

# THINK NATIONALLY

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Connecting Americans to Their Health Care 2005



**Connecting Americans to Their Health Care**  
*Empowered Consumers, Personal Health Records  
and Emerging Technologies*

2005

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**Think Nationally:**

**Consumer Principles and Policy  
Implications**

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# Consumer and Patient Principles: *Prologue*

Improving health and health care depends upon accurate, timely, understandable, and relevant information in the hands of consumers, patients and health professionals where and when they need it. To improve quality and prevent medical errors, health care professionals must shift away from today's reliance on paper health records and adopt trustworthy methods to gather, store and share patient data electronically ("electronic health data exchanges").

New technologies, networks and organizations are emerging to provide greater electronic connectivity and data exchange across health care institutions and with consumers, patients and families. To ensure that our personal health information is used appropriately, to protect privacy, and to create a climate of public trust, all of the many custodians of our health data should adhere to a set of fundamental principles.

# Consumer and Patient Principles

1. Individuals should be able to access their health and medical data conveniently and affordably.
2. Individuals should be able to decide (i.e., authorize) when their health data are shared, and with whom. Individuals should be able to refuse to make their health data available for sharing (i.e., opt-out).
3. Individuals should be able to designate someone else, such as a loved one, to have access to and exercise control over how their records are shared.
4. Individuals should receive easily understood information about all the ways that their health data may be used or shared.
5. Individuals should be able to review which entities have had access to their personal health data.
6. Electronic health data exchanges must protect the integrity, security, privacy and confidentiality of an individual's information.
7. Independent bodies, accountable to the public, should oversee the electronic health data exchanges. No single stakeholder group should dominate these oversight bodies. Consumer representatives selected by their peers should participate as full voting members.

# Endorsements of Principles

- AARP
- AFL-CIO
- American Hospice Foundation
- Consumers Union
- Families USA
- Health Privacy Project
- International Association of Machinists and Aerospace Workers
- Maternity Center Association
- National Coalition for Cancer Survivorship
- National Consumers League
- National Partnership for Women and Families
- SEIU – Service Employees International Union