When The Web Leaks Health Data:
Implications for Consent, PI, and Regulatory Compliance

Dan Frechtling
CEO

Boltive

Justin Brookman
Director, Privacy and Technology Policy

CR Consumer Reports™

Past Collaboration Between Consumer Reports And Boltive

I Said No to Online Cookies. Websites Tracked Me Anyway.

Companies may show you targeted ads even after you opt out of tracking on their websites, Consumer Reports finds

By Thomas Germain

September 29, 2022

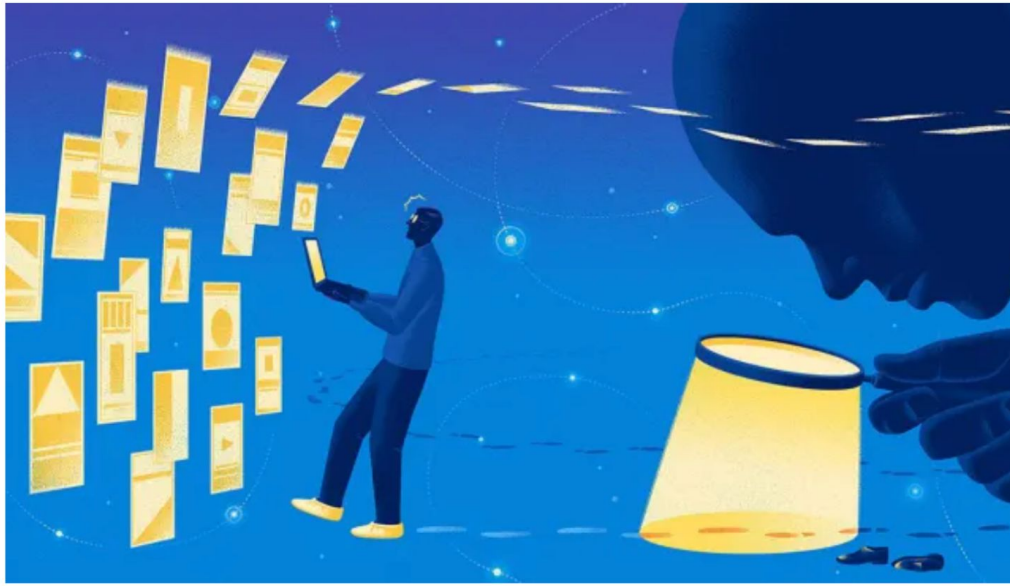


Illustration: Kouzou Sakai

Boltive created a program we called ThomasBot (yes, named after me). The bot would surf the internet using a custom-built web browser that made websites think it was a real guy. Boltive gave the bot a browsing history, just like a real person's. We picked 21 websites to test and sent out an army of ThomasBots to opt out of cookies. Then we watched as they surfed the web for months, taking pictures of every ad they saw.

The goal was to learn whether opting out of cookies prevents targeted ads. The results supported my experience: It seems like the opt-out boxes often don't work.

Boltive

CR Consumer Reports

When The Web Leaks Health Data

Introduction: Closing the loop(holes) In health-relevant data

Methods: *Secret Shoppers* sweep *Target Sites* for compliance

Findings: Privacy disorders present many symptoms

Recommendations: Prevention is better than treatment

Boltive

CR Consumer Reports

Introduction: Closing The Loop(holes) In Health-Relevant Data

- **The HIPAA (and CMIA) cliffs**
  - The Health Insurance Portability and Accountability Act (and California's Confidentiality of Medical Information Act) provide certain protections for medical data
    - Access
    - Security
    - Prohibitions on many secondary uses
  - However, they generally only apply to doctors, insurance companies, and immediate "business associates"
    - Not websites or apps

Boltive

CR Consumer Reports

Consumer Expectations

- **Consumers expect their sensitive health data to be protected**
  - 82% of consumers in a recent UPenn study didn't understand that HIPAA didn't protect data shared with commercial apps
  - Consumers more worried about commercial app usage

Montana becomes latest state to ban gender-affirming care for trans minors

SUPREME COURT OVERTURNS ROE V. WADE

Boltive

CR Consumer Reports

Rise Of New State Laws

- **Comprehensive state laws — opt-out rights**
  - CCPA out of “sale”
    - Updated to opt out of “sharing” (with exceptions)
  - Other states allow opt out of “sale,” “targeted advertising,” and sometimes “profiling”
    - Different definitions, different exceptions
      - Generally OK to share with siloed service providers for operational purposes

Boltive

CR Consumer Reports

Rise Of New State Laws

- **Comprehensive state laws — opt-out rights**
  - Access, deletion, correction
  - Nondiscrimination
    - In many states you can’t treat someone worse after exercising rights
  - Global opt-outs and authorized agents
    - Makes it easier for consumers to exercise at scale

Boltive

CR Consumer Reports

Rise Of New State Laws

- **Comprehensive state laws have expanded to include heightened protections for “sensitive data”**
  - Always includes health data, but with slightly different definitions (e.g., condition vs diagnosis)
  - CPRA expands CCPA to include a right to opt out of first party processing of sensitive data
  - Other states (VA, CO, CT, &c) require affirmative consent before processing sensitive data

Boltive

CR Consumer Reports

Rise Of New State Laws

- **Targeted health data legislation**
  - *My Health, My Data* — just signed in Washington state
    - One of the strongest and most prescriptive privacy laws in the country
    - Separate, specific consent for processing, sharing health data
    - Similar legislation has been introduced in other jurisdictions
  - CA amends CMIA to extend to fertility app data
    - Mental health apps covered in 2022
    - Legislature considering AB 571 to extend to fertility and sexual health apps in 2023
  - CA enacts other protections for fertility data
    - Prohibition on cooperating with law enforcement in jurisdictions that criminalize abortion

Boltive CR Consumer Reports

Expanded Enforcement Of Consumer Protection Law

- **The FTC has brought hundreds of privacy and security cases under its general purposes Section 5 (prohibition on unfair and deceptive practices) authority**
  - Traditionally has relied on "deception"
    - Predicated on a company making an affirmative misstatement about how it treats data
    - *Eli Lilly*
  - But has characterized health information as "sensitive" for at least ten years
    - At least since its 2012 Privacy Report

- In recent years, the FTC has increasingly taken the position that sharing "sensitive data" without clear permission is inherently "unfair"
  - *Vizio* (Smart TVs)
  - *Kochava* (geolocation)

