

June 3, 2008

The Honorable John D. Dingell
Chairman, Committee on Energy and Commerce
United States House of Representatives

The Honorable Joe Barton
Committee on Energy and Commerce
United States House of Representatives

The Honorable Frank Pallone, Jr.
Committee on Energy and Commerce
United States House of Representatives

The Honorable Nathan Deal
Committee on Energy and Commerce
United States House of Representative

Dear Chairman Dingell and Representatives Barton, Pallone, and Deal:

We are writing to applaud your proposed legislation (the “Discussion Draft”) to promote health information technology adoption and establish a framework for protecting the privacy and security of Americans’ personal health information. As members of the Consumer Partnership for e-Health, a non-partisan group of consumer, labor, patient, and research organizations representing over 127 million people, we believe that health information technology and exchange (HIT/HIE) are critical underpinnings of a more patient-centered health care system. They can facilitate better coordination of care, encourage higher quality and more efficient care, increase system transparency, and empower consumers to more actively engage in health care decision-making. At the same time, such a system raises serious concerns among consumers about personal privacy, data security, and the potential misuse of their information. 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.

Your proposed legislation takes very positive steps toward achieving a balance between promoting HIT/HIE and protecting personal health information. These steps are consistent with our coalition’s Consumer Principles for Health Information Technology in the following ways:

- **Promoting individuals’ access to their health information** by requiring covered entities that have an electronic medical record to maintain a log of all disclosures for treatment, payment, and health care operations and giving patients a right to receive an accounting of such disclosures.
- **Helping consumers have better knowledge and understanding about how their health information may be used** by requiring HHS to fund a public education initiative on the uses of protected health information (PHI) and designating an individual in each regional office of HHS to offer guidance and education to covered entities, business associates and the public on their rights and responsibilities related to PHI.
- **Granting individuals more control over whether and how their health information is shared** by tightening the definition of “marketing” under the current HIPAA Privacy Rule so that consumers have the right to consent to uses of their health information for marketing.
- **Protecting the privacy, security, and confidentiality of an individual’s health information** by requiring regional or local health information exchange networks to include

plans for the privacy and security of individually identifiable health information and notification of breach in order to be eligible for federal grants; applying the HIPAA security rule and penalties to business associates; requiring notification of breach by covered entities and business associates; and requiring breach notification by vendors of personal health records. In addition, the legislation's requirement that HHS issue an annual report on compliance with the HIPAA Privacy and Security Rules will provide greater transparency of federal enforcement efforts, and further encourage entities holding PHI to strengthen their privacy and security protections.

- **Ensuring transparency and accountability for how various entities handle and use the information entrusted to them** by establishing Policy and Standards Committees that will conduct deliberations and make recommendations in a transparent and publicly accountable fashion, as required by the Federal Advisory Committee Act. The legislation also appropriately structures the authority and functions of the two committees to ensure that a sound policy framework governs the adoption of technical standards, implementation specifications, and certification criteria. We also strongly support the inclusion of consumer and health care worker representatives on the Policy and Standards Committees.

We look forward to working with you to advance this legislation, and identify the following specific topics for additional discussion:

- Ensuring that efforts to advance adoption of HIT/HIE are appropriately integrated into broader health system changes that will effectively improve the quality of patient care, decrease errors, and improve the affordability of health coverage. As recently noted by the Congressional Budget Office, adoption of HIT alone will not be sufficient to achieve the high quality, affordable health care system that all Americans deserve. Evaluation of the impact on quality, safety, and cost of full HIT and HIE integration will be vital.
- Strengthening the building blocks for health system reform by:
 - Supporting the development and endorsement of national performance measures to give health care providers, purchasers and consumers the tools they need to deliver and receive high quality care, facilitate quality improvement, and advance opportunities to make comparisons against regional and national benchmarks.
 - Providing a pathway for the release of federal health claims data to allow for the public reporting of quality performance information at the individual provider level.
- Addressing the potential benefits and risks of achieving an electronic health record for all Americans by 2014.

We are delighted to offer our strong support for this Discussion Draft. Thank you for your leadership and commitment to achieving a modern, high performing health care system that enhances patient care and engenders consumers' trust.

Sincerely,

AARP
AFL-CIO
AFSCME
American Federation of Teachers
Childbirth Connection
Consumers Union
Department for Professional Employees, AFL-CIO
Health Care for All
International Union, United Auto Workers
National Consumers League
National Partnership for Women & Families
SEIU

Members of the Consumer Partnership for eHealth