

Coalition For Healthcare Communication: 2019 Rising Leaders Conference

How Will Data Privacy Be Regulated?

Alison Pepper, 4A's, SVP, Government Relations

May 22, 2019



DATA PRIVACY

The Media Coverage Has Gotten Louder

Menu

Search

Bloomberg

Sign In

Subscribe

Politics

Facebook, Google Data Collection Under Fire in New Privacy Bill

By [Ben Brody](#)

May 20, 2019, 9:30 AM EDT

- ▶ Republican Senator Josh Hawley proposes 'Do Not Track' Measure
- ▶ Measure would ban companies from profiling users that opt out

DICKINSON WRIGHT PLLC
global leaders in law.

United States: App Users Beware: Most Healthcare, Fitness Tracker, And Wellness Apps Are Not Covered By HIPAA And HHS's New Faqs Makes That Clear

Last Updated: May 13 2019

Article by [Sara H. Jodka](#)

Dickinson Wright PLLC



Opinion

LETTER

Facial Recognition Technology Ban: A Victory for Privacy

A reader hails San Francisco's blocking of a law-enforcement tool.

BECKER'S
HEALTH IT & CIO REPORT

BECKER'S
HOSPITAL REVIEW

**5TH ANNUAL HEALTH IT +
REVENUE CYCLE CONFERENCE**

OCTOBER 9-12, 2019
HYATT REGENCY | CHICAGO, ILLINOIS

[CLICK HERE TO REGISTER](#)



Hillary Rodham Clinton
Former Secretary of State



Peyton Manning
NFL Legend



Kevin O'Leary
HBA, Chairman, O'Shang CP Investments,
and Star, ABC's Shark Tank

14 healthcare privacy incidents in April

[Mackenzie Garrity](#) - Wednesday, May 1st, 2019 [Print](#) | [Email](#)

A's

Do Consumers Actually Care About Privacy?

As the hysteria and media frenzy settles down (slightly) after the data breach of-the-moment with Facebook, the imperative to protect and ensure data privacy grows even stronger. We're all wondering, who will be hacked next?

In fact, a new [survey](#) by IBM conducted by The Harris Poll found that **60 percent of global consumers are actually more concerned about cybersecurity than a potential war.**

The online survey of 10,000 global consumers also found that:

- 69 percent said it is extremely important that companies are accessible in the wake of a data breach;
- 73 percent indicated it is extremely important companies quickly take proper actions to stop a data breach;
- 75 percent will not buy a product from a company – no matter how great the products are – if they don't trust the company to protect their data;
- 73 percent think businesses are focused on profits over addressing consumers' security needs.

Congress On Privacy

Refined by: [privacy](#) ✕ [Legislation](#) ✕ [116 \(2019-2020\)](#) ✕

Hide Filters ^

Hide Tracker ^

1-100 of 209

Sort by

Relevancy

View

Expanded

Limit Your Search



[Check all](#)

☒ [Legislation](#) [209]

☐ [Congressional Record](#) [168]

☐ [Committee Reports](#) [35]

☐ [Nominations](#) [3]

☐ [Treaty Documents](#) [2]

☐ [House Communications](#) [7]

☐ [Senate Communications](#) [8]

BILL

1. [S.189](#) — 116th Congress (2019-2020)

Social Media Privacy Protection and Consumer Rights Act of 2019

Sponsor: [Sen. Klobuchar, Amy \[D-MN\]](#) (Introduced 01/17/2019) **Cosponsors:** (1)

Committees: Senate - Commerce, Science, and Transportation

Latest Action: Senate - 01/17/2019 Read twice and referred to the Committee on Commerce, Science, and Transportation. ([All Actions](#))

Tracker:

Introduced

Passed Senate

Passed House

To President

Became Law

BILL

2. [S.583](#) — 116th Congress (2019-2020)

What's Included In Privacy Legislation?

- Transparency
- Accountability
- Privacy Policy
- Portability
- Consent
- Opt-Out
- Consumer Access Rights
- Social Media
- Genetic Information
- Facial Recognition
- COPPA Amendments
- FERPA Amendments
- Prohibit Aircraft From Having Cameras
- Artificial Intelligence
- Algorithmic Fairness



PRIVATE

Algorithmic Accountability Act Of 2019 (S. 1108, H.R. 2231)

Under the bill(s), the FTC could require companies to perform “impact assessments” on their own algorithmic decision-making systems. Those assessment would assess potential consequences for “accuracy, fairness, bias, discrimination, privacy and security” within automated systems and companies would be required to correct any issues they uncovered during the process.

