



GENERAL COMMITTEE MEETING

Thursday, April 11, 2019

3:00 PM to 4:00 PM

Healthcare Leadership Council

750 9th Street, NW, Suite 500 Washington, D.C. 20001

Conference Line: 857-232-0157, **Code:** 30-40-73

1. Welcome and Introductions

2. Proposed Rules (Privacy and Security)

*ONC: Information Blocking Interoperability
and the ONC Health IT Certification Program*

CMS: Interoperability & Patient Access

a. Patient Matching

- i. **Guest Speakers:** Ben Moscovitch, Project Director, Health Information Technology, The Pew Charitable Trusts; Rita Torkzadeh, Officer, Health Information Technology, The Pew Charitable Trusts

3. Federal Privacy Legislation

- a. Hill Meetings
- b. Federal Data Privacy Proposals
- c. Privacy Focused Lobbying Effort

Attachment 1
Attachment 2

Next Meeting: May 16, 3:00 pm - 4:00 pm

Federal data privacy proposals

An overview of privacy proposals introduced in the 115th and 116th Congresses

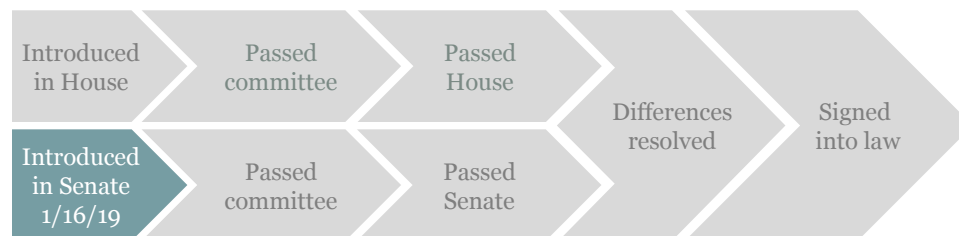


Legislation tracker: data privacy in the 116th Congress

S. 142: American Data Dissemination Act

Sponsor: Sen. Marco Rubio (R-FL)

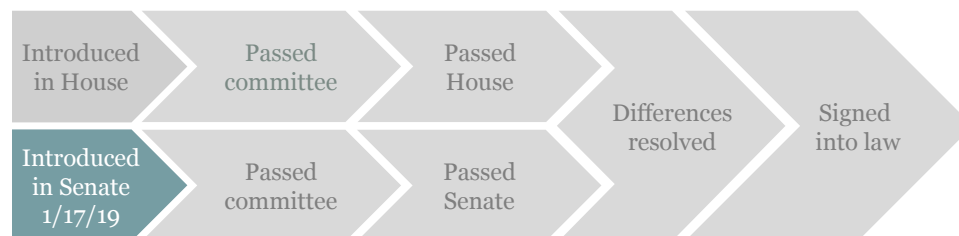
- Requires the FTC to provide Congress with recommendations for privacy legislation for Internet Service Providers within six months, using the 1974 Privacy Act as a framework
- Authorizes the FTC to create privacy regulations based on the Privacy Act, should Congress fail to act on the FTC's recommendations within two years; with exceptions for newer or smaller companies



S. 189: The Social Media Privacy Protection and Consumer Rights Act

Sponsors: Sen Amy Klobuchar (D-MN)

- Requires companies to report data breaches to consumers within 72 hours of discovery
- Requires companies to inform consumers that their personal data will be collected by operators or third parties, and allows access to the data collected
- Allows users to opt out of data collection, but permits companies to deny products or services if the users' privacy options are not operable



Sources: Congress.gov; Sen. Marco Rubio, "Congress needs to address consumer data privacy in a responsible and modern manner," The Hill, Jan. 16, 2019; "The American Data Dissemination Act," Marco Rubio Press Release, January 16, 2019.



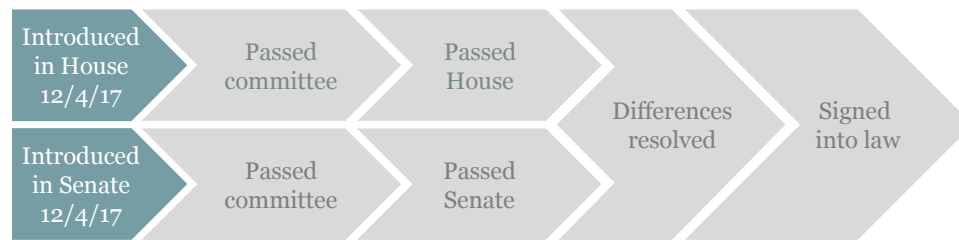
Legislation tracker: data privacy in the 115th Congress

