The deadly state of surveillance capitalism

Thursday, March 16 | 12pm ET

Andrea Downing
Co-Founder
The Light Collective

Jennifer Goldsack
CEO
Digital Medicine Society (DiMe)
But first, housekeeping…

- Please note: **today’s session is being recorded**
  - Slides and recording will be available on DiMe’s webinar page after the session
- To ask a question for discussion during live Q&A, please either:
  - ‘Raise your hand’ in the Reactions and the moderator will unmute you to ask your question live, or
  - **Type your question** into the chat box

*** Participants are not permitted to transcribe this webinar, violators will be removed from the session.***
The deadly state of surveillance capitalism

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The Deadly State of Surveillance Capitalism in Healthcare
The Problem

HIPAA Covered Entity

Patient Population
The Problem
The Problem

HIPAA Covered Entity
The Problem

HIPAA Covered Entity
The Problem

Threat Actors:
- Scammers
- Snake Oil Peddlers
- Troll Farms
- Nation-State Actors
The Problem

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Andrea Downing

- BRCA Advocate
- Security Researcher
- Patient Co-Author

History & Physical Exam Findings

- Female
- Symptoms:
  - Protective of BRCA Community
  - Prophylactic Surgeries 2013-2019
- History:
  - Spokesperson for AMP v. Myriad in 2013
  - Launched FTC Complaint in 2019 on Facebook Group

Testing & Diagnostics

- BRCA1 Positive

Clinical Course

- Seeking digital rights & governance on the internet for BRCA and other patient communities
MISSION: To represent collective rights, interests, and voices of patient communities in healthcare technology.
How We Got Here: Cross Site Tracking Research
Viewpoint

June 14, 2019

Employ Cybersecurity Techniques Against the Threat of Medical Misinformation

Eric Perakslis, PhD; Robert M. Califf, MD

Author Affiliations


Although the sharing of misleading information is likely as old as humanity, an unfortunate concomitant of the current digital environment is the amplification and accelerated spread of medical misinformation. Growing distrust of medical professionals is causing some people to eschew drugs that have been proven effective, such as statins for hypercholesterolemia and chemotherapy for cancer. Communities marked by pockets of vaccine refusal have seen the re-emergence of diseases, such as measles, that had been virtually eliminated from the United States. A child who neglected to receive a diptheria-tetanus vaccine developed diphtheria. Soaring...
Off Facebook Tracking: Sample Data

Vendors Embed 3rd Party Tracker in Website Examples:

1. User signs up for digital health company’s service and agrees to the TOS.
2. Privacy Policy does not include sharing of 3rd party ad services.
3. Multiple Trackers Share “Off Facebook Activity” about User without consent.
4. Facebook Activity Feeds User Ad Interests:
5. Vendor Targets Ads to User on Facebook Using Signups and “Quizzes”.
6. Lead Data Inbound Vendor’s CRM from Facebook.

Sample Data:

```
11:
  name: "hereditarycancerquiz.com"
  events:
    0:
      id: 1488344785329502
      type: "CUSTOM"
      timestamp: 1632458720
    1:
      id: 1488344785329502
      type: "PAGE_VIEW"
      timestamp: 1632458480
```

```
41:
  name: "color.com"
  events:
    0:
      id: 107333746069147
      type: "VIEW_CONTENT"
      timestamp: 1577472420
    1:
      id: 107333746069147
      type: "VIEW_CONTENT"
      timestamp: 1577472240
```
Genetic Testing Site Example

Know that you are in control of your DNA. Discovery should never come at the expense of privacy. Your data is encrypted, protected and under your control. You decide what you want to know and what you want to share.

Learn more

Privacy Badger: 18 potential trackers blocked

- 9214610.fits.doubleclick.net
- googleads.g.doubleclick.net
- connect.facebook.net
- www.facebook.com
- www.google-analytics.com
- www.google.com

[Options: Disable for this site, Report broken site, Donate to EFF]

version 2021.11.28.1
What Patients See: Predicting Ads & Behavior Based On Your Health Interests

About the ad:

Boosting my Immunity with nutrient dense foods like kale and blueberries.

References:

PTI alters the tumor microenvironment

Learn More at protumorinflammation.com
Timeline...

18-Jan-22  Arixiv pre-pub: Health Advertising on Facebook: Privacy & Policy Considerations
06-Feb-22  Wired story: Health Sites Let Ads Track Visitors Without Telling Them
16-Jun-22  *Markup story: Facebook Is Receiving Sensitive Medical Information from Hospital Websites
15-Aug-22  Cell press (patterns) story: Health advertising on Facebook: Privacy and Policy Considerations
15-Aug-22  Forbes story: Digital Medical Companies Funnel Patient Data To Facebook For Advertising
19-Sep-22  Senate scrutiny of Meta begins: Meta faces mounting questions from Congress on health data privacy as hospitals remove Facebook tracker
20-Oct-22  Aurora Health Discloses Data Breach: Advocate Aurora says 3M patients’ health data possibly exposed through tracking technologies
31-Oct-22  ECRI issues safety alert to 5000 hospitals: Third-Party Web Analytic Tools Installed on Provider Websites May Expose Patient Data [ECRI Exclusive User Experience Network]
04-Nov-22  First Class action suit: Advocate Aurora, WakeMed get served with class action over Meta's alleged patient data mining
16-Nov-22  Indiana Community Health Network Discloses Data Breach: 5M Are Affected by This Breach and 2 Similar Incidents
01-Dec-22  HHS OCR Guidance: HHS Office for Civil Rights Issues Bulletin on Requirements under HIPAA for Online Tracking Technologies to Protect the Privacy and Security of Health Information