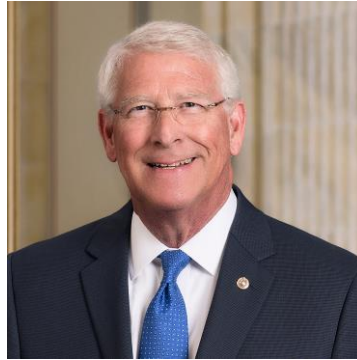


While the thresholds for applicability are high in these bills, these types of bills will likely proliferate (both at the federal and state level) as more and more predictive algorithms come into use. This could impact the use of algorithms in finding patterns across disparate clinical data sets.

Senate Bipartisan Efforts On Privacy



Sen. John Thune
(R – SD)



Sen. Roger Wicker
(R – MS)



Sen. Jerry Moran
(R – KS)



Sen. Maria Cantwell
(D - WA)

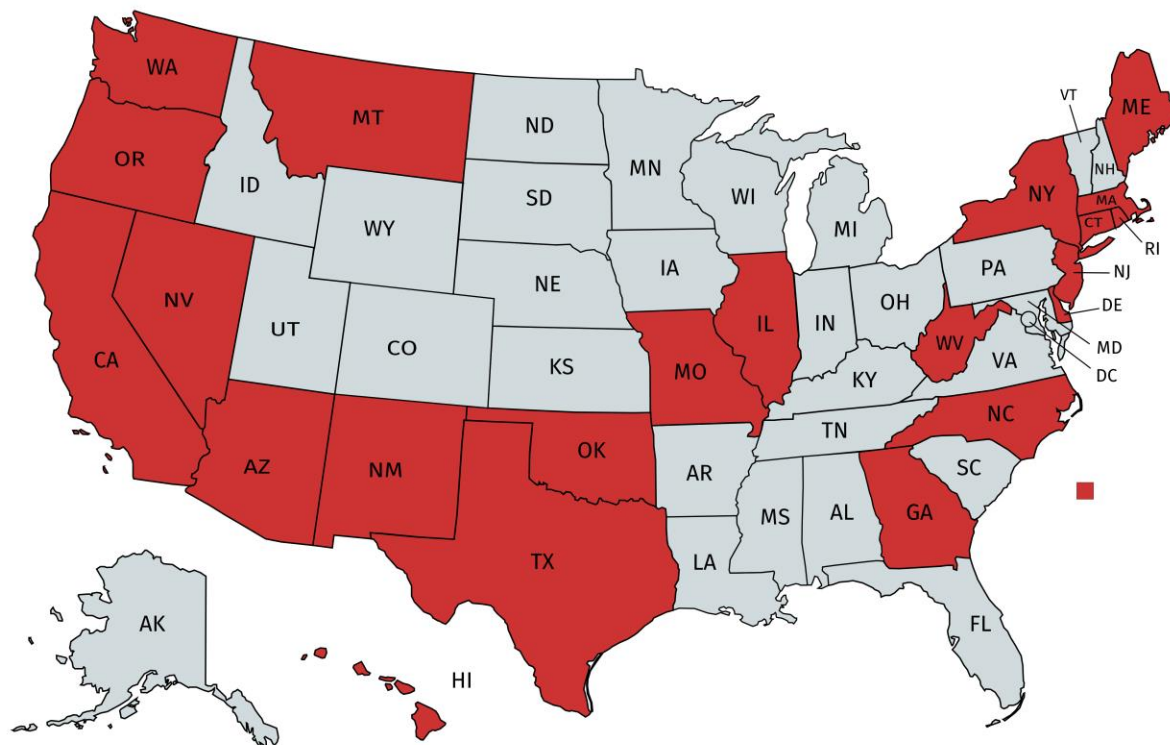


Sen. Richard Blumenthal
(D - CT)

