making re-identification easier
- Covered entity paradigm no longer works
- Lack of robust enforcement

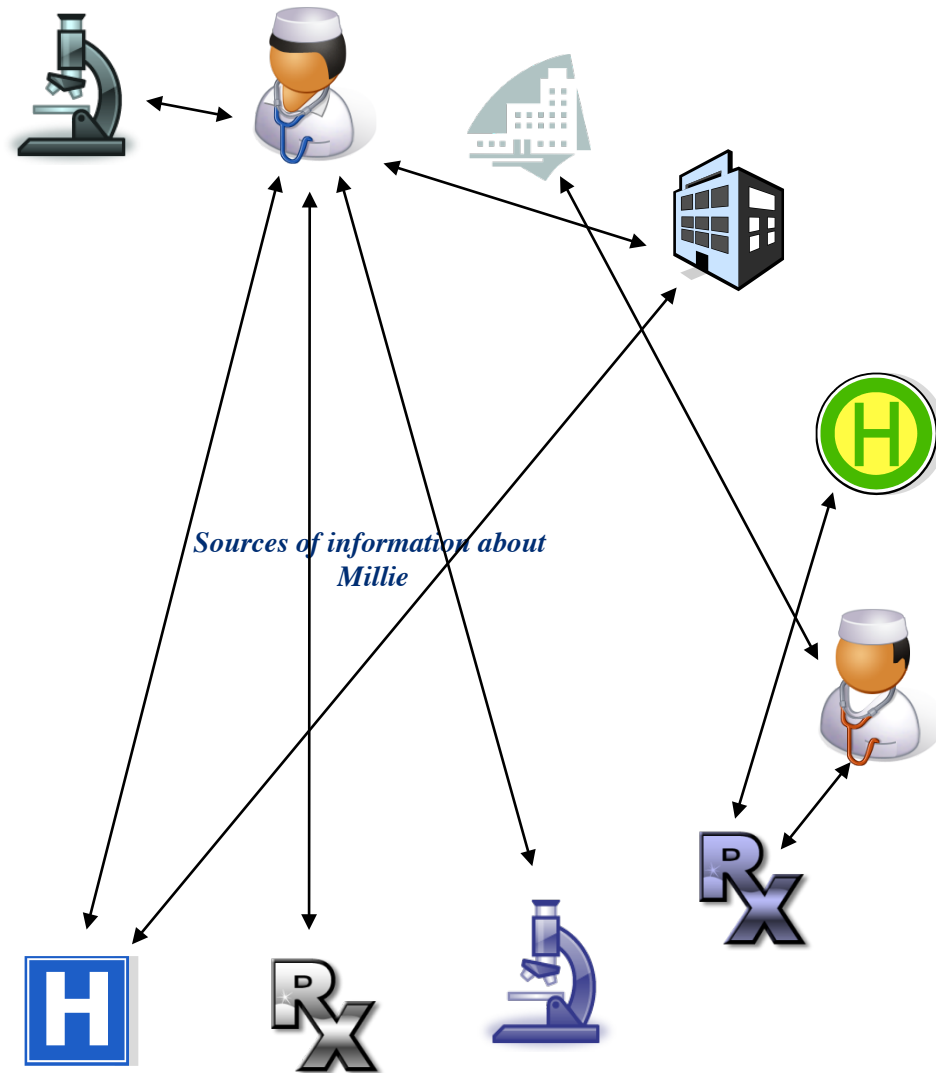
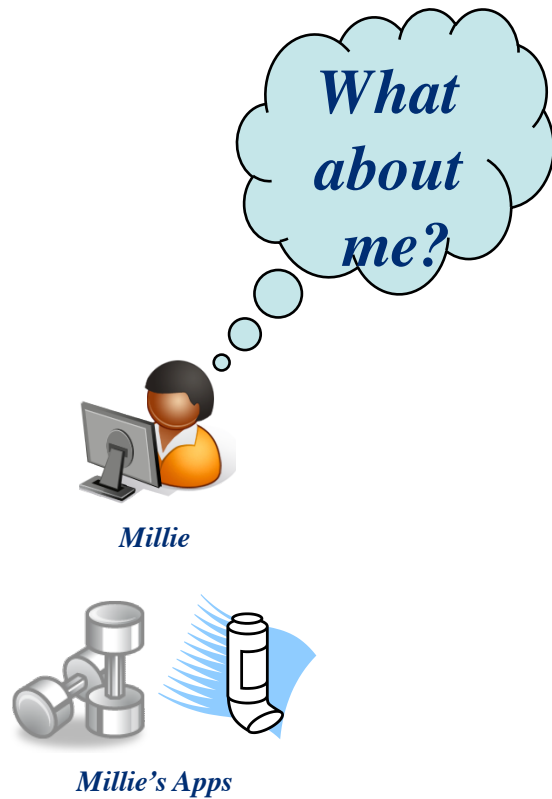
Paradigm Shift: *Need a 21<sup>st</sup> Century approach*