H.R. 4543/S. 2187: Commercial Privacy Bill of Rights Act of 2017 (short title)

House Sponsor: Rep. Albio Sires (D-NJ-08)

Senate Sponsor: Sen. Robert Menendez (D-NJ)

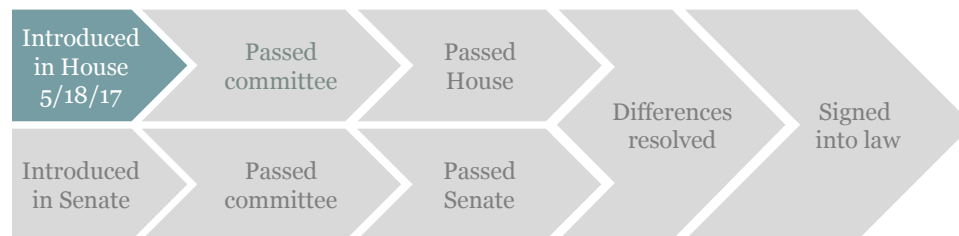
- Amends the Children's Online Privacy Protection Act of 1998 to improve provisions relating to collection, use, and disclosure of personal information of children



H.R. 2520: BROWSER Act of 2017

Sponsor: Rep. Marsha Blackburn (R-TN-07)

- Reinstates the FCC's Obama-era internet privacy rules that prohibit ISPs from sharing or selling individuals' personal data without their consent — Congress voted in 2017 to repeal the FCC's rules
- Extends the FCC's rules to apply to companies such as Google and Facebook, which were not subject to the rules before
- Establishes the FTC as the enforcer of internet privacy rules



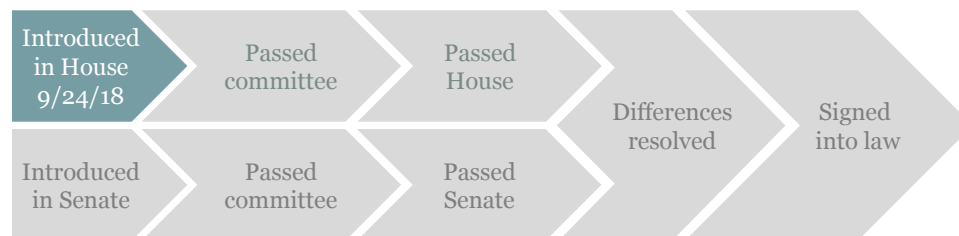


Legislation tracker: data privacy in the 115th Congress

H.R. 6864: Information Transparency & Personal Data Control Act

Sponsor: Rep. Suzan DelBene (D-WA-01)

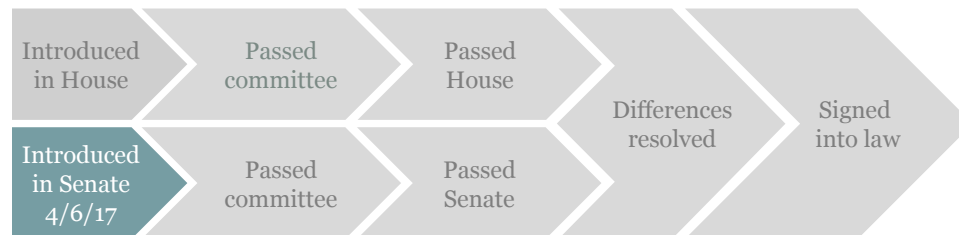
- Requires companies to obtain opt-in consent before collecting and using sensitive personal data
- Requires companies to notify consumers if and with whom their personal data is being shared as well as the purpose of disseminating such data
- Provides rulemaking authority to the FTC



S. 878: A bill to establish privacy protections for customers of broadband Internet access service and other telecommunications services

Sponsor: Sen. Edward Markey (D-MA)

- Amends the Communications Act of 1934 to require ISPs to notify individuals about the collection, use, and sharing of personal data
- Require ISPs to obtain opt-in consent before using and sharing sensitive personal data



Sources: Congress.gov, 2019; Govtrack.us; "DelBene Introduces Legislation to Regulate Consumer Privacy," Suzane DelBene Press Release, September 20, 2018; "Senator Markey Leads Senators in Legislation to Fully Restore Broadband Privacy Protections," Edward Markey Press Release, April 7, 2017.