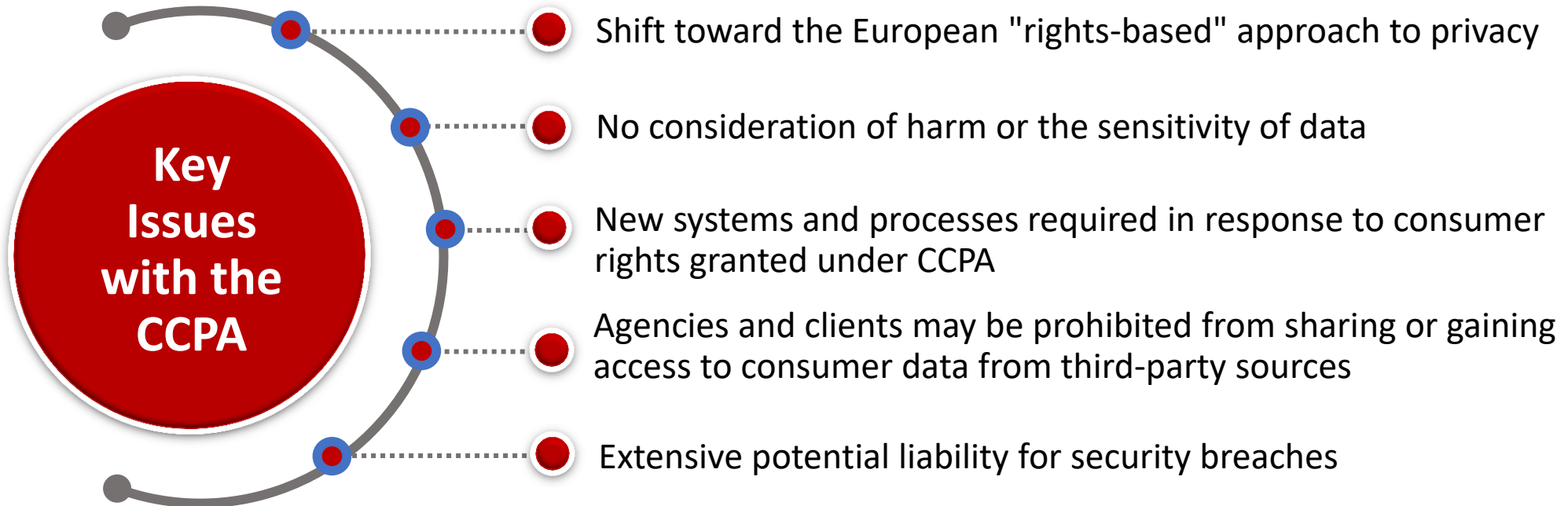


Sen. Brian Schatz
(D - HI)

In The Absence Of Federal Legislation, The States Have Moved Quickly To Fill The Vacuum: Highlighted States Below Have Privacy, Data, Security Or Other Advertising Legislation Active



Enter The CCPA



How Is The CCPA Being Shaped After Passage?

Post-passage, the CCPA is being shaped in two main ways:

1. Since January, the California Attorney General's Office has been holding a series of public hearings around the state to get input into problems with the CCPA. The AG's Office is tasked with providing interpretive guidance on complying with the CCPA.
2. Legislative amendments are being introduced by both the Assembly and the Senate. Some of these amendments are technical clarifications, and some of these amendments are proposing big changes.

CCPA Exemptions And Health Companies

- CCPA does not apply to medical information already covered by California's Confidentiality of Medical Information Act (CMIA), Protected Health Information (PHI) already covered by the Health Insurance Portability & Accountability Act (HIPAA), and information covered as part of a clinical trial that is already subject the Common Rule, GCP guidelines, or FDA requirements.
- CCPA also does not apply to aggregate consumer information or de-identified information.
- There is also a research exemption for personal information used for public or peer-reviewed research in the public interest (also states that the personal information is not to be used for any commercial purpose).
- **Non-Exempt Data (i.e. covered by CCPA): marketing data, customer service call information, social media and app data, data licensed by a third party, etc.**

The 4A's Advocacy With The California AG's Office



March 8, 2019

The Honorable Xavier Becerra
California Department of Justice
ATTN: Privacy Regulations Coordinator
300 S. Spring Street
Los Angeles, CA 90013

Submitted via privacyregulations@doj.ca.gov

RE: California Consumer Privacy Act Regulation

Dear Attorney General Becerra:

As the nation's leading advertising and marketing trade associations, we collectively represent thousands of companies in California and across the country, from small businesses, to household brands, across every segment of the advertising industry, including a significant number of California businesses. Our combined membership is responsible for more than 85 percent of the U.S. advertising spend. Locally, our members help generate some \$767.7 billion dollars for the California economy and support more than 2 million jobs in the state.