# **How has the privacy landscape been changed by the Web?**

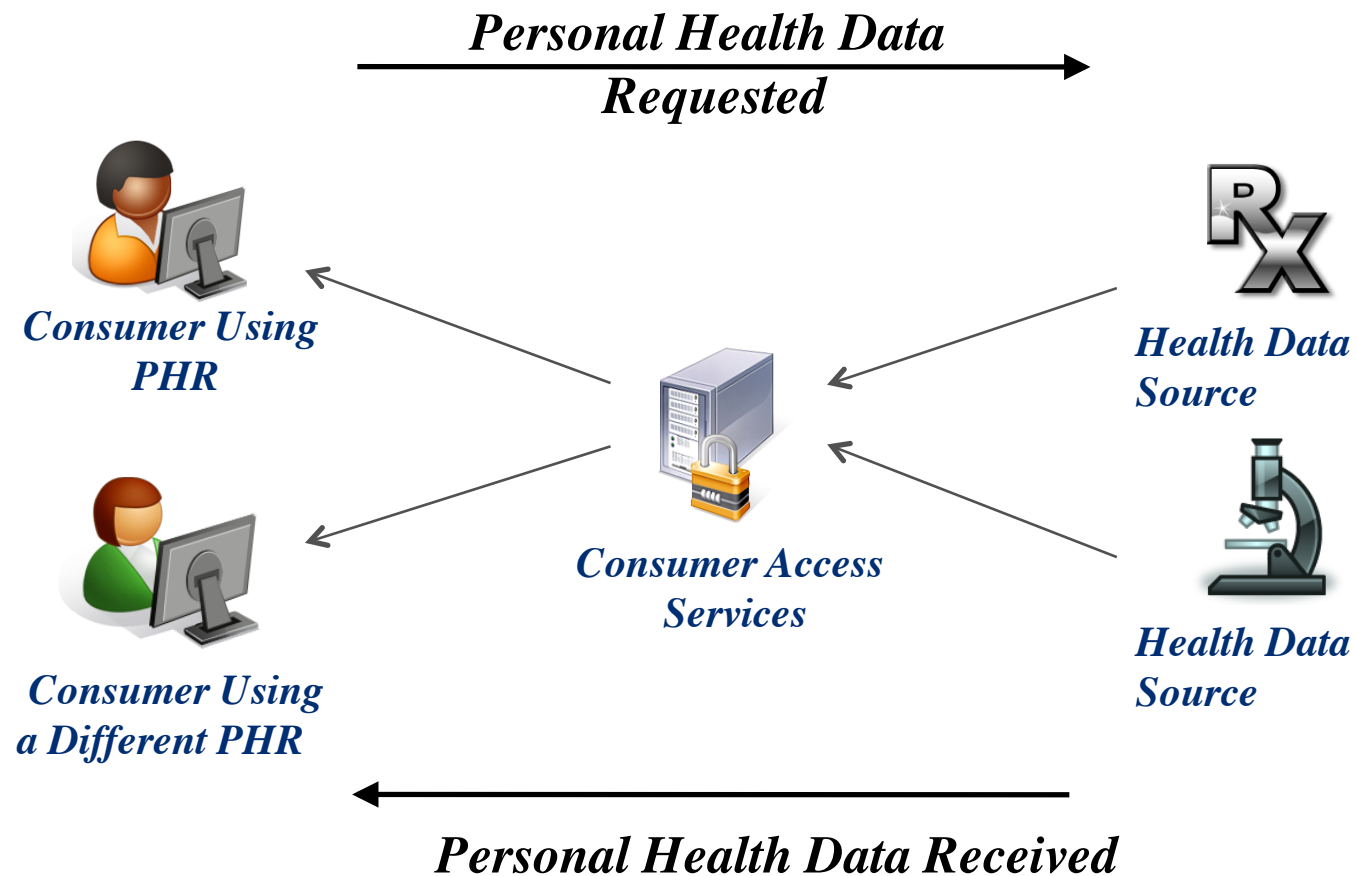
Health 2.0

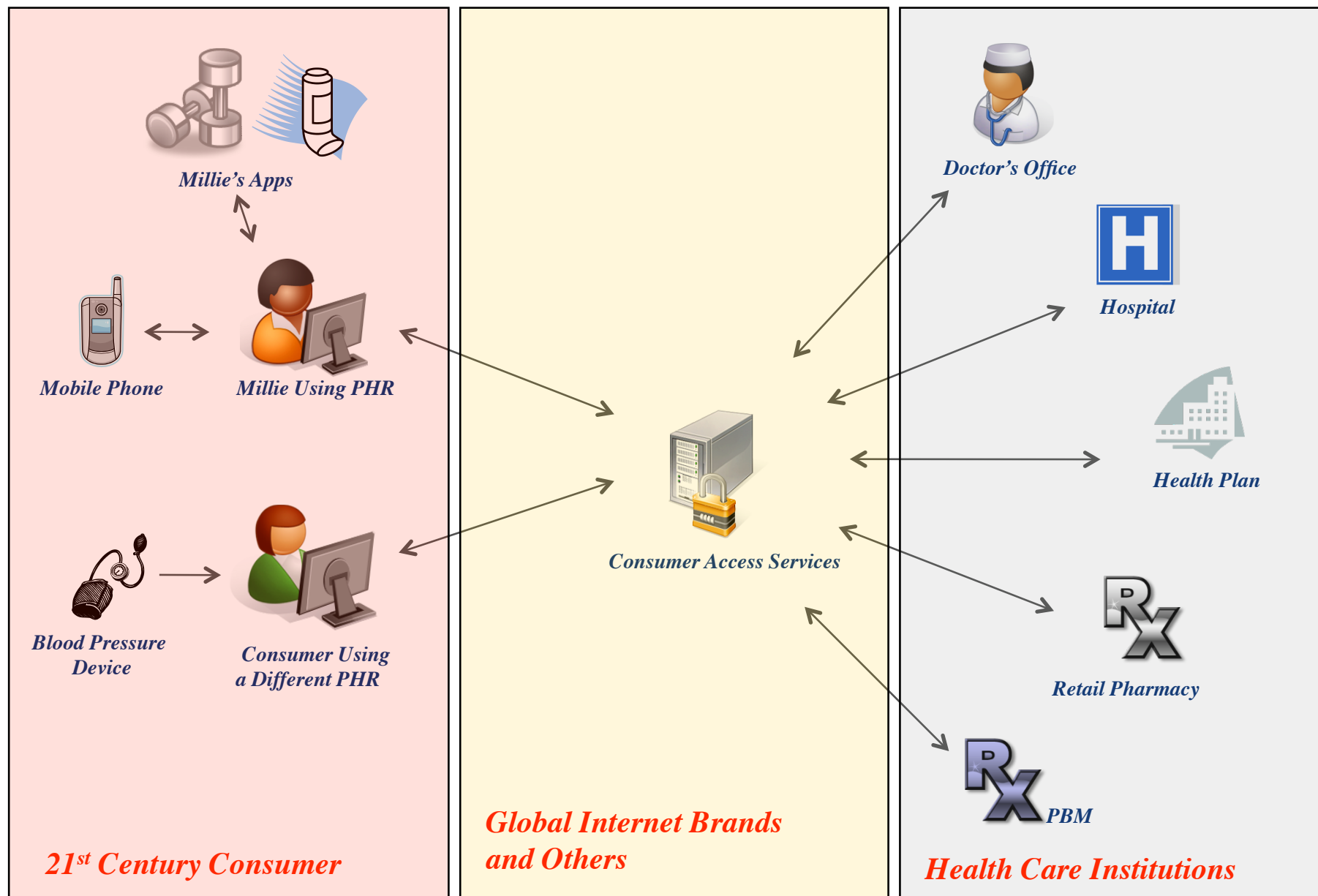


*Business data streams  
of Millie's information*



## *Consumer data streams*





CONNECTING FOR HEALTH COMMON FRAMEWORK

# “Colliding Worlds”

- Innovation has challenged existing business models
- Traditional players are used to old business practices
- New players have not yet identified new business models for sustainability
- There is no policy framework that unites these worlds
- To prosper, all players must identify and align strategy with policy to ensure trust

Paradigm Shift: *Sectors need to work together to make innovation in health care sustainable and trustworthy*

# Changing the Current Paradigm

Focus on a 21<sup>st</sup> Century Trust paradigm that ...