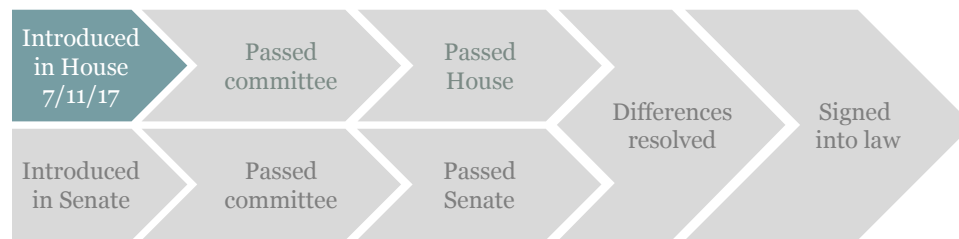


Legislation tracker: data privacy in the 115th Congress

H.R. 3175: Online Privacy Act

Sponsor: Rep. Keith Ellison (D-MN-5)

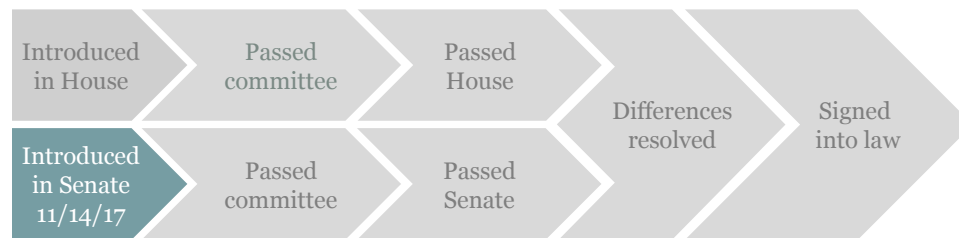
- Amends the Communications Act of 1934 to require ISPs to notify individuals about the collection, use, and sharing of personal data
- Requires ISPs to obtain opt-in consent before using and sharing sensitive personal data



S. 2124: Consumer Privacy Protection Act of 2017

Sponsor: Sen. Patrick Leahy (D-VT)

- Requires companies to meet certain baseline standards for consumer privacy and data security
- Requires companies to notify consumers when a data breach occurs





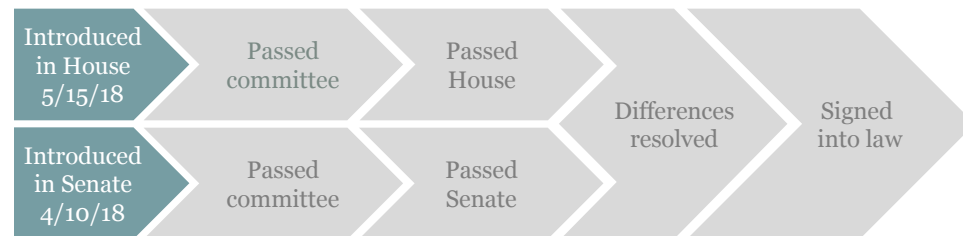
Legislation tracker: data privacy in the 115th Congress

S. 2639/H.R. 5815: CONSENT Act

House Sponsor: Rep. Michael Capuano (D-MA-07)

Senate Sponsor: Sen. Edward Markey (D-MA)

- Requires edge providers, such as Facebook and Google to obtain opt-in consent from consumers to use, share, or sell personal data
- Requires edge providers to implement reasonable data security practices
- Requires edge providers to notify consumers about any collection, use, and sharing of personal data
- Requires edge providers to notify consumers when a data breach occurs
- Authorizes the FTC to enforce these regulations

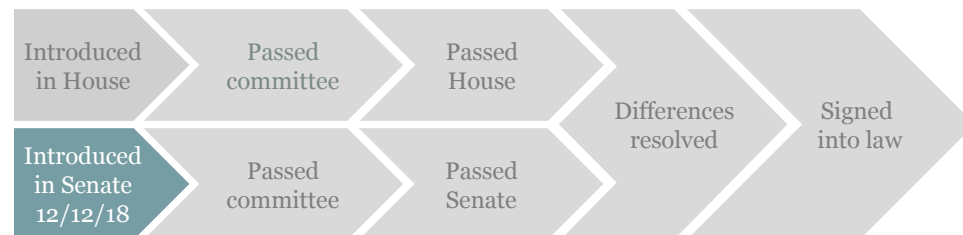


S. 3744: Data Care Act of 2018

Sponsor: Sen. Brian Schatz (D-HI)

Establishes “duties” that require ISPs to protect consumer data and privacy:

- Duty of Care — ISPs reasonably secure personal data and notify consumers if a data breach occurs
- Duty of Loyalty — ISPs must not use data in a way that harms consumers
- Duty of Confidentiality — ISPs must ensure that the duties of care and loyalty apply to third parties when sharing or selling personal data
- Authorizes the FTC to enforce these regulations



Sources: Congress.gov, 2019; “As Facebook CEO Zuckerberg Testifies to Congress, Senators Markey and Blumenthal Introduce Privacy Bill of Rights,” Edward Markey Press Release, April 10, 2018; “Schatz Leads Group of 15 Senators in Introducing New Bill to Help Protect People’s Personal Data Online,” Brian Schatz Press Release, December 12, 2018.