Boltive CR Consumer Reports

Expanded Enforcement Of Consumer Protection Law

- **Recently the FTC has expanded its use of "unfairness" charges to apps that share health data without express permission**
  - *BetterHelp*
    - Mental health app that shared data with advertisers for targeting
  - *GoodRX*
    - Prescription drug discount app shared data with advertisers for targeting
    - The FTC further alleged that sharing health data in this case amounted to a breach of the Health Breach Notification Rule
    - $1.5M penalty

Boltive CR Consumer Reports

Expanded Enforcement Of Consumer Protection Law

- **Expanded state enforcement under consumer protection laws**
  - *Glow*
    - California brought an enforcement action against a fertility app for failing to safeguard data, allowed access to private data
    - $250,000 penalty
  - *Copley Associates*
    - Massachusetts charged an ad targeting company for allowing targeted ads to “abortion-minded women” based on proximity to healthcare facilities without consent

Boltive Consumer Reports

Class Action Litigation

Louisiana Hospitals Added to Class Action Lawsuit

According to multiple local and national news outlets, LCMC Health in New Orleans and Willis-Knighton Medical Centers in northwest Louisiana were recently named in class action lawsuits accusing both healthcare providers of sharing confidential patient health information via social media tracking tools.

Boltive

CR Consumer Reports

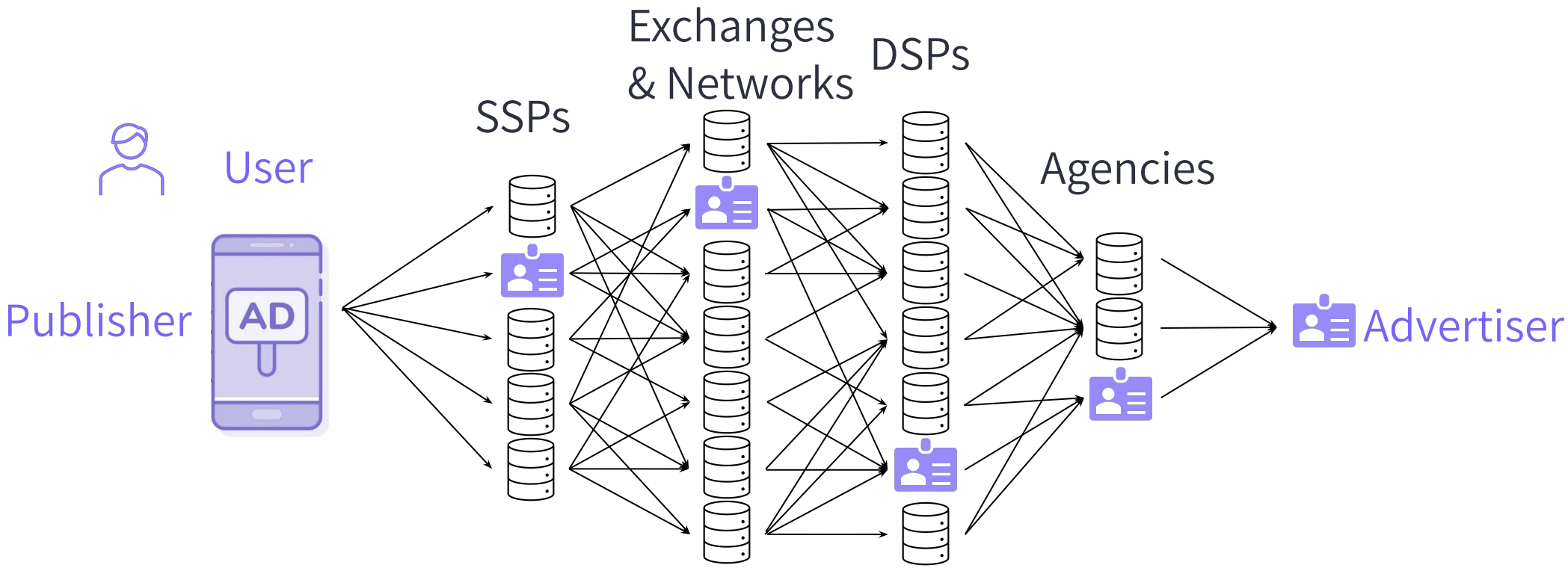
Summary

- New comprehensive privacy laws
- New comprehensive privacy laws with special rules for “sensitive data”
- New health-specific privacy laws
- Expanded use of consumer protection law to address misuse of health data
- Expanded class-action litigation