Consumer trust is vital to our members' ability to successfully operate in the marketplace, and they take that responsibility seriously. A prime example of this commitment is through the Digital Advertising Alliance ("DAA") YourAdChoices Program. We helped create the DAA to establish a self-regulatory code for all companies that collect or use data for interest-based advertising, based on practices recommended by the Federal Trade Commission ("FTC") in its 2009 report on online behavioral advertising.¹ The effectiveness of the Self-Regulatory Program also has been recognized by the United States government. At a 2012 White House event, Obama Administration officials including the then-FTC Chairman and Secretary of Commerce publicly praised the DAA's cross-industry initiative. The DAA approach has also garnered kudos from the leadership at the FTC under recent administrations for the program's pioneering privacy work.²

We agree that privacy deserves strong meaningful protections in the marketplace, while also allowing for innovative new uses of data to continue to grow the data-driven economy. We appreciate the opportunity to comment on the California Consumer Privacy Act ("CCPA") or "the Act" and its implementation, and to work with the Attorney General ("AG") on these matters. While our members support the CCPA's intent to provide consumers privacy protections, consumers and businesses would benefit from clarification concerning certain provisions of the

¹ DAA, *Self-Regulatory Principles for Online Behavioral Advertising* (Jul. 2009); FTC, *FTC Staff Report: Self-Regulatory Principles For Online Behavioral Advertising* (Feb. 2009).

² The White House recognized the Self-Regulatory Program as "an example of the value of industry leadership as a critical part of privacy protection going forward." The DAA also garnered kudos from then-FTC Commissioner Maureen Ohlhausen who stated that the DAA "is one of the great success stories in the [privacy] space." In its cross-device tracking report, the FTC staff also praised the DAA for having "taken steps to keep up with evolving technologies and provide important guidance to [its] members and the public. [Its] work has improved the level of consumer protection in the marketplace."

Some Of the Problems With CCPA:

- Unclear As To Explicit Downstream Uses
- Appears to Limit Almost All Uses Of Publicly Available Data
- Suggests Customized Privacy Policies Might Be Required
- Verifying And Responding To Consumer Requests For Data Could Counterintuitively Require Companies To Collect More Data To Verify A Request



Statement of the American Association of Advertising Agencies (4A's) to the California Attorney General on the California Consumer Privacy Act

February 13, 2019

Good afternoon, and thank you for allowing me to make brief comments on the California Consumer Privacy Act (CCPA) and its impact on the digital advertising industry, specifically the advertising agency community. My name is Alison Pepper, and I am the Senior Vice President of Government Relations at the American Association of Advertising Agencies (4A's).

Founded in 1917, the 4A's is a trade association representing advertising agencies across the country. The 4A's helps empower our members to deliver insightful creativity that drives commerce and influences culture all while moving the industry forward. We are dedicated to, and vested in, our members' success, just as they are dedicated to helping brands create, distribute, and measure effective and insightful advertising and marketing. Today the 4A's serves 700+ member agencies across 1,300 offices, which control more than 85% of total U.S. advertising spend. Currently, the 4A's has 213 member agencies based in California, representing approximately 30% of all 4A's members.

The 4A's supports the goals of the CCPA, and understands the need for providing California consumers with more transparency in an increasingly complex online environment. As a founding supporter of the Digital Advertising Alliance ("DAA") back in 2009, an organization dedicated to providing consumers with more control over their data, the 4A's has an established track record of providing consumers with more control over their data and choices when it comes to advertising.

While supporting and recognizing the value of the CCPA, we do have concerns with the CCPA as passed that leaves many agencies unclear on questions as to the future of loyalty programs and promoted by our members. While supporting and recognizing the value of the CCPA, we do have concerns with the CCPA as passed that leaves many agencies unclear on questions as to the future of loyalty programs and promoted by our members. While supporting and recognizing the value of the CCPA, we do have concerns with the CCPA as passed that leaves many agencies unclear on questions as to the future of loyalty programs and promoted by our members.



The 4A's Advocacy With The California Legislature



February 20, 2019

Chairman Ed Chau
Privacy and Consumer Protection Committee
Room 156A, Legislative Office Building
1020 N Street
Sacramento, CA 95814

Dear Chairman Chau:

As the nation's leading advertising and marketing trade associations, we write to recommend a set of amendments to the California Consumer Privacy Act ("CCPA") to prevent unintended consequences, including harmful privacy outcomes for California residents.