Key privacy principles

Since the passage of GDPR and CA privacy law, several organizations and lawmakers have released proposed policy recommendations for a federal privacy law, which generally cover these key concepts:



Enforcement

1. Federal preemption

Should federal or state regulators be responsible for enforcing privacy laws?

2. Regulatory scope

Should a privacy law apply equally to all industries, technologies, and sizes of companies?

3. Regulatory flexibility

Should the law draw a clear distinction between required protections and treatment of “personal data” vs. “sensitive personal data?”



Corporate responsibility

1. Transparency

What responsibilities should companies have to inform consumers regarding data collection, use, and sharing?

2. Collection limits

Should there be restrictions on the types of data that companies are allowed to collect?

3. Data breach notification

Should there be a single federal standard for notifying consumers in the event of a data breach?



Consumer rights

1. Right to access, modify, export, and delete

What types of rights should consumers have to access, modify, export, and delete their data?

2. Consent

Should consumers have to provide explicit consent for companies to collect any personal data? What mechanism of consent is necessary?

3. Private right of action

Should the law enable consumers to sue an organization directly for civil penalties if that entity violates the privacy law?

Trends in selected privacy proposals

Draft legislation from Sen. Ron Wyden (D-OR), the US Chamber of Commerce, and Intel reach consensus on these broad themes:

Federal baseline standards

There is an urgent need for a federal law that:

- Establishes baseline cybersecurity and privacy standards
- Ensures strong privacy protections while promoting innovation

Transparency

Companies should be required to be transparent with consumers about:

- The type of personal data they have collected
- The purpose for its collection
- If and when their data is being shared

Expanded FTC Authority

The FTC should have expanded authority and resources to:

- Create and implement privacy rules
- Address threats to consumer privacy
- Enforce penalties for violations

Consumer control

Consumers should have more control over their personal data, and should have opportunities to:

- Access and correct inaccuracies in data that a company has collected about them
- Make informed choices about their data (opt-in/opt-out)



Comparison of proposed federal privacy bills

The proposals have differing policy recommendations for key privacy principles

Principle	Sen. Wyden proposal	US Chamber proposal	Intel proposal
Federal preemption	<ul style="list-style-type: none"> • Does not preempt any existing state data security & privacy laws, including data breach notification laws 	<ul style="list-style-type: none"> • Preempts any existing state data security & privacy laws, including data breach notification laws 	<ul style="list-style-type: none"> • Preempts any existing state data security & privacy laws, except for data breach notification laws
Enforcement	<ul style="list-style-type: none"> • Expands the FTC's powers and resources, but does not provide authority to preempt state laws 	<ul style="list-style-type: none"> • Establishes the FTC as the primary enforcer of the regulations 	<ul style="list-style-type: none"> • Establishes the FTC as the primary enforcer of the regulations
Scope	<ul style="list-style-type: none"> • Applies only to companies with over \$50M in avg. annual revenue or data on at least 1M consumers • Does not address sector neutrality 	<ul style="list-style-type: none"> • Sector neutral – applies equally across all industry sectors 	<ul style="list-style-type: none"> • Applies to all companies under the FTC's authority, except for organizations with fewer than 25 employees and those that collect personal data from fewer than 50,000 individuals
Consent	<ul style="list-style-type: none"> • Opt-out – requires companies to honor requests to not share consumers' personal data with third-parties 	<ul style="list-style-type: none"> • Opt-out – requires companies to honor requests to not share consumers' personal data with third-parties 	<ul style="list-style-type: none"> • Tailored – requires corporations to provide explicit notice ("opt-in") when collecting sensitive data, but not necessarily for other types of data
Penalties	<ul style="list-style-type: none"> • Enforces fines of up to 4% of annual revenue for a company's first offense and imprisonment of up to 20 years for noncompliance 	<ul style="list-style-type: none"> • Does not specify fines or other penalties for noncompliance 	<ul style="list-style-type: none"> • Enforces fines of up to \$1M and imprisonment of up to 10 years for noncompliance
"Safe harbor"	<ul style="list-style-type: none"> • Does not include a safe harbor 	<ul style="list-style-type: none"> • Includes a safe harbor for companies that certify they are in compliance 	<ul style="list-style-type: none"> • Includes a safe harbor for companies that certify they are in compliance

Sources: "Section-by-Section Analysis and Explanation Consumer Data Protection Act of 2018" Sen. Ron Wyden, November 2018; "An Ethical and Innovative Privacy Law," Intel Corporation, January 28, 2019; "Model Privacy Legislation," US Chamber, February 2019.

