



*The Confidentiality Coalition, convened by the Healthcare Leadership Council (HLC), is a broad group of organizations that work to ensure that we as a nation find the right balance between the protection of confidential health information and the efficient and interoperable systems needed to provide the very best quality of care. We advocate for policies and practices that safeguard the privacy of patients and healthcare consumers while, at the same time, supporting policies that enable the essential flow of patient information that is critical to the timely and effective delivery of healthcare. Timely and accurate patient information leads to both improvements in quality and safety and the development of new lifesaving and life-enhancing medical interventions.*

*The Confidentiality Coalition is the only organization bringing together hospitals, medical teaching colleges, health plans, pharmaceutical companies, medical device manufacturers, vendors of electronic health records, biotech firms, employers, health product distributors, pharmacies, pharmacy benefit managers, health information and research organizations, clinical laboratories, patient groups, and others on these important issues. Through this unique diversity, we are able to provide a nuanced perspective on the impact of any legislation or regulation affecting the privacy and care of health consumers.*

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## **Key 2014 Accomplishments**

### **A key resource for Congress during the drafting of 21<sup>st</sup> Century Cures legislation**

HLC and the Confidentiality Coalition have served as an important resource for the House Energy and Commerce Committee as it works to draft reforms designed to reduce the regulatory burden of HIPAA on efforts to accelerate the use of digital health data and tools in developing treatments and cures.

- In July, the Confidentiality Coalition contributed to HLC President Mary R. Grealy's testimony before the Energy and Commerce Subcommittee on Health hearing on "21st Century Cures: Examining Barriers to Ongoing Evidence Development and Communication." Her testimony identified three areas to allow greater innovation in health research and care, and included comments on possible reforms to the HIPAA Privacy Rule to facilitate research.
- In September, the Confidentiality Coalition briefed key committee staffers on the HIPAA Privacy Rule, health industry concerns related to balancing information exchange and protecting sensitive information, and discussed legislative priorities in connection with the 21<sup>st</sup> Century Cures initiative.

- The Confidentiality Coalition held several special calls and meetings to analyze and respond to potential legislation provided by committee staff in the fall. Coalition members drafted and shared consensus points that were shared with committee staff.
- The Confidentiality Coalition has stressed the importance of a uniform privacy standard aligned with the HIPAA privacy rule already in effect. Currently, covered entities using patient health information interact with any number of the thousands of state laws across the country regulating health information. These provisions create enormous complexity that has resulted in substantial impediments to the implementation of health information exchanges within and across state borders.

### **The leading voice on the unworkable “accounting of disclosures” regulation**

The Confidentiality Coalition continues to lead the health industry in seeking an alternative to the unworkable “accounting-of-disclosures” proposed HIPAA privacy regulation. As proposed in 2011, the accounting-of-disclosures regulation would require HIPAA-covered entities to provide patients, upon request, an accounting of all disclosures made for treatment, payment, and healthcare operations purposes over a three-year period, along with an access report identifying all individuals who gained access or viewed protected health information (PHI). This approach would require massive and expensive changes to healthcare information systems across the country, with little resulting benefit to individuals.

- This proposed rule has not gone into effect largely because of significant opposition and activity by health organizations, consumer groups, and others convened by the Confidentiality Coalition.
- In March, the Confidentiality Coalition built on a significant legacy of work completed since 2011 by submitting comments to the Department of Health and Human Services (HHS) Office for Civil Rights (OCR) detailing concerns with the recommendations on audit trail requirements provided by the ONC Policy Committee’s Privacy and Security Tiger Team.
- According to Acting Deputy Director for Health Information Privacy Christina Heide, OCR will issue another request for comment in 2015.

### **A convener for leaders in health information confidentiality**

The Confidentiality Coalition serves as an important nexus for health information privacy experts and regulators. Through the Coalition, we are able to build industry consensus, and educate policymakers on important issues in advance of regulation. By developing and maintaining relationships with key policymakers in this area, we are able to proactively address many issues and prevent them from becoming contentious.

