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INDUSTRY REQUESTING A BLANK CHECK FOR HEALTH IT IN ECONOMIC STIMULUS PACKAGE

Washington, DC – With a renewed commitment in Congress and by the President-elect to protecting consumers over special interests a "Confidentiality Coalition" boldly came forward recommending that NO privacy or consumer protections be included in any health IT provisions incorporated in the economic stimulus.

Who does the Confidentiality Coalition represent? Health plans, pharmaceutical companies, vendors, employers, health product distributors, and pharmacy benefit managers, among others. In reaction to this coalition's recent letter to Congress, the founder of Patient Privacy Rights noted, "notably absent from this coalition are patients and doctors, those who stand to lose the most when they lose all control over personal health information and such information is used in ways other than promoting health."

"At the heart of the argument is whether we have learned anything from the last few years of letting industry set its own rules. Today we are all paying a very painful price for a failure to protect consumers and letting the financial industry steer the ship. **We must not repeat the same mistake with the health industry**," says Peel.

"Giving for-profit corporations (that have a duty to their shareholders to make money) a blank check for health IT paves the way to establish a goldmine of information that can be used to increase profits, promote expensive – not necessarily more effective – drugs, cherry pick and market. Including privacy protections, up front, is the only way to engender public trust and thereby innovate and improve health care"

Patient Privacy Rights and the Coalition for Patient Privacy representing over 50 consumer organizations and up to 12 million Americans has been working together with Congress to promote health IT and at the same time ensure our nation's health IT system does not put Americans' jobs, access to health care and credit at risk by dismissing the need for privacy. Trust is essential to health IT adoption and participation, and only attainable with privacy.

Patient Privacy Rights urges Congress to ensure accountability, control and transparency with health IT, including the following minimum protections:

ACCOUNTABILITY – Hold every entity with access to health information accountable.

- Those who hold or store personal health information should ensure that the data is accurate, reliable and secure.[1] Minimum standards should include: encrypt data at rest and in transit, limiting access to specific individuals via informed, electronic consent and audit trails of all electronic transactions.

- Authorize and fund Health & Human Services (HHS) and the Federal Trade Commission (FTC) to increase their oversight of data flow and sharing practices including random audits of contracts. Require breach notification and whistleblower protections.

CONTROL – Ensure individuals control the use of personal health information.
Fundamental to the Code of Fair Information Practices and most professional Codes of Ethics is an individual's right to control how their personal information is used; the same code should apply to our most sensitive information, our health records.

- Codify a federal right to health information privacy.

- All systems should ensure individuals can segment sensitive information so safeguards are built in up front.

- Provide incentives for health IT systems to use electronic informed consent and innovative consumer privacy controls.

TRANSPARENCY – Protect consumers from abusive practices.
Personal health information shouldn't be sold and shared as if it were some other commodity like stocks or mortgages.[2] Health information is significantly different from other data collected by marketers and data miners.

- Prohibit direct or indirect remuneration for the sharing, disclosure or use of personal health information with limited exceptions for research and public health. Ensure that corporations cannot obtain exclusive or contractual rights to own or control personal health information. [3]

- Personal health information obtained for one purpose must not be used or made available for other purposes without informed consent.[4] We strongly support provisions re-defining and limiting the broad category of "Health Care Operations."

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[1] Code of Fair Information Practices, Principle 5
[2] See "Evidence of Disclosure," http://www.patientprivacyrights.org/site/DocServer/Evidence_of_Disclosure.pdf?docID=4501
[3] For example, CVS Caremark's *iScribe* electronic prescribing program obtains absolute rights to all data inputted into their system via their service agreement with providers allowing them to sell or share the data with third party partners including drug manufacturers, healthcare clearinghouses and data analysis companies.
[4] Code of Fair Information Practices, Principle 3

About Patient Privacy Rights:

As the nation's health privacy watchdog, Patient Privacy Rights works to ensure that we don't have to choose between privacy and health care or health IT. Patient Privacy Rights is a 501(c)3 nonprofit headquartered in Austin, Texas with an office in Washington D.C., funded solely by individuals. Founded by a practicing physician, our mission is to ensure Americans control access to their personal health information so that we progress with privacy. When our most intimate information can be sold and shared with the click of a mouse, many may lose opportunities for work, wealth and well being.

Patient Privacy Rights leads the bi-partisan Coalition for Patient Privacy, representing nearly 12 million Americans and including over 50 consumer organizations and technology corporations such as the ACLU, American Conservative Union, American Association for People with Disabilities, AIDS Action, Family Research Council and Microsoft.

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