

THE COALITION FOR PATIENT PRIVACY

Who We Are

The Coalition for Patient Privacy is a diverse, multi-partisan group of organizations, individual experts and technology corporations. Today we represent 10 million patients and consumers. We are a collaborative group united by a common goal: to protect patient privacy and encourage adoption of Health IT. Ensuring individuals can keep their medical information private is a fundamental right with very deep roots:

Medical Ethics: *“Whatsoever I shall see or hear of the lives of men or women which is not fitting to be spoken, I will keep inviolably secret.”* Hippocratic Oath

The Constitution: *“the right to privacy is a personal and fundamental right protected by the Constitution of the United States”* Privacy Act of 1974, Section 2(a)(4), Pub. L. 93-579

The Coalition includes:

- consumer and patient groups
- disability groups
- disease groups
- civil liberties groups
- doctors
- psychiatrists
- social workers
- mental health advocates
- GLBT groups
- students
- whistleblowers
- health care reform groups
- privacy advocates
- conservatives, libertarians and progressives
- privacy and security experts and academics
- small and large technology corporations

The lack of privacy can harm jobs, promotions, insurance, reputations, credit and more: everyone has a stake in this issue!

What We Do

- Educate the public about health privacy rights and ways to protect their privacy.
- Provide technical, ethical, legal, and health policy expertise from the consumer point of view for Health IT challenges and opportunities. Innovative technology, policy, laws, and regulations can strengthen privacy protections and assure that electronic health systems will be trusted and used.
- Engage policy makers and advocate for consumers’ right to privacy and control of their health information.

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Unifying Privacy Principles

- Personal health information is the most sensitive information on earth.
- Regardless of technological advances, 2,400 years of human experience has shown that following the Hippocratic Oath and preserving the sacred, ethical relationship between a physician and patient enables trust and participation in health care systems.
- Health IT must be trusted, transparent and accountable.
- All individuals, regardless of ability, education or income must:
 - Have a right to health privacy
 - Be able to control how their personal health information is used
 - Know who has their personal health information and what they are doing with it
 - Be able to opt-in and opt-out of electronic systems, segment sensitive information, correct and amend information, have audit trails of all disclosures

Coalition Goals & Activities

- Monitor the Health IT Policy & Standards Committees.
 - Provide summaries and action item recommendations for every meeting.
- Make recommendations to the relevant federal committees and regulatory agencies, Office of National Coordinator for Health IT, Health and Human Services, Federal Trade Commission and others.
- Activate members and groups to advocate for privacy-enhancing technologies, laws, and policies.
- Empower individuals to protect their personal health information and provide them with tangible, user-friendly tools.
- Ensure clear and consistent communication among Coalition partners.
- Provide a Rapid Response Kit for media and decision makers.
- Engage private sector to adopt innovative privacy-enhancing technologies and policies and promote a strong culture of protecting individual privacy regardless of regulations and law.
- Tap into technical expertise and collaborate with industry and the marketplace to provide privacy solutions for Health IT products and systems.

For more information, please contact:

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