

Health Information Technology – Consumer Principles

March 2006

An interoperable system of electronic health information holds many potential benefits for consumers, including: better coordination of health care regardless of patient location, higher quality and more efficient care, increased system transparency, and patient access to information about providers that allows them to make better decisions. At the same time, such a system raises serious concerns among consumers about personal privacy, data security, and the potential misuse of their information. And while an interoperable system of electronic health information holds great promise, the many possible benefits will not be realized unless appropriate policy measures are established up front.

Consumer protections and potential benefits from health information technology (HIT) should not be left to chance. The success of efforts to promote widespread adoption of HIT, including electronic connectivity and data exchange across health care institutions, ultimately will depend on the willingness of consumers to accept the technology. Given the pervasive concerns expressed by the public about unauthorized disclosure and use of their health information, it is critical to build a foundation of public trust. To that end, as efforts move forward to develop networks for the electronic exchange of information between institutions, there must be a clear, deliberate, and open forum for addressing and setting matters of policy. As organizations representing a broad and diverse set of consumer interests, we believe that the following set of principles should underpin such efforts.

Principles

Individuals should be able to access their personally identifiable health information conveniently and affordably.

- Individuals should have a means of direct, secure access to their electronic health information that does not require physician or institutional mediation.
- Individuals should have access to all electronic records pertaining to themselves (except in cases of danger to the patient or another person).
- Individuals should be able to supplement, request correction of, and share their personally identifiable health information without unreasonable fees or burdensome processes.

Individuals should know how their personally identifiable health information may be used and who has access to it.

- Individuals should receive easily understood information identifying the types of entities with access to their personal health information and all the ways it may be used or shared. The explanation should include any sharing for purposes other than the immediate care of the individual, and should explicitly identify intentions for data use such as public health protection, quality improvement, prevention of medical errors, medical research or commercial purposes.

- Access to personal health information must be limited to authorized individuals or entities.
- Tracking and audit trail systems should be in place that permit individuals to review which entities have entered, accessed, modified and/or transmitted any of their personally identifiable health information.

Individuals should have control over whether and how their personally identifiable health information is shared.

- Individuals should be able to opt out of having their personally identifiable health information – in whole or in part – shared across an electronic health information network.
- Individuals should be able to limit the extent to which their health information (with or without personal identifiers) is made available for commercial purposes.
- Individuals should be able to designate someone else, such as a family member, caregiver or legal guardian, to have access to and exercise control over how records are shared, and also should be able to rescind this designation.

Systems for electronic health data exchange must protect the integrity, security, privacy and confidentiality of an individual's information.

- Personally identifiable health information should be protected by reasonable safeguards against such risks as loss or unauthorized access, destruction, use, modification, or disclosure of data. These safeguards must be developed at the front end and must follow the information as it is accessed or transferred.
- Individuals should be notified in a timely manner if their personally identifiable health information is subject to a security breach or privacy violation.
- Meaningful legal and financial remedies should exist to address any security breaches or privacy violations.
- Federal privacy standards that restrict the use and disclosure of personally identifiable health information should apply to all entities engaged in health information exchanges.

The governance and administration of electronic health information networks should be transparent, and publicly accountable.

- Independent bodies, accountable to the public, should oversee electronic health information sharing.
- Consumers should have equal footing with other stakeholders.

Recognizing the potential of electronic patient data to support quality measurement, provider and institutional performance assessment, relative effectiveness and outcomes research, prescription drug monitoring, patient safety, public health, informed decisionmaking by patients and other public interest objectives, systems should be designed to fully leverage that potential, while protecting patient privacy.

Implementation of any regional or national electronic health information network should be accompanied by a significant consumer education program so that people understand how the network will operate, what information will and will not be available on the

network, the value of the network, its privacy and security protections, how to participate in it, and the rights, benefits and remedies afforded to them. These efforts should include outreach to those without health insurance coverage.

AARP
AFL-CIO
American Federation of State, County and Municipal Employees
American Federation of Teachers
Center for Medical Consumers
Communications Workers of America
Consumers Union
Department for Professional Employees, AFL-CIO
Childbirth Connection
Health Care for All
Health Privacy Project
International Association of Machinists and Aerospace Workers
International Union, United Auto Workers
National Coalition for Cancer Survivorship
National Consumers League
National Partnership for Women & Families
Service Employees International Union
Title II Community AIDS National Network
United Steelworkers International Union (USW)
