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25 NATIONAL ORGANIZATIONS URGE PRIVACY IN E-PRESCRIBING

What Could Be Scary About E-Prescribing? Plenty.

Washington, DC – Twenty five organizations, including the ACLU, the Republican Liberty Caucus, the American Council for the Blind and the National Association of Social Workers joined forces via the Coalition for Patient Privacy to urge Congress to include privacy protections in any federal electronic prescribing legislation. Read the Coalition’s letter to Congress [here](#).

What is scary about e-prescribing? Much more than you might think. Today, plenty of private corporations and employers have access to Americans’ private prescription use that includes individually identifiable data. Deborah Peel, MD, Founder of Patient Privacy Rights and leader of the Coalition explains the need for privacy with e-prescribing, “Our current system allows every prescription in the United States to be data mined and sold. This has been the reality for over a decade. You cannot keep a prescription private in the U.S. or stop your data from being sold, even if you pay cash.” This practice is completely compliant with the Health Information Portability and Accountability Act (HIPAA).

While e-prescribing is attractive to many, Americans do not want their private prescription information data mined and used without their permission. Many Americans would be quite alarmed to discover their employer and others know they take an anti-anxiety medication or that they are being treated for an STD. West Virginia is a perfect example: when state employees recently learned that Express Scripts was selling their prescription records to data miners, they were outraged. Express Scripts promptly agreed to stop this practice when faced with losing 200,000 customers.

Some argue the e-prescribing bills do not change anything. While the fact that the U.S. has a systemic, extensive system for prescription data mining and sale is NOT a secret anymore, the Coalition argues that now is the ideal time to end this unethical use of our private prescription records. When you know something bad is happening, that is the time to stop it. “Would you sit there and watch a house burn down, or let somebody bleed to death before your eyes and do nothing? Or would try to stop those harms?” asks Peel. “Now that we know beyond a shadow of a doubt that the systemic theft and misuse of personal data is occurring, why wouldn’t we do all we can to stop it now, starting with e-prescribing?” Members of the Coalition for Patient Privacy actually see this debate as a golden opportunity to ensure both progress and privacy.

The Coalition for Patient Privacy recommends the following basic principles in any e-prescribing legislation:

- include a right to health information privacy (the right to control access to personal health information);
- require that any prescription data transmitted via e-prescribing be used only for the express purpose of prescription filling and submitting the necessary codes to the insurer for payment;
- include a provision requiring prompt notification of privacy breaches;
- include a provision that creates meaningful penalties and enforcement mechanisms for violations detected by patients, advocates and government regulators;
- include provisions enhancing the security of e-prescription data such as encryption when data is transmitted, stored or retained in any storage and retrieval systems, including access devices, readable cards or other methods;
- ensure physicians who decline to use e-prescribing are not penalized;
- ensure transparency by requiring annual reporting to patients listing everyone who has accessed their prescription data;
- include a provision ensuring stronger state privacy laws are not pre-empted;
- require reporting of privacy complaints to the Centers for Medicare and Medicaid Services (CMS);
- require CMS to provide an annual report to Congress on privacy complaints made; and
- ensure prescription technology allows those with disabilities to be able to use e-prescribing tools efficiently and effectively.

The Coalition for Patient Privacy

American Association of People with Disabilities www.aapd.org

American Association of Practicing Psychiatrists

American Association of Small Property Owners www.aaspo.org

American Civil Liberties Union www.aclu.org

American Council for the Blind www.acb.org
American Psychoanalytic Association www.apsa.org
Citizens for Health www.citizens.org
Confederation of Independent Psychoanalytic Societies www.cipsusa.org
Consumer Action www.consumer-action.org
Consumers for Health Care Choices www.chcchoices.org
The Cyber Privacy Project
Electronic Privacy Information Center www.epic.org
Equal Justice Alliance www.EqualJusticeAlliance.org
Fairfax County Privacy Council www.fairfaxcountyprivacycouncil.org
Gun Owners of America www.gunowners.org
Just Health www.justhealthnow.org
Liberty Coalition www.libertycoalition.net
The Multiracial Activist www.multiracial.com
National Association of Social Workers www.socialworkers.org
National Center for Transgender Equality www.nctequality.org
Pain Relief Network www.painreliefnetwork.org
Patient Privacy Rights www.patientprivacyrights.org
Private Citizen, Inc. www.privatecitizen.org
Republican Liberty Caucus www.rlc.org
Tolven, Inc. www.tolven.org

The [Coalition for Patient Privacy](#) first formed in 2006 and represents millions of Americans. Dr. Peel leads the Coalition and is the founder of [Patient Privacy Rights](#), a national consumer health privacy watchdog organization based in Austin, TX.

Background Material

[The elimination of consent for health records](#)

[The millions of individuals and entities who legally have rights to your personal information](#)

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