

Electronic Health Data Exchanges: Patient and Consumer Principles for System Design

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.

Patient and Consumer Principles:

Within organizations or networks designed for electronic patient data exchange between health care institutions:

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 BY ORGANIZATIONS

These Consumer and Patient-Focused Principles are endorsed by the following organizations:

AARP
ACOR – Association of Cancer Online Resources
AFL-CIO
American Hospice Foundation
Center for Medical Consumers
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

ENDORSEMENT BY THE PERSONAL HEALTH TECHNOLOGY COUNCIL

The Markle Foundation's Personal Health Technology Council endorses these Consumer and Patient-Focused Principles. Endorsement by the Council, whose members are listed below, does not imply endorsement by the organizations of the Council members, except as indicated above. An asterisk (*) in front of a member's name designates a government employee who participated in the Council deliberations but makes no endorsement.

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