*Methodology and data shared with markup at time of preprint and Wired Story
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<th>Name of Covered Entity</th>
<th>State</th>
<th>Covered Entity Type</th>
<th>Individuals Affected</th>
<th>Submission Date</th>
<th>Type of Breach</th>
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<td>Business Associate</td>
<td>3179835</td>
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<td>Community Health Network, Inc. as an Affiliated Covered Entity (Notice)</td>
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<td>Novant Health Inc. on behalf of Novant Health ACE &amp; as contractor for NMG Services Inc. (Notice)</td>
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<td>Business Associate</td>
<td>1362296</td>
<td>08/14/2022</td>
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<td>Healthcare Provider</td>
<td>85466</td>
<td>10/31/2022</td>
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</tbody>
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**Total as of Today**  
61,351,232
Facebook Is Receiving Sensitive Medical Information from Hospital Websites

Experts say some hospitals’ use of an ad tracking tool may violate a federal law protecting health information.

By Todd Feathers, Simon Fondrie-Teitler, Angie Waller, and Surya Mattu

A tracking tool installed on many hospitals’ websites has been collecting patients’ sensitive health information—including details about their medical conditions, prescriptions, and doctor’s appointments—and sending it to Facebook.
'Pixel' data breach may affect 134,000 at Wisconsin clinic that gets Epic EHR access through Advocate Aurora Health

Giles Bruce • Monday, January 23rd, 2023

A Wisconsin specialty clinic that gets its Epic EHR access through Advocate Aurora Health said 134,000 patients may have had their personal and health information compromised in a data breach involving the health system which has dual headquarters in Milwaukee and Illinois.

DIVE BRIEF

Louisiana systems hit with lawsuits for allegedly sharing patient data with Facebook

Published Feb. 16, 2023

By Mike Miliard | October 20, 2022 | 11:02 AM

Advocate Aurora notifies patients of potential tracking pixel breach

The health system says that, "out of an abundance of caution," it's assuming that anyone with Advocate Aurora Health MyChart account, including users of its LiveWell app, could be affected – as many as 3 million people.
Patient groups are aware, concerned & expect protection

Senators Demand Answers from Telehealth Firms on Pixel-Related Data Sharing Practices

A bipartisan group of senators has written to three telehealth companies demanding answers about the use of third-party tracking technologies on their websites and have requested details of the sensitive health data that they share with third parties such as Meta, Google, and social media networks.

In the summer of 2022, The Markup/STAT conducted an investigation into the use of tracking technologies on the websites of U.S. hospitals and found that around one-third of the hospitals investigated had these technologies on their websites. Website tracking code could capture and transmit...
Use of Online Tracking Technologies by HIPAA Covered Entities and Business Associates (Dec, 2022)
https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/hipaa-online-tracking/index.html
Tracking on user-authenticated webpages

- E.g. Patient portals

Tracking on unauthenticated webpages

- Portal login or registration pages, “webpages that addresses specific symptoms or health conditions, such as pregnancy or miscarriage, or that permits individuals to search for doctors or schedule appointments”
- + collects an identifier (email address or IP address)

Tracking within mobile apps

- “Mobile apps that regulated entities offer to individuals”
BAAs

- “all tracking technology vendors have signed a BAA and that there is an applicable permission prior to a disclosure of PHI”
- “only the minimum necessary PHI to achieve the intended purpose is disclosed”

No Small Print Waivers of Privacy Rule

- No hiding acceptance in “Privacy policy, notice, or terms and conditions of use”
- No acceptance in “Website banners that ask users to accept or reject a website’s use of tracking technologies, such as cookies”

No post-collection de-identification
Complying with the Health Breach Notification Rule

First Enforcement Actions As of 2023:

GoodRx
BetterHelp

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.

FTC to Ban BetterHelp from Revealing Consumers’ Data, Including Sensitive Mental Health Information, to Facebook and Others for Targeted Advertising
BetterHelp will be required to pay $7.8 million for deceiving consumers after promising to keep sensitive personal data private, agency says.
Where do we go from here?
Characterizing cyber harms from digital health

Eric D. Perakslis, Megan L. Ranney & Jennifer C. Goldsack

Nature Medicine (2023) | Cite this article

The expansion of digital health comes with benefits, but also potential harms, including those to economic, psychological and societal wellbeing. This article presents a framework to characterize cyber harms so that they can be prevented and mitigated.
Examples of Cyber Harms

- Doxing
- Blackmailing
- Account Hijacking
- Medication Theft
- Ransomware
- Disinformation
- Malinformation
- Phishing
- Impersonation
- Device Takeover
Healthcare privacy beyond compliance (The Patient Perspective).

Effects of a health information disclosure:
- Can be permanent (cannot be discarded and exchanged like a credit card number)
- Targeting (ads) or discrimination based on medical condition
- Violation of right to privacy

What power does an impacted patient have to recover from an disclosure?
- A small check from a class action lawsuit
- Another free year of identity monitoring service
- Difficult or impossible to remove

Healthcare data mining from third party analytic tools on your web applications is 100% preventable.
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Thursday, March 16 | 12pm ET
Virtual Journal club

The Patient Matters in the End(point)

Thursday, April 13th, 2023 | 11am ET

Diana Rofail, PhD, MBA
Global Head and Senior Director, PCOR
Regeneron

Pip Griffiths, PhD
Program Lead
Digital Medicine Society (DiMe)

Candice Taguibao
(Moderator)
Program Lead
Digital Medicine Society (DiMe)
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The DiMe webinar series hosts leading experts from across a variety of disciplines to discuss critical topics on digital medicine with our community.

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THANK YOU