Boltive

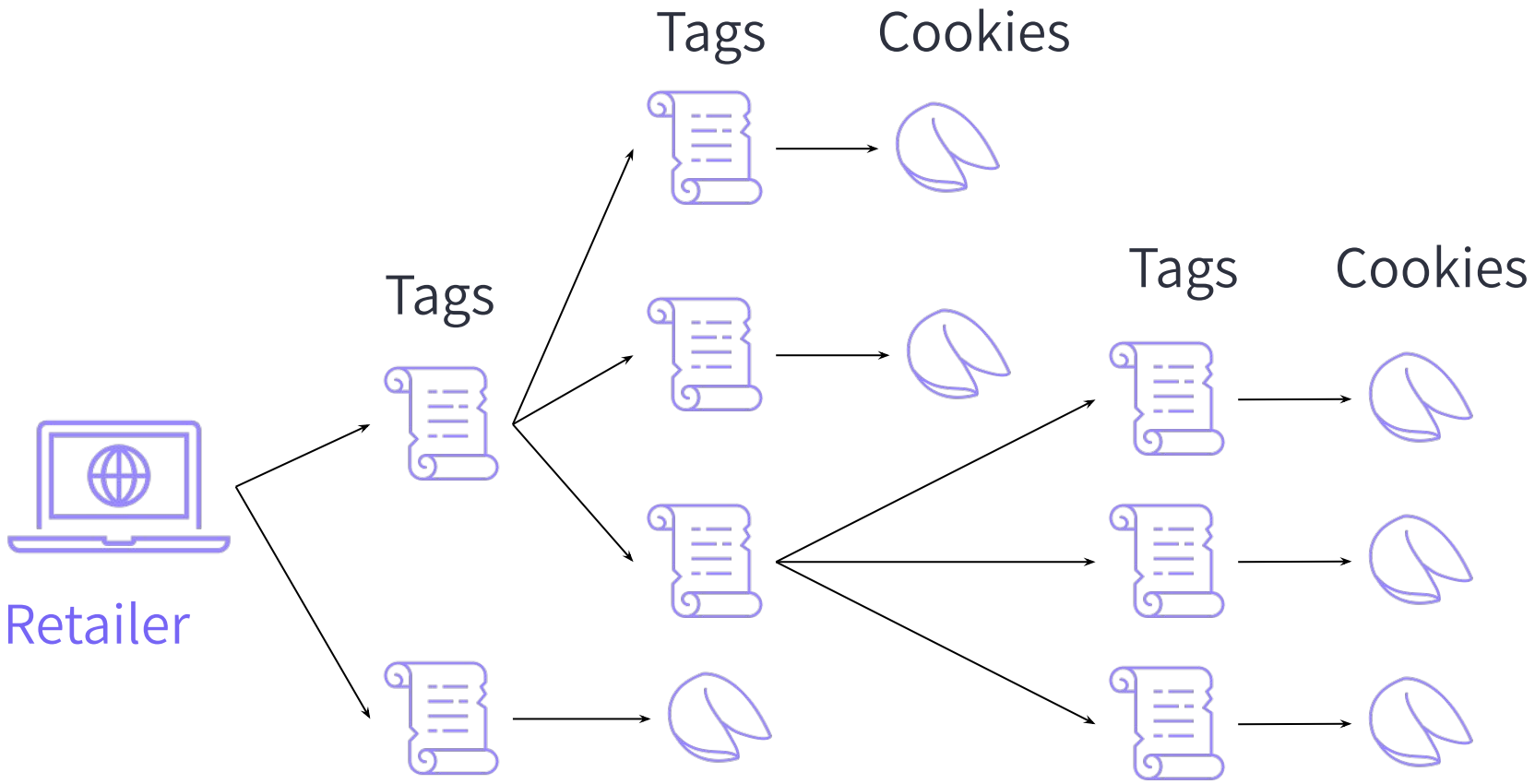
CR Consumer Reports

Interest-Based Ads Share Sensitive Private Information



Hundreds of data elements may be shared, such as health, religion, political beliefs, location, ethnicity and other personal data

Tags Can Piggyback, Allowing 3rd Parties Access To Consumer Web Data



Tags are code snippets or scripts present on web pages. They come from analytics, advertising, and other martech vendors

When The Web Leaks Health Data

Introduction: Closing the loop(holes) In health-relevant data

Methods: *Secret Shoppers* sweep *Target Sites* for compliance

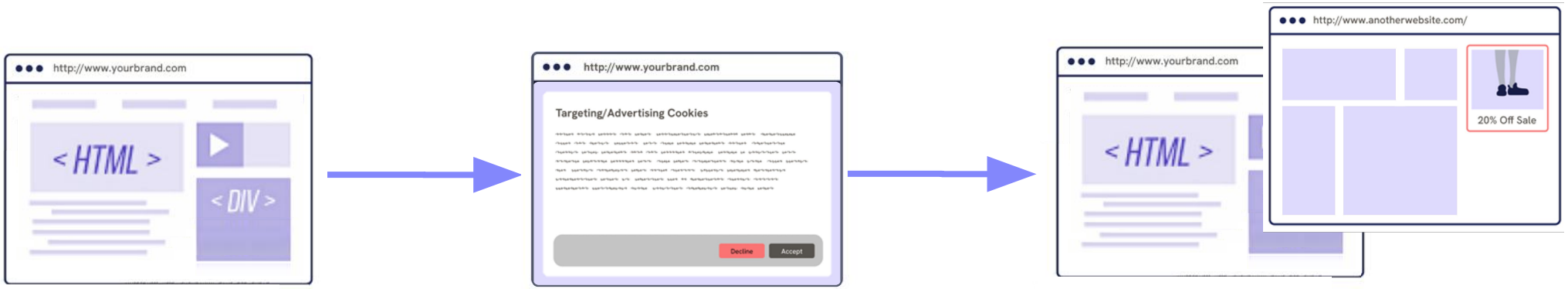
Findings: Privacy disorders present many symptoms