The undersigned organizations collectively represent thousands of companies in California and across the country, from small businesses to household brands, advertising agencies, and technology providers. Our combined membership includes more than 2,500 companies, is responsible for more than 85 percent of the U.S. advertising spend, and drives more than 80 percent of our nation's digital advertising spend. Locally, our members help generate some \$767.7 billion dollars for the California economy and support more than 2 million jobs in the state.

Our members believe consumers deserve effective and consistent privacy protections supported by reasonable government policies, and we strongly support the objectives of the California Consumer Privacy Act (CCPA), but we have notable concerns around certain negative impacts the law as written will have for California consumers and businesses.

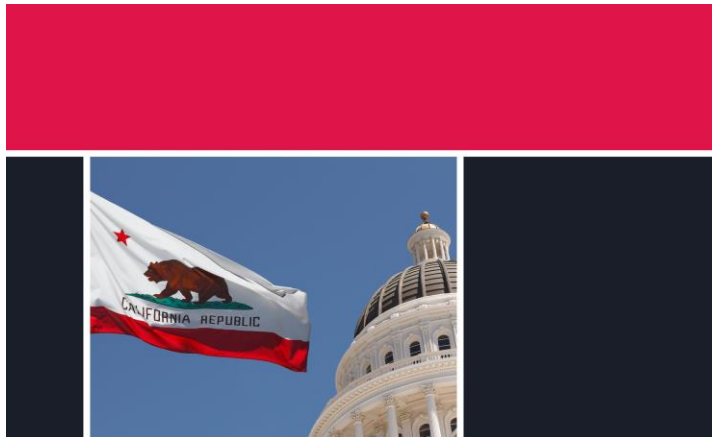
This letter is intended to share some important information about the data-driven and ad-supported online ecosystem, outline ongoing industry efforts to protect privacy, and highlight four fundamental flaws, among others, in the law as it stands today that will ultimately harm consumers. By focusing on these specific issues, we hope policymakers can address them before they have unintended negative effects on consumer privacy, restrict consumer choice, and reduce access to ad-supported digital content and services in California.

I. The Data-Driven and Ad-Supported Online Ecosystem Benefits Consumers and Fuels Economic Growth

The free flow of data online has powered the growth of the Internet by funding innovative tools and services for consumers and businesses to connect and communicate. Data-driven advertising supports and subsidizes most popular digital content and services, including video, news, music, and much more, at little or no cost to the consumer. Companies also collect data for numerous operational purposes including ad delivery and reporting, fraud prevention, network enhancement, and customization. These uses are necessary for a seamless cross-channel, cross-device consumer experience and a functioning digital economy.

The California Legislature, both the Senate and the Assembly, are continuing to introduce new amendments to the CCPA. While some of these amendments could be considered technical fixes, others seek to broaden and expand the CCPA to allow for even broader consumer rights.

Coming Soon: CCPA Guidance For Agencies



THE CCPA: CALIFORNIA CONSUMER PRIVACY ACT
WHAT AGENCIES NEED TO KNOW

4's | VENABLE LLP

A JOINT PUBLICATION OF THE 4A'S AND VENABLE LLP

The 4A's has partnered with Venable LLP to provide CCPA compliance guidance written specifically for agencies. This guidance includes key information for agencies, including:

- Is my agency covered by CCPA?
- What kind of contractual changes with partners do I need to consider?
- My agency already went through a GDPR compliance review –how different is CCPA?
- If I'm already in compliance with COPPA, is there anything to worry about under CCPA when it comes to minors?



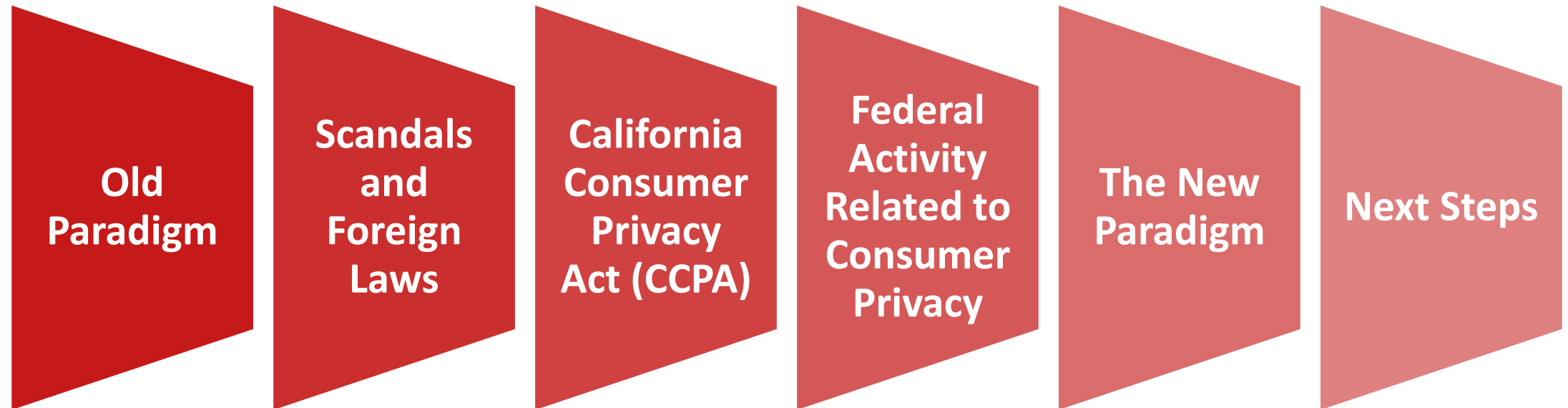
Privacy For America – A Joint Initiative



