

July 26, 2006

The Honorable Dennis Hastert  
Speaker  
United States House of Representatives  
Washington, D.C. 20515

The Honorable Nancy Pelosi  
Minority Leader  
United States House of Representatives  
Washington, D.C. 20515

Dear Mr. Speaker and Minority Leader Pelosi:

The undersigned consumer and patient organizations support federal efforts to accelerate the adoption of policies and standards that will enable electronic health information exchange throughout the nation's health care system. We believe that expanded use of health information technology will help patients and their families assume a more participatory role in their own health care, improve the safety and quality of care, and increase system efficiency. We support federal legislation that will accelerate the adoption of health information technology standards, foster the development of a national health information exchange architecture, encourage HIT adoption in the private sector, and establish a structure of governmental oversight.

This crucial initiative will only succeed if all Americans are confident that their personal health information is being handled in a secure and confidential manner, that no improper use will be made of information they provide to their doctor or another party, and that remedies are in place should improper use or security breach be discovered.

We are concerned that neither of the versions of H.R. 4157 reported by the Ways and Means Committee and the Energy and Commerce Committee will result in significant progress toward greater adoption of health information technology or more interoperability among health information systems. In fact, the state privacy and security law preemption language regarding interoperability that is in the Ways and Means bill could actually have the opposite impact because patients and providers would fear expanded use of electronic systems could result in disclosure of currently protected sensitive data. As you deliberate this legislation we hope you will consider the following comments.

*Privacy and security laws and regulations.* It is critical that we move rapidly toward the adoption of standards for electronic exchange of health information, but it also is critical that this not be done in a manner that erodes patient privacy. HIPAA was intended to provide a floor for protections, not a ceiling. Recent surveys document that fear of privacy breach causes patients to withhold information from their physicians, thereby jeopardizing appropriate treatment – or worse, forego treatment altogether. We therefore oppose provisions such as Sec. 4(b) of the bill as reported by the Ways and Means Committee which would preempt state laws or regulations that go further than HIPAA to ensure patient privacy. We also have concerns about Section 271(c)(3)(D) in Section 2(a) of the Ways and Means bill as it, also, could be read to authorize such preemption.

We believe that any interoperable health information technology system must address privacy and security in a manner consistent with the series of principles our organizations have endorsed that include:

- Individuals should have control over whether and how their personally identifiable health information is shared, including the ability to opt out of having it shared – in whole or in part – across an electronic health information network.

- Individuals should be notified if their health information has been subject to a privacy violation or breach.
- Tracking and audit trail systems should be in place that permit individuals to review which entities have entered, accessed, modified and/or transmitted any of their personally identifiable health information.
- Meaningful legal and financial remedies should exist to address any security breaches or privacy violations

We urge that any health information technology legislation incorporate these principles.

*Exemptions from the physician self-referral and anti-kickback statutes for donations of health information technology assistance.* We believe it is premature to grant new statutory exemptions from the physician self-referral and anti-kickback laws for this purpose. The drive to promote the wider use of electronic information exchange capability should not trump the consumer protection and program integrity brought by these antifraud and abuse prohibitions. Of much greater importance in encouraging more health information technology adoption are the grant programs authorized under S. 1418 and the standards harmonization and product certification initiatives the Department of Health and Human Services already has underway. The standards need to be in place to ensure that donated technology will enhance, not impede, reaching the goal of a common platform for information exchange.

If, however, such exceptions are made, all donated products should be required to be certified as complying with federally-approved standards for functionality, security and interoperability in place at the time of donation. There should also be protection against donors picking and choosing recipients in a manner that would tend to generate referrals or other business between donor and recipient, or that would reward such referrals.

We understand a substitute amendment may be offered that reflects S. 1418 as unanimously passed by the Senate as well as our privacy and security principles. We believe S. 1418 is the preferable approach for advancing our shared goals of improved health care quality and enhanced patient safety. We urge your support for that amendment.

Thank you for your consideration of our views. Please do not hesitate to call upon any of our organizations if we can provide further assistance.

Sincerely,

National Partnership for Women & Families  
 AFL-CIO  
 Center for Medical Consumers  
 Childbirth Connection  
 Communications Workers of America  
 Consumers Union  
 Health Care For All

Health Privacy Project  
 International Union, United Auto Workers  
 National Consumers League  
 National Health Law Program, Inc.  
 Service Employees International Union  
 The Title II Community AIDS National Network

cc: All Members of the House