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A Moveable Feast: The Shifting Landscape of Tracking Technologies and Health Data

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With You Today

Moderator



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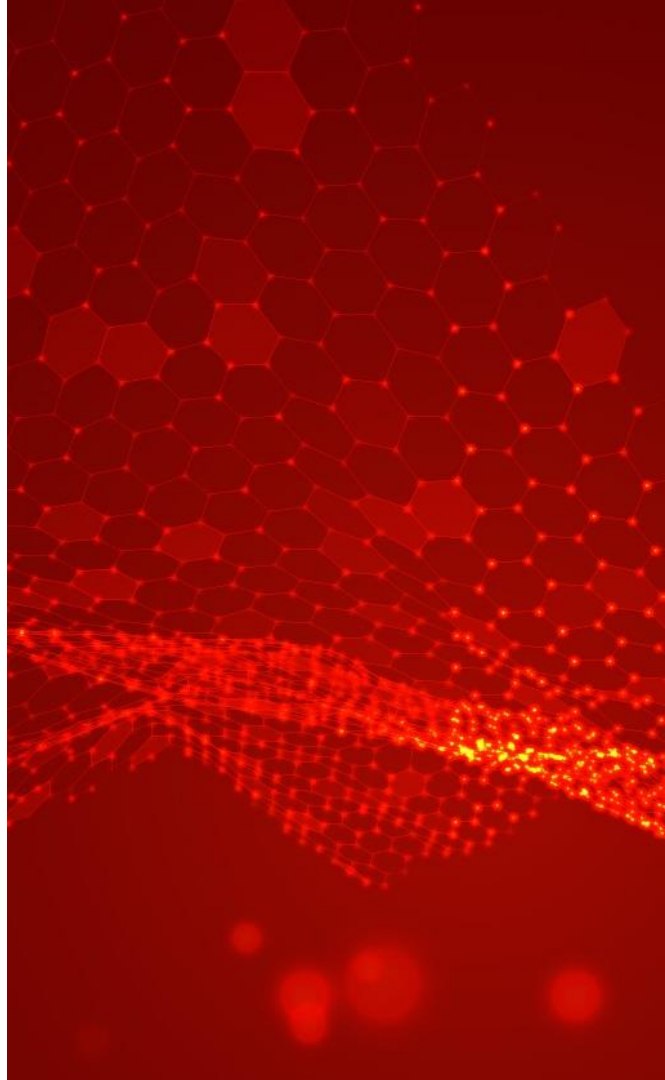
Panelists



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Agenda

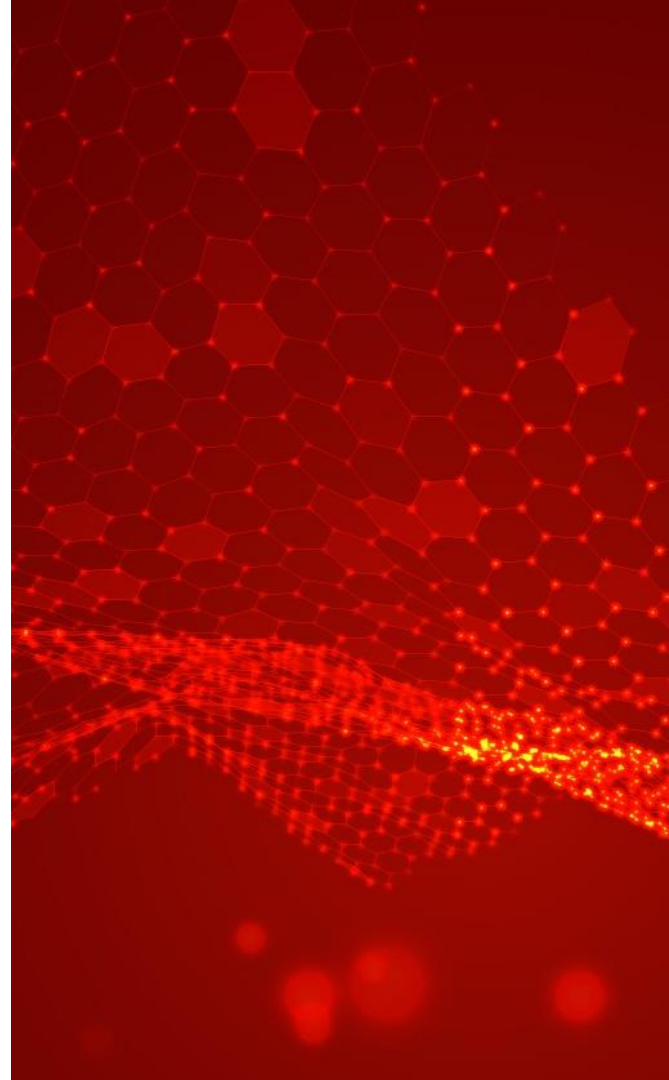
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01 Why Should We Care?



In the News...

Kaiser waited five months to disclose massive data leak

In a letter to customers dated May 31, Kaiser said it “determined” on Oct. 25 that it **might have been transmitting customer data to Google, Microsoft and X via tracking technologies on its websites and mobile apps**. The Oakland-based health-care giant hadn’t previously given a date for when it discovered the data leak.