Recommendations: Prevention is better than treatment

Boltive

CR Consumer Reports

Average North American Consumer Faces 100 Consent Drops Per Day



1. User visits website

2. User opts out of data sharing, then browses

3. User opt-out is lost and data is shared by vendors

CMPs: ~30% GPC: ~80% Forms: ~50%

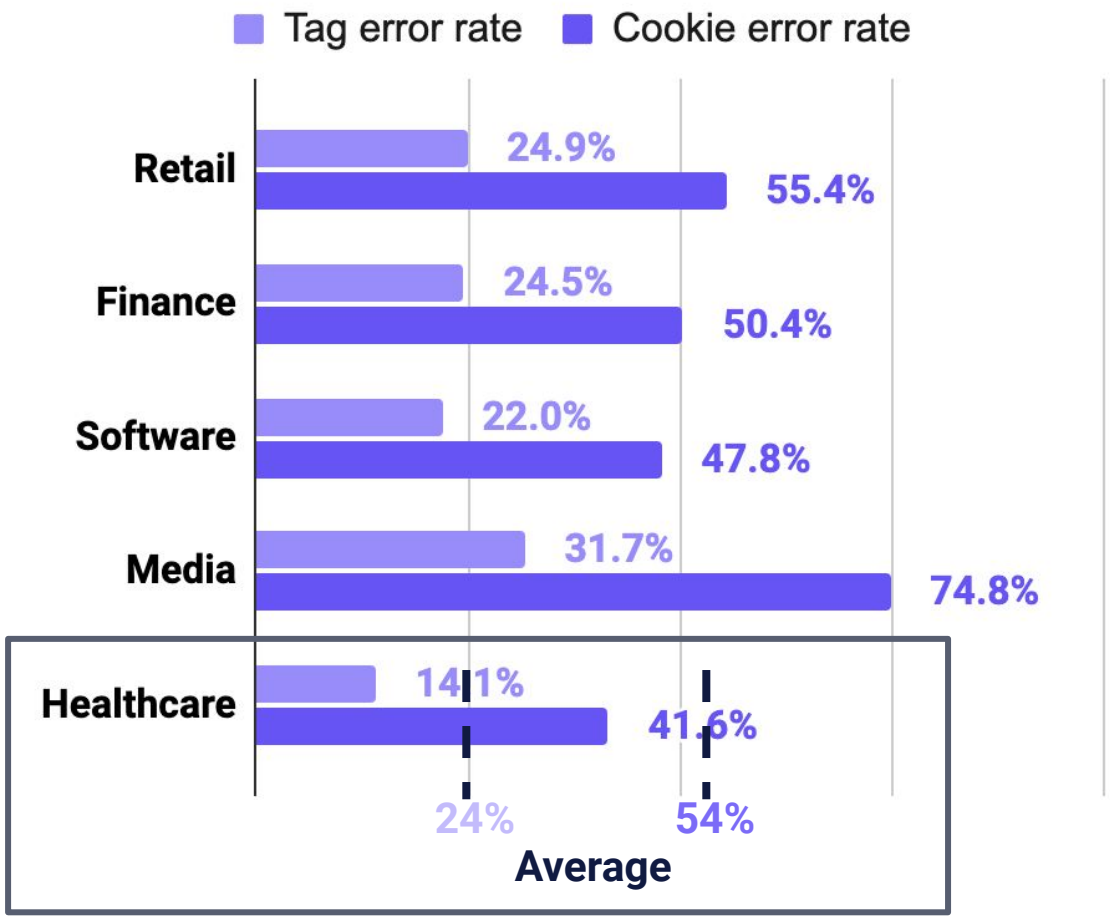
Pixels: ~25% Cookies: ~60%

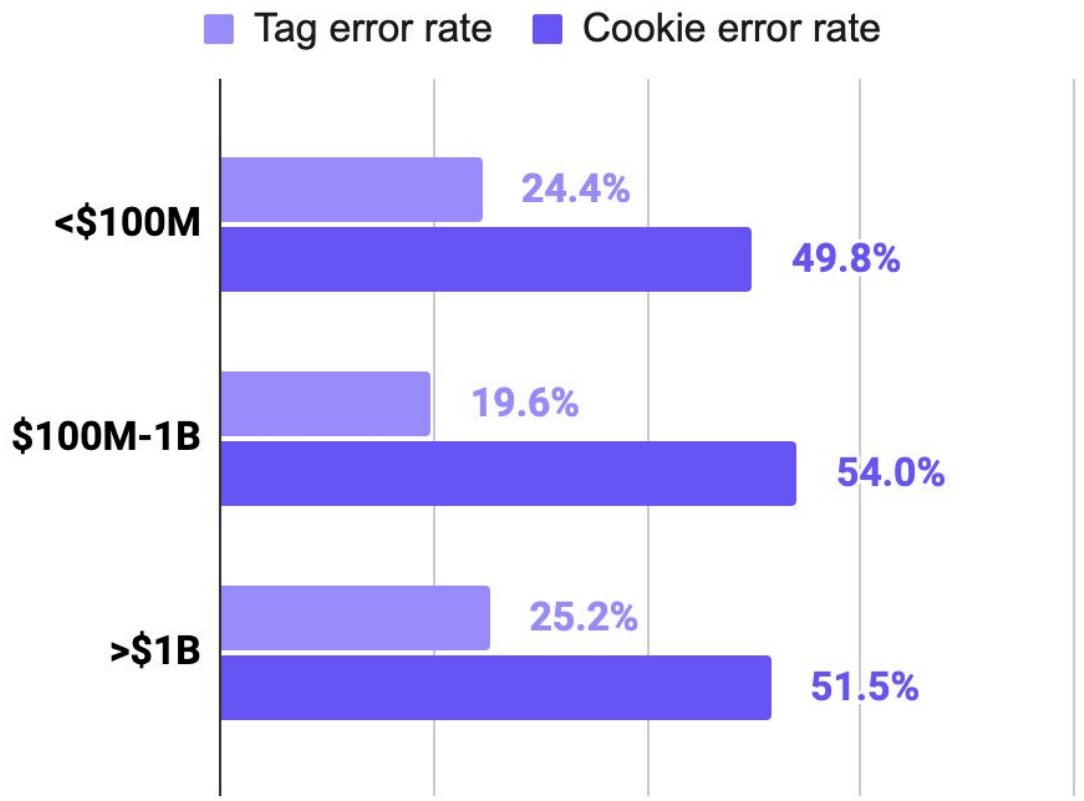
Very challenging for companies to orchestrate transmission of data across many vendors

Boltive

Consumer Reports

Errors Are Consistently High Across Vertical and Revenue Segments





Healthcare errors are lower than average but still common.
No significant differences by company size.

Source: Boltive analysis

Boltive

CR Consumer Reports

When The Web Leaks Health Data

Introduction: Closing the loop(holes) In health-relevant data

Methods: *Secret Shoppers* sweep *Target Sites* for compliance

Findings: Privacy disorders present many symptoms

Recommendations: Prevention is better than treatment

Boltive

CR Consumer Reports

Drill Down Into Three Health Companies Shows Specific Risks

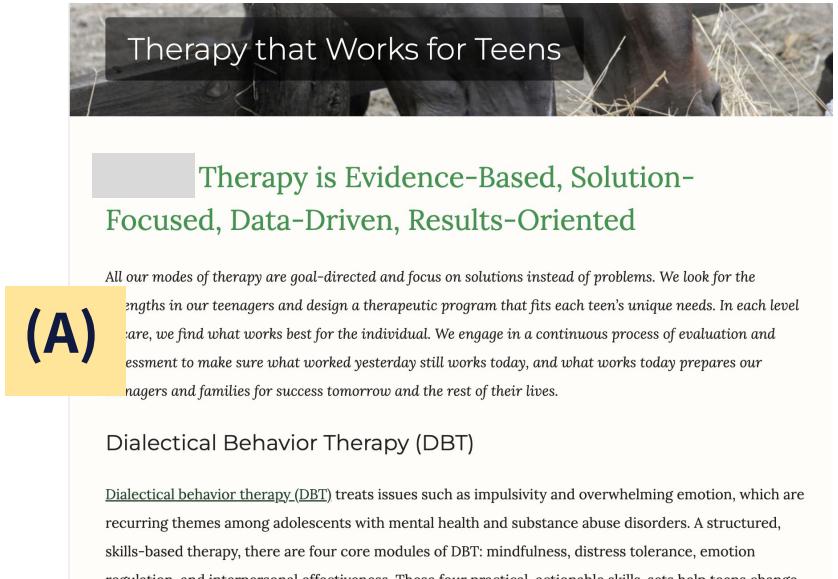
1. Teen Treatment Centers
2. Pharmaceutical Information Site
3. Personalized Vitamin Retailer

