



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 our unique diversity, we are able to provide consensus perspectives on the impact of legislation or regulation affecting the privacy and care of health consumers.

Key 2015 Accomplishments

Unlocking Innovation

Served as a partner and resource for Congress and the Administration as they work to unlock new information that will accelerate medical innovation while continuing to protect health information

- ✓ Worked closely with House Energy and Commerce Subcommittee on Health staff, assisting in its efforts to enact reforms through its 21st Century Cures initiative to reduce the regulatory burden of HIPAA and to accelerate the use of digital health data and tools in developing treatments and cures. Confidentiality Coalition members drafted several rounds of feedback and remain involved as the “21st Century Cures Act,” proposals proceed in the Senate.
- ✓ Maintained close communication with Senate HELP Committee staff about the forthcoming Senate medical innovation legislation expected to be released early in 2016. The Senate approach to health privacy will likely focus less on researcher access and more on privacy issues related to interoperability and patient access.

Ensuring Security

Brought together a unified healthcare voice to influence cybersecurity information sharing law and potential data breach legislation

- ✓ The Confidentiality Coalition convened major healthcare organizations on critical national cybersecurity legislation. In 2015, this work revolved around S. 754, the “Cybersecurity Information Sharing Act” (CISA).
 - In November and December, HLC led a group of healthcare associations in discussions to improve CISA’s healthcare language during last-minute House and Senate negotiations before and after Senate passage.
 - In October, HLC endorsed CISA and worked closely with sponsors to ensure successful passage in the full Senate. On October 28, the U.S. Senate voted 74-21 to approve CISA.
 - Members met with leaders in the cybersecurity space, including Senator Burr, chairman of the Senate Intelligence Committee and leaders from the U.S. Department of Homeland Security.
- ✓ The Confidentiality Coalition emphasized the importance of avoiding efforts that would duplicate privacy and security rules and efforts already underway in the health sector. We worked closely with committee staff from the Senate Health, Education, Labor, and Pensions (HELP) Committee and the Senate Select Committee on Intelligence, among others, to ensure cybersecurity and breach notification legislation does not create duplication with existing information security structures or conflict with existing laws, such as HIPAA.
 - Throughout 2015, the coalition continued to lobby on potential data breach legislation in both the House and Senate to discuss the potential problems with dual regulation of HIPAA-covered entities and their business associates by non-HHS agencies. As a result of these meetings, draft data breach notification bills have been edited to be more favorable to healthcare organizations.
- ✓ The Confidentiality Coalition convened members to share information from a healthcare company who had recently experienced a major cyberattack – leading to shared experience and recommendations for best practices in working with federal officials and others after a cyberattack.

Simplifying Health Information Flow

A leading voice for clear and consistent regulation of health information across state borders and federal government programs

- ✓ The Confidentiality Coalition provided multisector consensus feedback to the Department of Health and Human Services (HHS) on the Notice of Proposed Rulemaking (NPRM) on Federal Policy for the Protection of Human Subjects. The coalition commended HHS proposals designed to streamline and improve the internal review board process, while expressing concerns that certain consent proposals could lead to confusion and may delay research studies.
- ✓ The Confidentiality Coalition continues to lead the health industry in seeking an alternative to the unworkable “accounting-of-disclosures” proposed HIPAA privacy regulation. According to various sources, the HHS Office for Civil Rights (OCR) may issue another request for comment soon.
 - As proposed in 2011, the regulation would require HIPAA-covered entities to provide consumers 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 to or viewed protected health information.
 - This approach would require massive, expensive changes to healthcare information systems across the country, with little benefit to individuals. The proposed rule has not gone into effect largely because of ongoing opposition and activity by health organizations, some consumer groups, and others convened by the Confidentiality Coalition.
- ✓ The Confidentiality Coalition supported the work of the Healthcare Leadership Council’s (HLC) National Dialogue for Health Innovation, which has convened senior experts to discuss outdated and ineffective laws and regulations. Several top priorities revolve around barriers to information flow, including harmonizing consent requirements for research institutions, promoting greater alignment between federal and state privacy rules, and “overinterpretation” of existing HIPAA protections in a way that hinders information flow.
- ✓ The Confidentiality Coalition continued to monitor increasing Federal Trade Commission (FTC) involvement in healthcare activity, particularly around health data breaches. In 2015, the FTC affirmed its beliefs that it has the authority and mandate to regulate HIPAA-covered entities in the instance of a data breach and is expanding its work to monitor non-HIPAA-covered health information held by various organizations. FTC authority was confirmed by an August appeals court ruling on the issue.

Convening and Educating Leaders

Convened leaders and experts to educate Washington about the need for and potential of safe, confidential, health information exchange

- ✓ The Confidentiality Coalition continues to serve as a partner to HHS in framing and participating in the annual Health Datapalooza summit. The Coalition hosted a privacy workshop for entrepreneurs in 2015, convening experts from HLC, OCR, FTC, and the Confidentiality Coalition. The Coalition began work with the administration to plan a privacy and security summit for the 2016 event.
- ✓ The Confidentiality Coalition has taken an active role in the implementation of a key provision in the HHS Office of the National Coordinator (ONC) for Health Information Technology's interoperability roadmap that was released in 2015. The provision seeks to ensure more consistency in health information privacy rules across state boundaries.
 - Subsequently, Coalition members provided recommendations and expertise to both ONC and the National Governor's Association (which has received a grant to support ONC's effort) on the potential harmonization of state privacy laws to facilitate interoperability.
- ✓ The Confidentiality Coalition held another successful HIPAA 101 congressional staff briefing in 2015. Experts from the Cleveland Clinic and Surescripts joined the coalition's chair and counsel in educating congressional staff and other attendees about the HIPAA privacy rule. Following this event, Coalition staff assisted several congressional offices with health privacy inquiries.
- ✓ The Confidentiality Coalition continues to provide a positive public voice for ensuring the right balance between the protection of confidential health information and the efficient and interoperable systems needed to provide high quality healthcare. These efforts are communicated through comment letters, correspondence, meetings, press activities, and the Coalition's website, www.confidentialitycoalition.org.