Mission

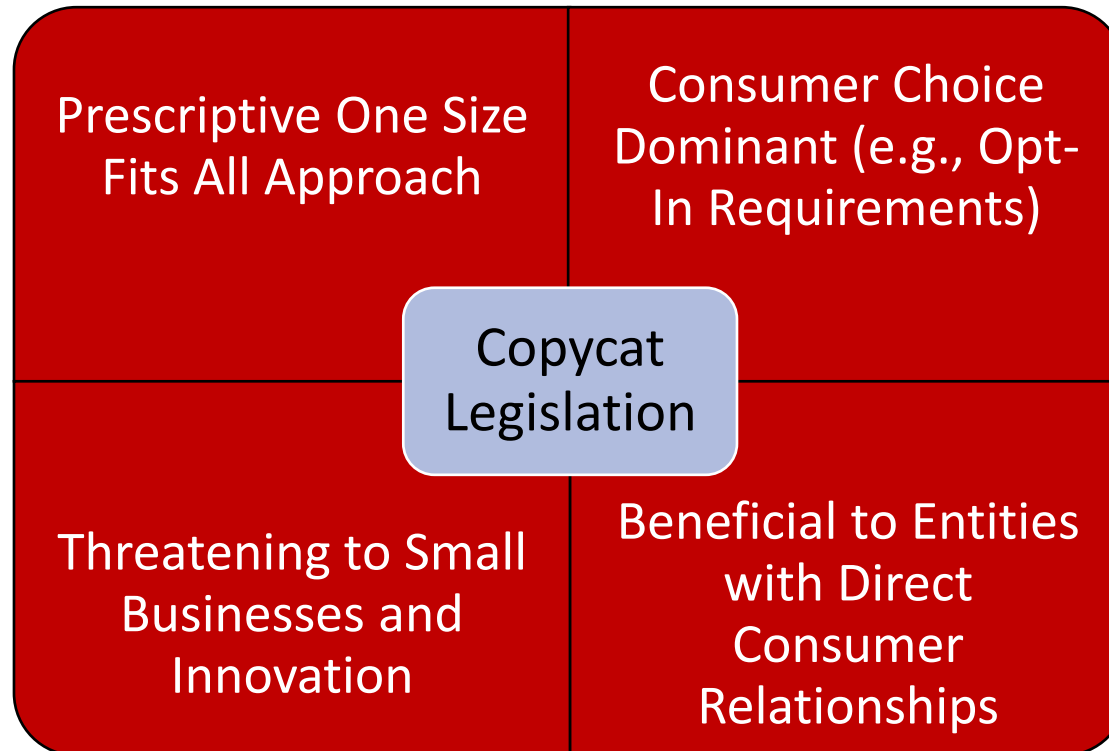
Privacy for America will work with Congress to support enactment of comprehensive federal consumer data privacy and security legislation. We have outlined a bold new paradigm for a national law that would make personal data less vulnerable to breach or misuse and set for clear, enforceable and nationwide consumer privacy protections for the first time.

The New Paradigm: Where We've Been, Where We're Going



Problems With Current Proposals

General Data Protection Regulation 2.0



Numerous stakeholders are advocating legislation modeled after Europe's General Data Protection Regulation. Such an approach fails to appreciate:

- Differences in enforcement culture
- Forces behind U.S. success in digital economy
- Costs on small businesses and non-profits
- Threats to subscription free Internet/services