Boltive

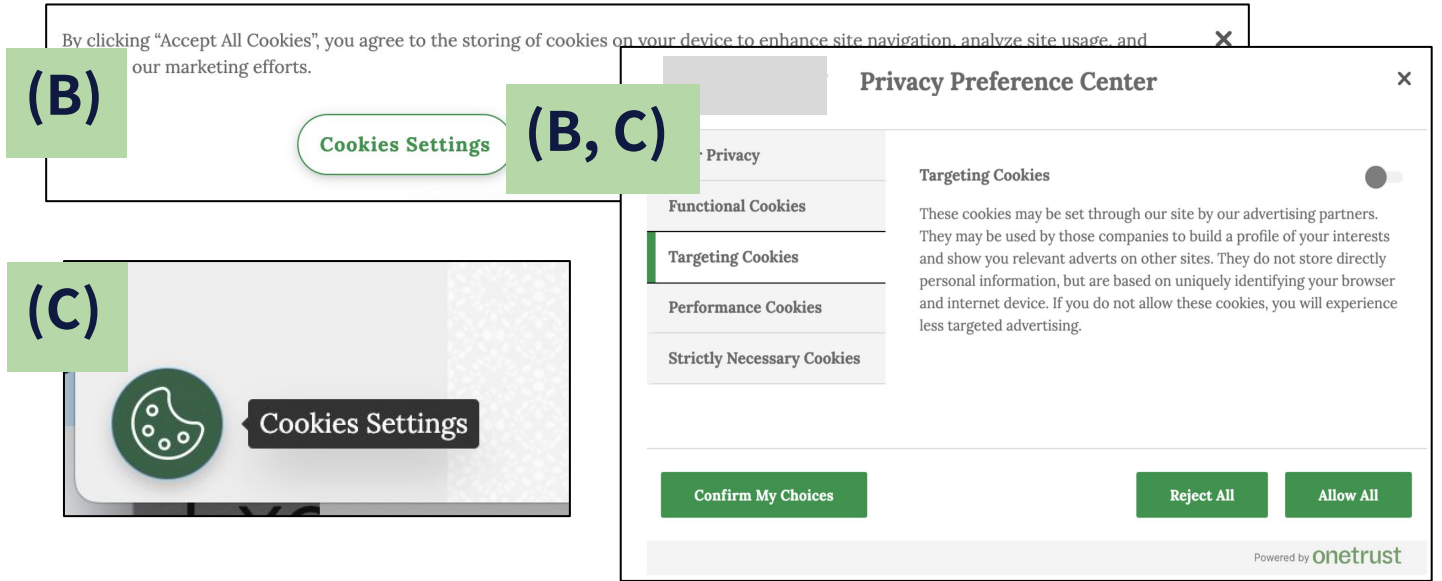
CR Consumer Reports

Teen Treatment Centers

	Teen Treatment Centers
Sensitivity	**Teen-directed web pages and content around therapies (A)**
Opt-in	**Basic cookie disclosure pop-up banner with a DNS link (B)**
Opt-out	**Banner plus persistent “cookie button” to modify choice (C)**
Tag errors	**22.8% (CA), 22.3% (VA) (D)**
Cookie errors	**60.0% (CA), 62.5% (VA) (D)**



(A)



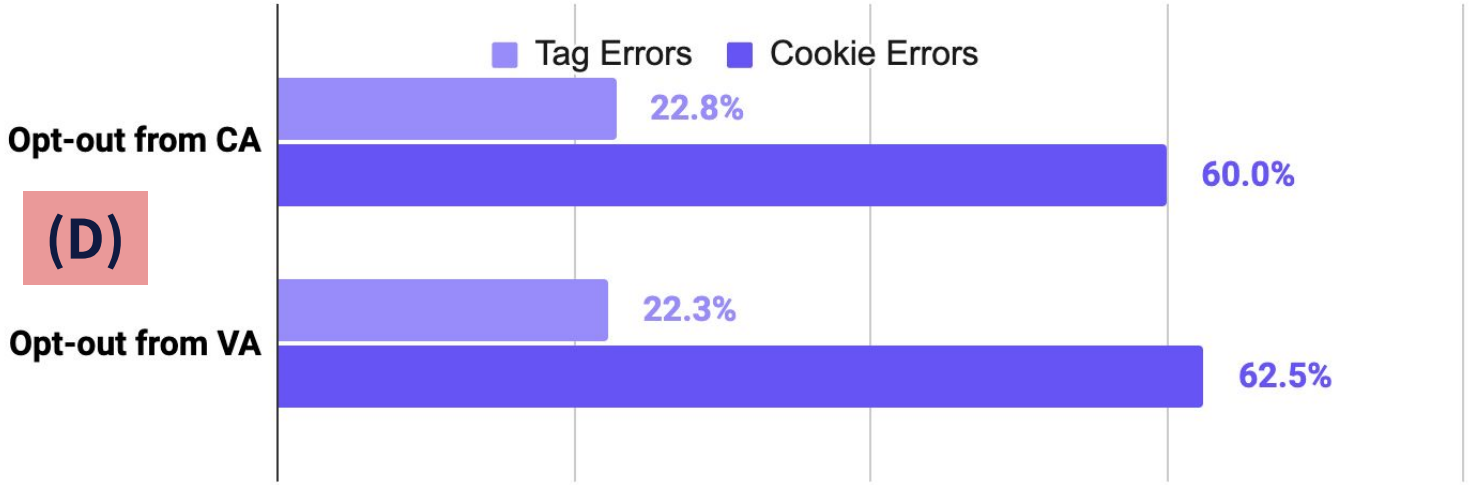
(B)

(B, C)

(C)

Teen Treatment Centers

	Teen Treatment Centers
Sensitivity	Teen-directed web pages and content around therapies (A)
Opt-in	Basic cookie disclosure pop-up banner with a DNS link (B)
Opt-out	Banner plus persistent “cookie button” to modify choice (C)
Tag errors	22.8% (CA), 22.3% (VA) (D)
Cookie errors	60.0% (CA), 62.5% (VA) (D)