Ad Industry Trade Groups Unite in New Privacy-Focused Lobbying Effort

Privacy for America set to meet with lawmakers, regulators and the White House

BY **SAM SABIN** April 8, 2019 at 4:33 pm ET

In the next few weeks, members of a nascent advertising industry-backed coalition are set to visit Washington to meet with stakeholders in Congress, the White House and a handful of agencies to make their case for a federal privacy bill that includes a stronger Federal Trade Commission enforcement arm and restrictions on which data is collected from consumers.

Privacy for America, which launched Monday, includes leaders of the American Association of Advertising Agencies (or 4A's), the Association of National Advertisers, the Interactive Advertising Bureau and the nonprofit Network Advertising Initiative. Its framework for a national privacy measure calls for limits on how data collected for advertising is used, including prohibiting discriminatory targeted advertising and restricting the collection and sharing of sensitive data without permission, as well as the creation of a Data Protection Bureau within the FTC and enhanced rulemaking authority and enforcement measures over companies in data breach cases.

A spokesperson for the group told Morning Consult that leaders are planning new aspects to the advocacy campaign in addition to the scheduled meetings and that funding will be dedicated to the effort; however, a set amount and range has not been established yet.

The framework, which also calls for pre-emption of similar state laws, comes from some industry groups who count tech giants such as Google

and Facebook Inc., as well as a mix of brands and advertising agencies, as members — signaling a readiness to increase lobbying efforts on data privacy as more states and countries pass strict rules of their own.

To draft the framework, Privacy for America conducted its own poll research on consumer interest in such a law and enlisted the help of the FTC's former Bureau of Consumer Protection Director Jessica Rich and Stuart Ingis, co-chair of Venable LLC's e-commerce, privacy and cybersecurity group, as advisers.

"It's imperative for our entire industry to get this right," IAB Chief Executive Randall Rothenberg said in a call with reporters. "We have to move forward. We have reached a point where there have been a number of faux pas in the industry that it's time to rectify and get this done right."

RELATED: [How Regulation Threatens Not Just Tech Giants' Business but Their Popularity Too](#)

While the group did not disclose which lawmakers it plans to meet with, Rothenberg said members of Congress have viewed the framework "favorably" in IAB's meetings. Aides to the House Energy & Commerce and Senate Commerce committees did not respond to requests for comment ahead of publication.

Dave Grimaldi, executive vice president for public policy at IAB, said in an interview following a call with reporters that the goal is to target not just the two committees that have jurisdiction over drafting a national bill, but also to reach groups that might have more niche interests in the issue.

"There are members we need to talk to in every corner of Congress," he said, noting that House Democrats have raised issues about discrimination enabled by broad data collection practices.

Facebook and Google are both members of the IAB, but Rothenberg said he has not heard back from the two companies regarding the

framework, which could change how the tech giants operate their advertising-fueled businesses.

ANA Chief Executive Bob Liodice said the framework is meant to impact the industry equally, rather than focus on a specific sector.

“We recognize that this is not going to be evenly done across the board, but I think that everybody is ready to sign on to this new paradigm because it’s fair and balanced for consumers and across different industries,” Liodice said during the call.

The Privacy for America spokesperson noted that the ad industry groups have worked together in a coordinated effort before, with recent work focusing on issues surrounding advertising taxes and rulemaking for a children’s online bill. Grimaldi pointed to the creation of the nonprofit Digital Advertising Alliance, a group that involves the same cast of industry associations, as an effort that focuses on self-regulation of privacy practices.

Grimaldi also said Privacy for America wanted to create a privacy framework that didn’t just focus on the advertising and tech industries, but rather on as many consumer-facing industries as possible, which is why they decided to launch the coalition now.

“We’ve reached a critical mass where it was time to announce that we were going to march forward together,” he said.

Calls for federal data privacy legislation and tougher enforcement regulations aren’t new among company executives: In January, Apple Inc. CEO Tim Cook laid out his principles for federal privacy legislation in a Time magazine op-ed, including the creation of a “data-broker clearinghouse” within the FTC. Facebook’s Mark Zuckerberg also said the United States needs tougher laws on internet content moderation, election integrity, privacy and data portability in a Washington Post op-ed earlier this month. Twitter Inc. CEO Jack Dorsey also joined the call for regulation following Zuckerberg’s piece last week.

Facebook and Google did not immediately respond to requests for comment.