- Integrates policy AND technology
- Goes beyond piecemeal approaches (focus on collection, use and information handling)
- Provides a strategic frame that limits risk

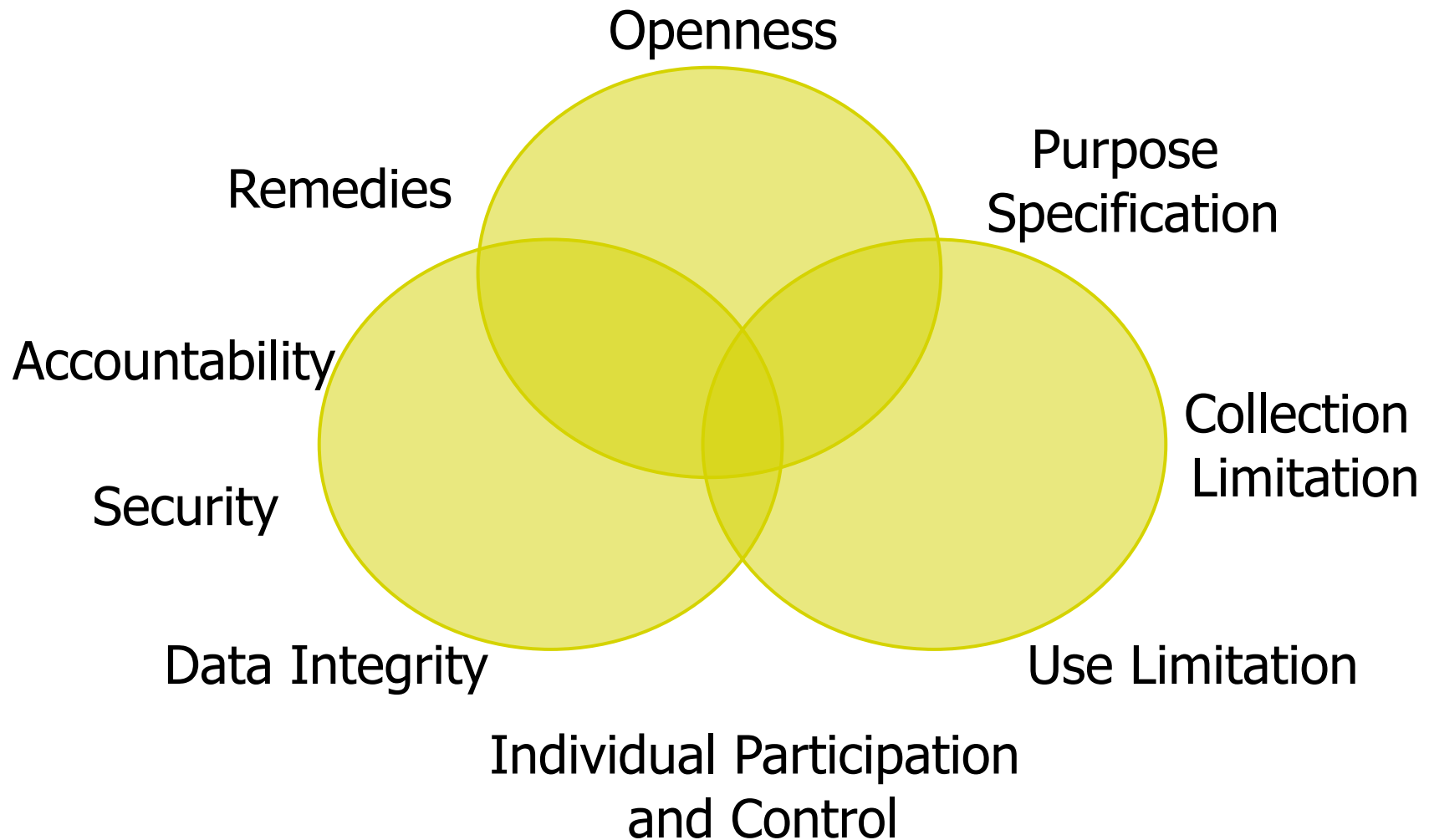
Through a common framework of attributes in which policies can be focused on preventing misuse, empowering individuals and enabling a virtuous cycle of information to shape policy and innovation

# 21<sup>st</sup> Century Trust Attributes

*A 21st Century health information environment that fosters trust must:*

1. Protect individual privacy through a set of policies that implement the core principles of fair information practice
2. Incorporate technical tools that facilitate trusted use: audit, access, authorization, authentication and accuracy
3. Promote technological choices that limit the potential for abuse (such as considering distributed architectures and separating demographic from clinical information)
4. Focus on interoperability as to allow for flexible, yet sustainable, platforms of innovation and diversity of applications

