



**Common Framework for Networked Personal Health Information:
Consumer Policy (CP) Briefs, June 2008**

How "Millie" — a 21st Century consumer — would benefit under a Common Framework to help her obtain and control electronic copies of her personal health information and connect to health information services.

Overview and Principles

The purpose of the **Connecting for Health** Common Framework is embodied in "Millie." Her character illustrates the needs of millions of U.S. adults who could benefit from greater connectivity in health and health care.

CP1 Policy Overview

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

CP2 Policy Notice to Consumers

Millie would have easy access to clearly stated rules for how her information will be handled. The roles of all actors handling her information — including her own roles — would be spelled out clearly.

CP3 Consumer Consent

Millie would understand and exercise meaningful choices about her information. She would be asked specifically about uses and disclosures of her personal health information.

CP4 Chain-of-Trust Agreements

The organizations that touch Millie's health information would be contractually bound to handle the information according to specified policies. For example, the policies would disallow business partners from assembling unauthorized profiles about Millie.

CP5 Notification of Misuse or Breach

If Millie's information or identity becomes compromised because of a mistake, data leak, or fraud, Millie would be notified about it in a timely way. She would be told what she can do, and what others will do, to limit any harm.

Consumers as Network Participants

Millie could manage her health the way she can manage her finances or travel. For example, she could choose applications to download and upload critical health information, track her vital numbers, order prescription refills, get lab results, and connect to professionals and communities of patients — all in an electronically interconnected environment that she trusts.

CP6 Dispute Resolution

If Millie has a problem with a service, or finds an error about her information, she would be able to easily figure out the process for resolving it.

CP7 Discrimination and Compelled Disclosures

Millie wouldn't lose her job, insurance, or other benefits because of information about her on the network. She also wouldn't be forced to allow insurers or employers to see her information in order to get a job or benefits.

CP8 Consumer Obtainment and Control of Info

Millie would be able to get copies of her records electronically, instead of on paper. She would be able to manage personal health record accounts for her children, and for her ailing mom. She would also be able to terminate those accounts and keep the information out of anyone's hands, if she wants to.

CP9 Enforcement of Policies

Millie would know that there are mechanisms to make sure that the organizations touching her information play by the rules.

See Consumer Technical (CT) Briefs

The Common Framework for Networked Personal Health Information

Consumer Policy (CP)

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Key messages of the policy resources in the Common Framework:

Overview and Principles

- Consumers should be able to collect, store, manage, and share copies of personal health information.
- The Common Framework is based on fair information practices and focuses on network rules, not application standards.

CP1 Policy Overview

- New services present potential benefits and risks for consumers.
- Many new information services are not covered by HIPAA.
- This emerging, innovative new space is evolving without a common set of information practices and expectations.
- This Common Framework of sound practices is a positive step that industry can take now toward increasing trust.
- All PHRs and supporting services should address each element of the Common Framework, whether they are covered by HIPAA or not.

CP2 Policy Notice to Consumers

- Notices should be easily accessible, clear, comprehensive, summarized, updated.
- Policy notice is necessary, but not sufficient protection.
- Many consumers don't read notices, so the full Framework is necessary.

CP3 Consumer Consent

- Obtaining the consumer's consent is a critical fair information practice.
- However, consent by itself does not adequately protect people.
- A complete framework of protections is necessary, no matter the 'I agree' statement.
- Specific, "independent consent" is advisable for practices that would be unexpected by a reasonable consumer.

CP4 Chain-of-Trust Agreements

- Contracts are one mechanism to bind parties to policies.
- Chain-of-trust agreements should disallow unauthorized uses of information.
- There are limitations to chain-of-trust agreements, including inconsistent enforcement and scaling difficulties.

Consumers as Network Participants

- Consumers can help transform the health sector, as they have in other sectors. "Networked PHRs" are a vital tool for consumer empowerment.
- Some basic rules should guide the emerging industry.

CP5 Notification of Misuse or Breach

- There should be policies to notify affected consumers in the event of a potentially harmful breach of information.

CP6 Dispute Resolution

- There should be mechanisms to resolve disputes such as breach or misuse, data quality or matching errors, allegations of unfair or deceptive trade practices, etc.

CP7 Discrimination and Compelled Disclosures

- Some new services will co-mingle information from professionals and consumers.
- It is important to disallow discrimination based on information in PHRs or similar consumer tools.
- Participating organizations should take a strong stand against "compelled disclosures" (i.e., when consumers must allow organizations access to personal information in their PHR as a condition of employment, benefits, or other critical services.)

CP8 Consumer Obtainment and Control of Info

- Consumers should be able to: request their personal information in electronic format; electronically collect, store, and control copies of their personal health information; request corrections; delete data; designate proxy access; terminate their account, and limit retention of data in inactive accounts.

CP9 Enforcement of Policies

- Many possible enforcement mechanisms should be considered, each with pros and cons.
- There should not be attempts to create a one-size-fits-all enforcement mechanism.
- Different practices will need different combinations of enforcement mechanisms.
- More thought and experimentation are needed to create optimal frameworks for enforcement.

See Consumer Technical (CT) Briefs