

Proposed Principles for Consumer Empowerment Breakthrough

The Markle Foundation, representing several consumer organizations¹, and the Blue Cross Blue Shield Association provided the following proposed principles for the Consumer Empowerment Breakthrough Initiative under the American Health Information Community.

Principles for Personal Health Records

- Each person controls his or her own Personal Health Record and decide who can access which parts of their PHR²
- PHRs contain information for one's lifetime
- PHRs contain information from all health care providers
- PHRs should have data integrity: data sources and age of data should be cited; consumers can annotate but are not permitted to destroy or change data electronically supplied by other systems
- Consumers and permitted providers can access PHRs at any place at any time
- PHRs should be portable; one system's PHR should permit easy exchange of information with other systems' PHRs
- PHRs are private and secure; all entities that provide or manage personal health information, whether or not defined as covered entities under HIPAA, should follow the privacy and security rules that apply to HIPAA-covered entities
- PHRS are transparent; consumers should be able to view who has accessed which parts of their PHR
- PHRs permit easy exchange of information; PHRs should be required to comply with interoperability requirements such as those required by certification bodies.

Principles for Information Access and Control

- People must have the ability to control who has access to their personal health information over an electronic health network – either directly or through the action of a designated proxy (or by choosing not to exercise that control). This control can be exercised in whole or only with regard to selected elements of their personal health information.
- At a minimum, the structure and rules of the breakthroughs must facilitate the ability of people to exercise their personal health information rights under the federal privacy regulation mandated by HIPAA.

¹ The consumer organizations included the AFL-CIO, Consumers Union, Families USA, Health Privacy Project, International Association of Machinists and Aerospace Workers, National Coalition for Cancer Survivorship, National Consumers League, National Health Council, and the National Partnership for Women and Families.

² The PHR should include a “break-the-glass” capability that would permit providers under very strict circumstances (e.g., when an individual is brought unconscious into an emergency room) to access the PHR without the individual's prior authorization.

- People should have the ability to review who has had access to their personal health information. Each individual or entity accessing personal health information over the network should have access authority and be authenticated.
- People should be able to supplement or annotate their personal health information. All self-reported data should be identified as such in order to help assure data quality.
- Unreasonable or unaffordable fees should not impair the ability of each person to access, review or supplement their personal health information available through network services or intermediaries.
- People must be able to request correction of their personal health information and receive a timely response to the request; consumers can annotate but are not permitted to destroy or change data electronically supplied by third parties.
- The breakthrough must provide a sound method for allowing secure access and authenticating patient users that does not require physician or institutional mediation.
- People must have the ability to designate (and withdraw designation from) proxies who have full authority to manage their personal health information on the network.
- People must be able to choose whether or not their information is shared for the purposes of the breakthrough across the network – in whole or in part – at any time, without coercion or pressure.

Disclosure and Accountability Principles

- Before a provider initiates a transfer of personal health information through the exchange, affected individuals should be fully informed of the policies in place and the possible uses of that information. (First-time disclosure is sufficient for subsequent transactions.)
- People should be informed of the ways their information may be used and must be able to choose whether to make their personal health data available for such use in various systems.
- Communications with people about the uses of and policies affecting their electronic health information must be conducted in simple, easily understood language for purposes of the breakthrough.
- People must be able to receive complete paper copies of any of their personal health information made available through the breakthrough.

Functionality

- The breakthrough should provide the capability for people to reliably and securely move all or portions of their personal health information from one health care entity to another.
- The breakthrough should permit aggregation of de-identified data to support medication management, patient safety, public health and other public interest objectives.
- The breakthrough should permit patients to transmit information to their health care providers as well as receive information from them.

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