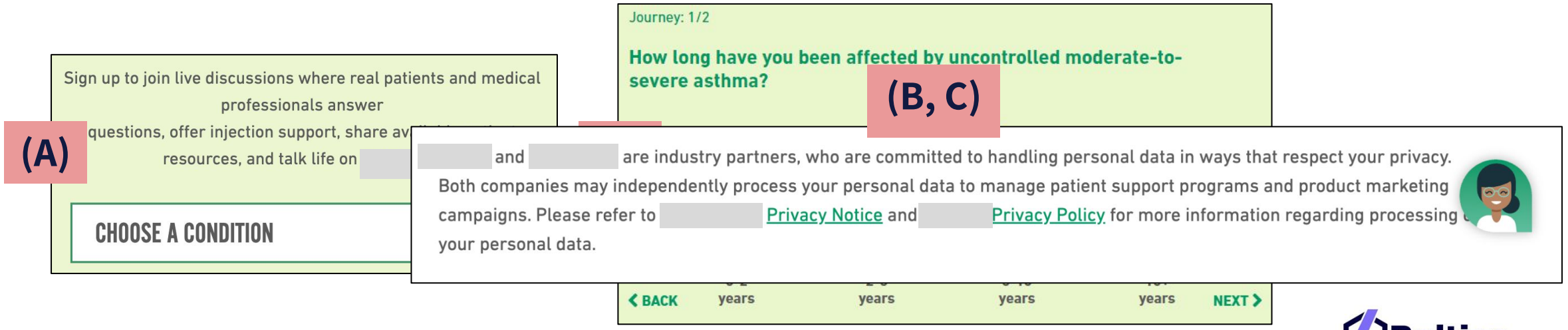
Tags and Cookies

- Facebook
- Google Ads
- Google Analytics

Boltive

Pharmaceutical Information Site

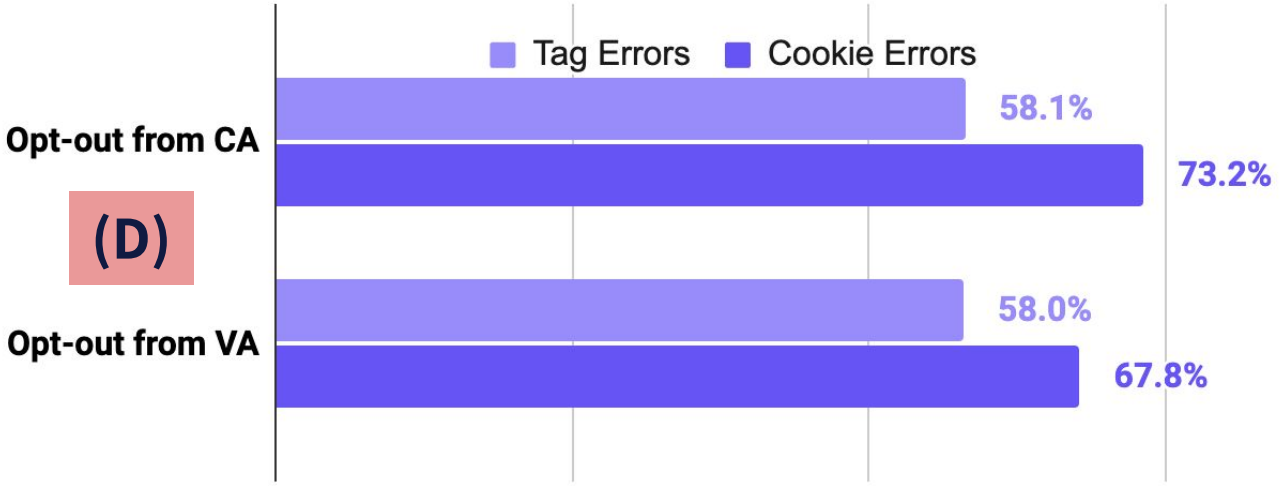
	Pharmaceutical Information Site
Sensitivity	**Quiz collecting specific information about health conditions (A)**
Opt-in	**None (B)**
Opt-out	**None (C)**
Tag errors	**58.1% (CA), 73.2% (VA) (D)**
Cookie errors	**60.0% (CA), 67.8% (VA) (D)**



Boltive

Pharmaceutical Information Site

	Pharmaceutical Information Site
Sensitivity	**Quiz collecting specific information about health conditions (A)**
Opt-in	**None (B)**
Opt-out	**None (C)**
Tag errors	**58.1% (CA), 73.2% (VA) (D)**
Cookie errors	**60.0% (CA), 67.8% (VA) (D)**



Tags and Cookies

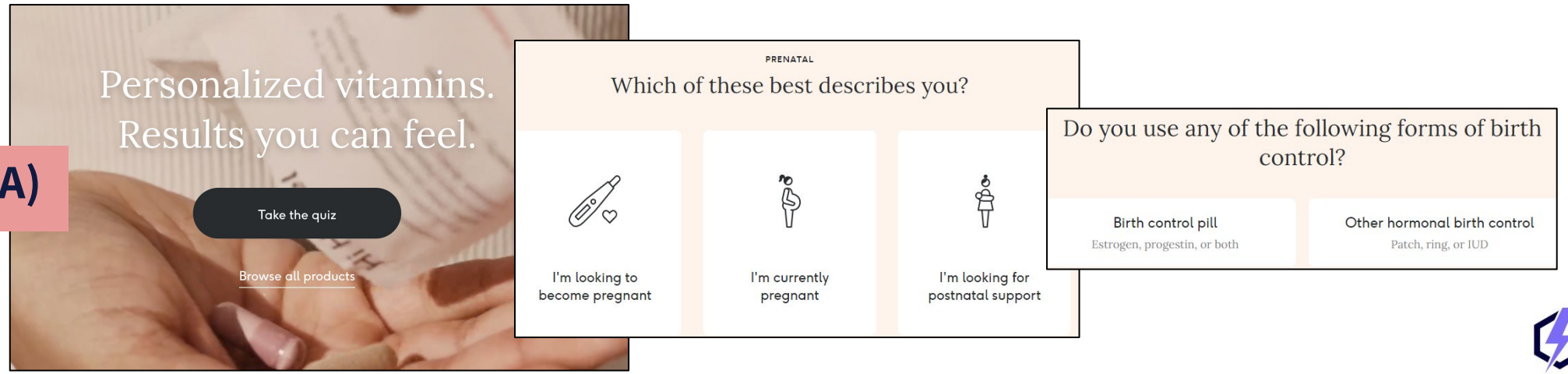
- Facebook
- Google Ads
- Google Analytics
- AppNexus
- Axonix
- Bidswitch
- Bing
- Blue Cava
- Context Web
- DeepIntent
- ID5
- LiveRamp
- RapLeaf
- TikTok
- Trade Desk
- Unruly
- Xandr

Boltive

Personalized Vitamin Retailer

	Pharmaceutical Information Site
Sensitivity	**Quiz collecting specific information about health conditions (A)**
Opt-in	**No prompt before quiz**
Opt-out	**None**
Tag errors	**0.0% (CA), 0.0% (VA) (D)**
Cookie errors	**41.7% (CA), 40.0% (VA) (D)**
Ad Trackers	**Hundreds (E)**