FTC Enforcement Action to Bar GoodRx from Sharing Consumers’ Sensitive Health Info for Advertising

Under proposed order, GoodRx will pay a \$1.5 million civil penalty for failing to report its unauthorized disclosure of consumer health data to Facebook, Google, and other companies

HHS Privacy Loss Not a Green Light for Health-Care Web Tracking

Use of Online Tracking Technologies by HIPAA Covered Entities and Business Associates

*On June 20, 2024, the U.S. District Court for the Northern District of Texas issued an order declaring unlawful and vacating a portion of this guidance document. See Am. Hosp. Ass’n v. Becerra, — F. Supp. 3d —, No. 4:23-cv-1110, 2024 WL 3075865 (N.D. Tex. June 20, 2024). Specifically, the Court vacated the guidance to the extent it provides that HIPAA obligations are triggered in “circumstances where an online technology connects (1) an individual’s IP address with (2) a visit to a[n] [unauthenticated public webpage] addressing specific health conditions or healthcare providers.” Id. at *2. HHS is evaluating its next steps in light of that order.*

FTC Fines Mental Health Startup Cerebral \$7 Million for Major Privacy Violations

The U.S. Federal Trade Commission (FTC) has ordered mental telehealth company Cerebral from using or disclosing personal medical data for advertising purposes.

02 What Is Health Data?



"Health Data" Can Come in Different Shapes and Sizes...



Protected Health Information

- Defined by HIPAA
- "Individually identifiable health information" held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral
- 18 identifiers



Sensitive Personal Information

- Defined under US state privacy laws
 - Mental or physical health diagnosis
 - Personal information collected and analyzed concerning a consumer's health
 - Mental or physical health condition or diagnosis



Other Laws and Regulations

- Health Breach Notification Rule – "personal health records"
- EU General Data Protection Regulation – "personal data concerning health"
- State laws on genetic privacy
- Washington's My Health My Data Act

... With Different Obligations



Protected Health Information

- Permitted/authorized uses and disclosures
- Limiting uses and disclosures to minimum necessary
- Restrictions on using PHI for marketing
 - Authorization may be needed
- Necessary Business Associate Agreements



Sensitive Personal Information

- Limit the Use of Sensitive Personal Information
- Consent for collection of sensitive personal information
- Additional documentation requirements (e.g., privacy impact assessments)



Other Laws and Regulations

- HBNR defines "breach" broadly, to include disclosures to third parties, such as Meta/Google
- EU GDPR – consent may be the only legal basis in some cases, DPIA needed, additional documentation
- State laws on genetic privacy have their own notice/consent requirements
- WA MHMDA has strict requirements about "consumer health data"



03 Why Do Businesses Want To Use Tracking Technologies?

Use of Tracking Technology for Marketing Objectives

75% of global marketing leaders rely on third-party cookies as a core part of their strategy

92.8% of advertisers are concerned about potential loss of third-party cookies

Key uses

Behavioral advertising	
Attribution	
Preferences	
User experience	



04 The Intersection of Health Data and Tracking Technologies

HHS Guidance



- HHS issued bulletin to highlight the obligations of HIPAA covered entities and business associates under the HIPAA Rules, when using online tracking technologies
- Bulletin arguably expanded the scope of the HIPAA Rules and created uncertainty about what information **could** be considered PHI
- Addressed tracking on: (i) authenticated pages; (ii) unauthenticated pages; and (iii) mobile applications

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FTC – Health Breach Notification Rule



- The Rule **does not** apply to HIPAA covered entities or business associates
- The Rule covers "**vendors**" of **electronic "personal health records"** (PHRs) **and PHR-related entities** who are **not** covered by HIPAA
- Similarly, FTC guidance explains that, in order to qualify as a PHR, a health app or website must be **capable of** drawing information from **multiple sources** (e.g., geolocation data through an API, plus data from the consumer themselves, plus information from a data broker)
- The FTC clarified that the Rule applies to instances of cyber incidents **and** unauthorized disclosures of PHR

Uncharted Territory



Patient support program web pages

- Targeted toward patients, but sometimes also caregivers
- Cover a specific medication, which could indicate medical condition
- Not necessarily authenticated



Targeted medication/services web pages

- General information, but could be targeted toward a certain disorder or more generic medication
- Can be accessed by the general public
- Not authenticated



Mobile applications

- Generally authenticated
- Can be "general use," but associated with an authenticated patient profile on the back end



05 Tips and Tricks on Working With the Business and Marketing Teams

Consumer Expectations and Quality Lead Conversion

65% of users worry about excessive cookie use invading their privacy

60% of internet users are willing to exchange data for discounts and premium services

Quality over quantity

10,000 Implicit Opt-ins

15% open rate
2% click rate
10% conversion

3 Leads

10,000 Explicit Opt-ins

40% open rate
5% click rate
10% conversion

20 Leads

Collaborate for a Trust-Forward Approach

Attract to convert



●
**Prioritize
Transparency**



●
**Get Creative
with UX Design**

Personalize to retain



●
**Preference &
Personalization**



●
**Compliant
Data-sharing &
Partnerships**

Establish Governance and Self-Monitor

Digital governance



- Rationalize existing tracking tech for cost savings and data minimization.
- Establish cross-functional cookie and tag governance working group and collaboratively evaluate and approve go-forward changes.

Monitor compliance



- Continuous testing to confirm cookies and tracking technologies are acting in accordance with user preferences.
- Monitor network traffic to proactively identify data leakage to third parties via tracking technologies.

The image features a white speech bubble shape on the left side, containing the word "Questions" in a bold, black, sans-serif font. The background is a dark red color with a glowing, textured pattern of small, interconnected hexagons or cells, resembling a molecular or crystalline structure. The overall aesthetic is modern and scientific.

Questions



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