

Consumer Partnership for e-Health Position Statement

The Consumer Partnership for e-Health is a non-partisan group of consumer, labor, research and policy-making organizations working together to improve health care quality through expanded use of information technology and sharing of knowledge. The combined membership of our organizations represents more than 127 million Americans. We have been meeting since 2005 to better understand electronic health information technology (HIT) and exchange (HIE) implementation and to inform the development of appropriate policies that will make it possible.

Over the past three years we have worked to:

- Expand federal funding for HIT and HIE.
- Encourage use of HIT in all provider settings.
- Promote passage of federal legislation that advances HIT and HIE for purposes of care coordination, quality improvement, public health, and research.
- Identify and promote pragmatic strategies for addressing critical privacy and security concerns.
- Inform the deliberations of the American Health Information Community (AHIC).
- Encourage the Office of the National Coordinator for Health Information Technology (ONCHIT) to establish a privacy and security policy framework to serve as a benchmark for consumer-focused market development.
- Assure meaningful consumer and health care worker involvement in local and national HIE planning and implementation.

Consumer Partnership for e-Health Members

- AARP
- AFL-CIO
- American Association of People with Disabilities (AAPD)
- American Federation of State, County, and Municipal Employees (AFSCME)
- American Federation of Teachers (AFT)
- Center for Democracy & Technology
- Childbirth Connection
- Clear Voice Consulting
- Consumers Union
- Consumer Coalition for Quality Health Care
- Department for Professional Employees, AFL-CIO
- Health Care for All
- National Coalition for Cancer Survivorship
- National Consumers League (NCL)
- National Partnership for Women & Families
- Service Employees International Union (SEIU)
- United Steel Workers

We believe the expanded use of HIT and HIE has enormous potential to improve clinical care and health outcomes, enhance access to care (including access for the underserved and people with disabilities), contain costs, and improve research and public health. By leveraging information across delivery systems, HIE can also enable consumers to take a more active and informed role in managing their own health and healthcare. In addition, these tools have the potential to enhance the provider-patient relationship by enabling more frequent, customized, and informed dialogue between patients and their providers.

Despite the promise of HIE, if its development is not guided by sound, patient-centered policies, it can pose considerable risks for consumers. Inappropriate use, transmission, or breaches of information could lead to discrimination, embarrassment, or worse. Ultimately, such negative outcomes would likely result in consumer reluctance to participate in health information exchange. HIE can only achieve its potential if consumers trust that their information is confidential, secure, and exchanged in a manner consistent with their preferences and values. Development of consumer trust requires a baseline of privacy protections that are built into underlying policy and technical design, and that are understandable and enforceable.

The Consumer Partnership for e-Health provides a sustained source of thoughtful input which is reflective of public concerns and preferences. Our goals for the successful development of HIE are articulated in our "Consumer Principles." To view a copy of these principles and learn more about the Consumer Partnership for e-Health, go to www.nationalpartnership.org/hit.