- In September, the Confidentiality Coalition convened at HLC to hear from Jocelyn Samuels, the recently appointed director of the OCR as well as Acting Deputy Director for Health Information Privacy, Christina Heide, who spoke with Coalition

members about their role in leading health information privacy strategy and enforcement efforts for the federal government. Coalition members were able to ask questions and share cross-industry concerns on upcoming issues.

- In February, the Confidentiality Coalition convened at HLC to meet with Cora Han from the Federal Trade Commission (FTC) to discuss FTC involvement in enforcing health data breaches. The FTC confirmed that it believes it has the authority and mandate to regulate HIPAA-covered entities in the instance of a data breach. The FTC is also expanding its work to monitor non-HIPAA-covered health information held by various organizations. The Confidentiality Coalition continues to monitor FTC activity and work with FTC regulators as appropriate.

### **A leading voice for safe, confidential, health information and exchange**

Confidentiality Coalition representatives regularly speak on privacy, security, deidentification, and information exchange. This voice is necessary to advocate for an appropriate balance of privacy policy with the important medical needs of consumers.

- In September, the Confidentiality Coalition made a statement to the National Committee on Vital and Health Statistics supporting its Community Data User Toolkit. The toolkit will provide an important framework for users who handle health data. In particular, the coalition strongly agreed with provisions on good data stewardship practices, the benefit of health data for the healthcare system and individuals, and the risk posed by a failure to use appropriate data stewardship practices.
- In August, the Confidentiality Coalition contributed to HLC comments submitted to Senate Finance Committee Chairman Ron Wyden (D-OR) and Ranking Member Charles Grassley (R-IA) in response to a public letter to roughly 100 groups and individuals asking how big data and transparency in healthcare could promote reform. Among other issues, HLC described how the use of big data to improve health and healthcare is limited by privacy regulations. HLC discussed the possibility of modernizing the HIPAA Privacy Rule to allow for the use of big data analytics in healthcare.
- In June, HLC President Mary R. Grealy moderated a panel at Datapalooza titled, “Building Trust in our Health Infrastructure During a Time of High-Profile Data Breaches” with private sector coalition members, as well as representatives from HHS OCR and the FTC’s Division of Privacy and Identity Protection.
- In the spring, the Confidentiality Coalition held its annual “HIPAA 101” briefing for congressional staff. This annual briefing is an important tool to educate both new and experienced congressional staffers about the protection of health information and the tools health organizations and HHS currently use to protect that information.
- The Confidentiality Coalition remains engaged with ONC on a patient data-matching strategy as it continues work to develop and implement policies for matching patients to their information.

## **The voice of healthcare on potential cybersecurity and data breach legislation**

The Confidentiality Coalition continues to monitor potential cybersecurity and data breach legislation. Legislation or administrative action on either of these topics has the potential to duplicate current regulation of healthcare organizations.

- In February, the Confidentiality Coalition submitted a statement to the Senate Judiciary Committee in connection with its hearing, “Privacy in the Digital Age: Preventing Data Breaches and Combating Cybercrime,” supporting an approach that preserves current HIPAA rules protecting data held by covered entities and business associates in any new privacy legislation.
- The Confidentiality Coalition remains in contact with the staff of the House Committee on Homeland Security to discuss how potential cybersecurity legislation might affect health organizations – specifically regarding the need to exempt HIPAA-covered entities and business associates from duplicative regulation by non-HHS agencies.

## **A resource for organizations handling confidential health information**

The Confidentiality Coalition is active on a variety of related policy areas and provides oral and written updates to its membership. Often, these areas fall outside of the core issues tracked by member organizations and help members stay informed on issues with potentially large market influence.

- The Confidentiality Coalition maintains a website, [www.confidentialitycoalition.org](http://www.confidentialitycoalition.org) with the latest health information news, resources for more information on a variety of health confidentiality topics, public statements from the Coalition, and other useful content. It also includes a member section with information from meetings and speakers.
- The Confidentiality Coalition also serves as a resource for the media when writing about health information exchange and privacy.