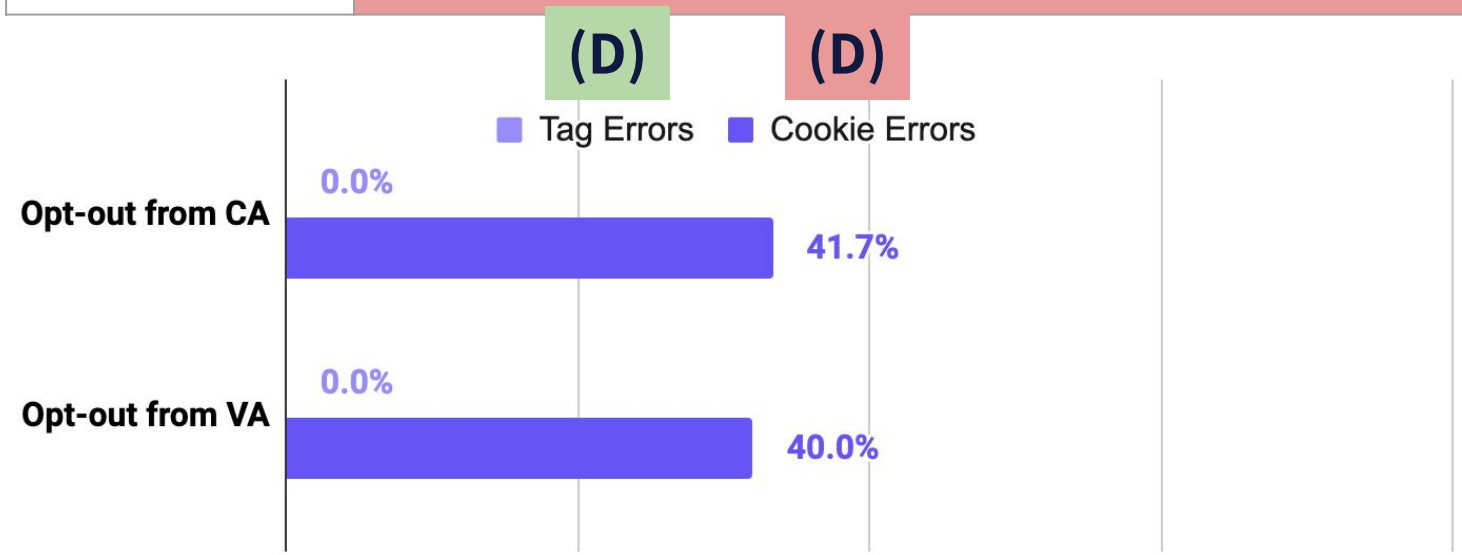
(A)



Boltive

Personalized Vitamin Retailer

	Pharmaceutical Information Site
Sensitivity	Quiz collecting specific information about health conditions (A)
Opt-in	No prompt before quiz
Opt-out	None
Tag errors	0.0% (CA), 0.0% (VA) (D)
Cookie errors	41.7% (CA), 40.0% (VA) (D)
Ad Trackers	Hundreds (E)



Tags and Cookies

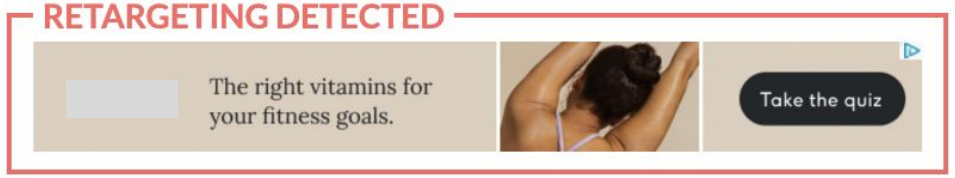
- First party

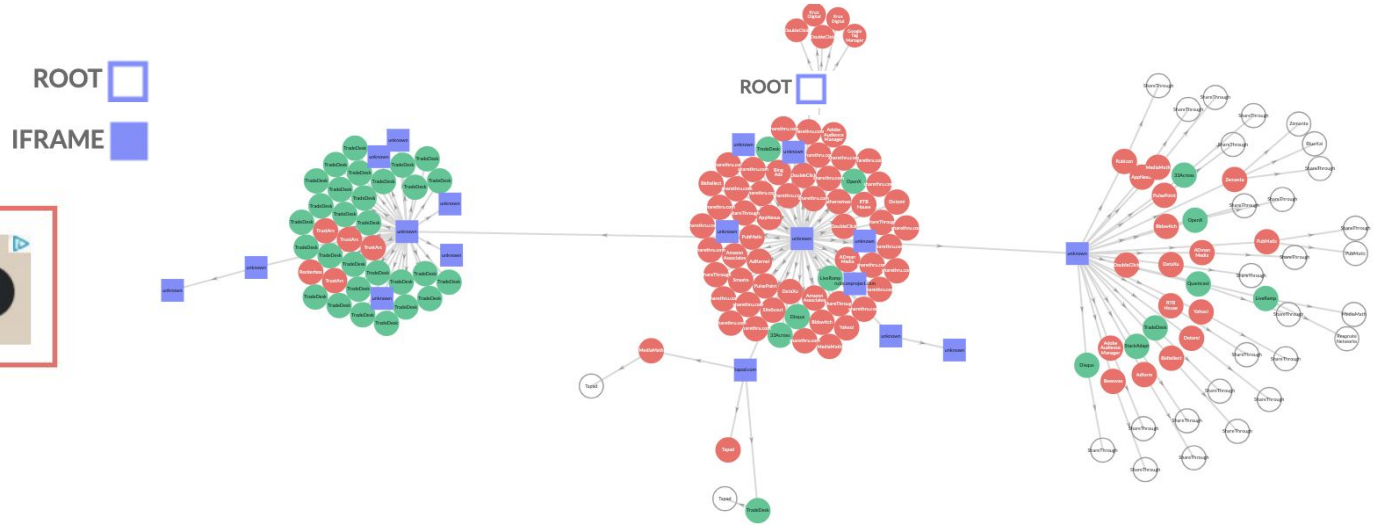
Boltive

Personalized Vitamin Retailer

	Pharmaceutical Information Site
Sensitivity	Quiz collecting specific information about health conditions (A)
Opt-in	No prompt before quiz
Opt-out	None
Tag errors	0.0% (CA), 0.0% (VA) (D)
Cookie errors	41.7% (CA), 40.0% (VA) (D)
Ad Trackers	Hundreds (E)