# P1: The Privacy Principles are Interdependent!

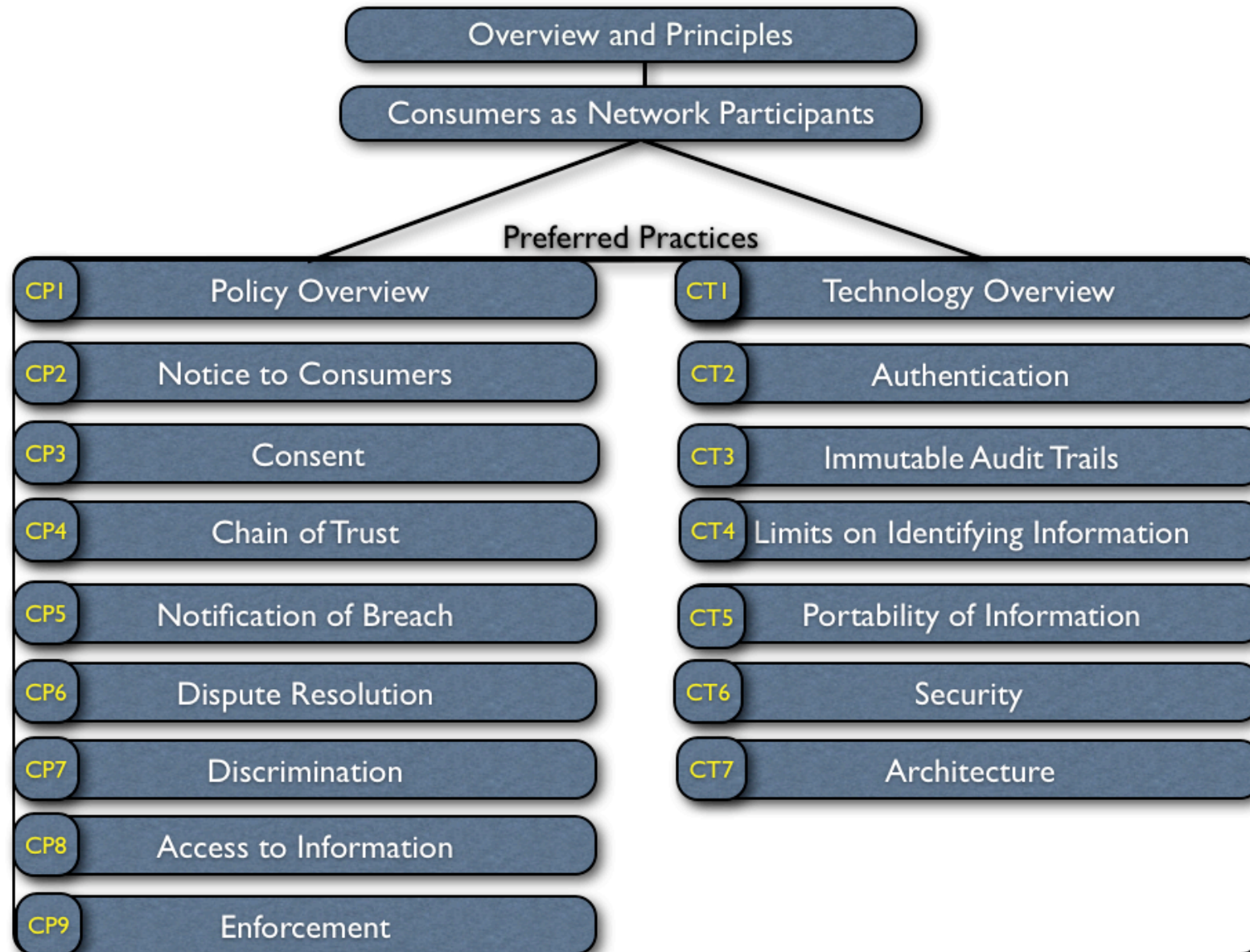


# 21<sup>st</sup> Century Technical Principles

1. Make it “Thin”
2. Avoid “Rip and Replace”
3. Separate Applications from the Network
4. Decentralization
5. Federation
6. Flexibility
7. Privacy and Security
8. Accuracy



# Common Framework for Networked Personal Health Information



# The Economist, April 2005

*"As the Markle Foundation puts it.....This goes to the very heart of the matter. For even though it is fine to start hoping for the day when interoperable electronic health records create vast pools of medical information that could be used to find new cures and battle epidemics in real time, their ultimate purpose is to make one simple and shockingly overdue change: to enable individuals, at last, to have access to, and possession of, information about their own health."*

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