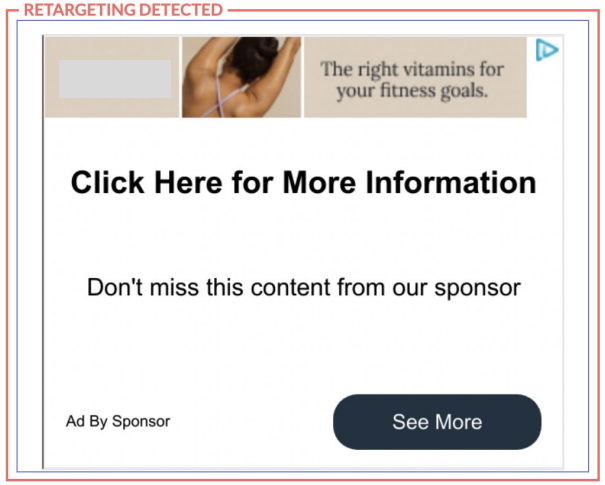
(E)



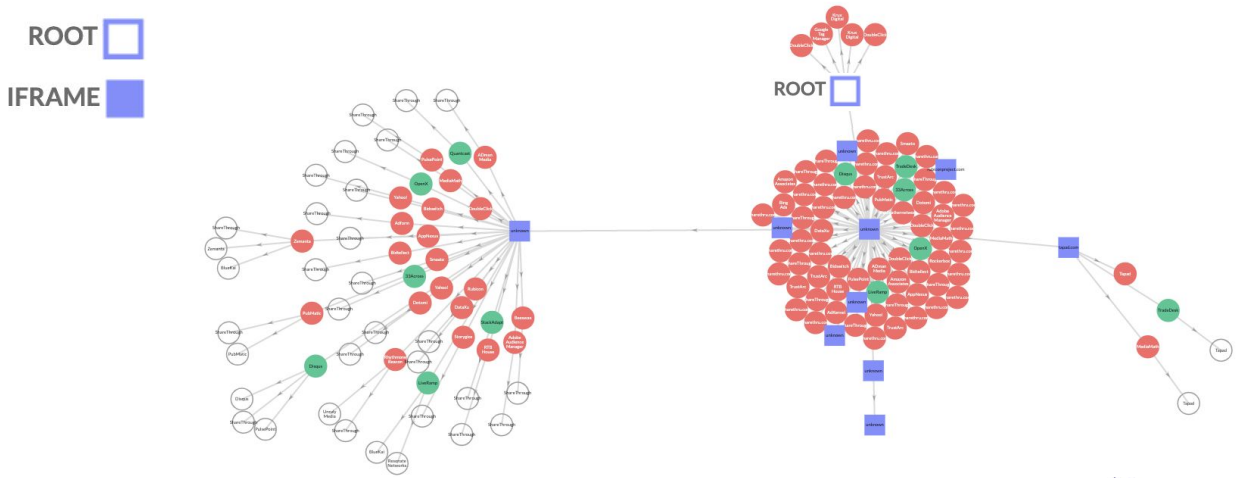


Personalized Vitamin Retailer

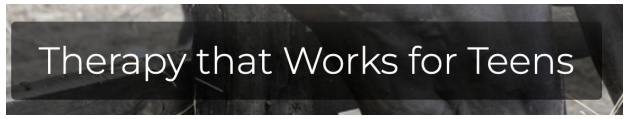
	Pharmaceutical Information Site
Sensitivity	**Quiz collecting specific information about health conditions (A)**
Opt-in	**No prompt before quiz**
Opt-out	**None**
Tag errors	**0.0% (CA), 0.0% (VA) (D)**
Cookie errors	**41.7% (CA), 40.0% (VA) (D)**
Ad Trackers	**Hundreds (E)**

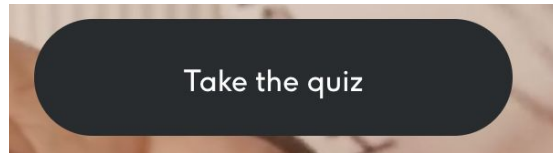


(D)



Summary





	Teen Treatment Center	Pharmaceutical Info Site	Personalized Vitamins Retailer
Sensitivity	**Teen-directed web pages and content around therapies**	**Quiz collecting specific information about health conditions**	**Quiz collecting specific information about health conditions**
Opt-in	**Basic cookie disclosure pop-up banner with a DNS link**	**None**	**No prompt before quiz**
Opt-out	**Banner plus persistent “cookie button” to modify choice**	**None**	**None**
Tag errors	**22.8% (CA), 22.3% (VA)**	**58.1% (CA), 73.2% (VA)**	**0.0% (CA), 0.0% (VA)**
Cookie errors	**60.0% (CA), 62.5% (VA)**	**60.0% (CA), 67.8% (VA)**	**41.7% (CA), 40.0% (VA)**
Ad trackers	**N/A**	**N/A**	**Hundreds**

When The Web Leaks Health Data

Introduction: Closing the loop(holes) In health-relevant data

Methods: *Secret Shoppers* sweep *Target Sites* for compliance

Findings: Privacy disorders present many symptoms

Recommendations: Prevention is better than treatment

Boltive

CR Consumer Reports

Recommendations For Regulators

- Provide clarity as to scope of law
  - Definition of “sensitive information”
  - Scope of exceptions
- Continue to expand legislation & regulation to align with consumer expectations
- Expand enforcement resources, including technology resources
- Evaluate strategic enforcement targets (novelty, sensitivity, # of affected consumers, nature of violations)

Boltive

Recommendations For Businesses

Before you collect…

- Stay up to date on rules
  - State regulations
  - Federal guidance (FTC, OCR)
  - Class action outcomes
- Think deeply about pixels, tags, cookies
  - Purpose?
  - Less intrusive method?

If you must collect…

- Audit vendors
  - Due diligence
  - Monitoring
- Check consent systems
  - Disclosure
  - Transmission: Opt-outs and opt-ins
- Check IBA and analytics
  - Tag and cookie relapses
  - Downstream adtech vendors

Boltive

Sign up To Receive The Research Paper (Free For Attendees)

We would like to thank the key contributors to this study

- Maggie Oates, Consumer Reports
- Matt Schwartz, Consumer Reports
- Christine Desrosiers, Boltive

Boltive

When The Web Leaks Health Data:
Implications for Consent, PI, and Regulatory Compliance

Justin Brookman
Dan Frechtling