



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

Thursday, March 16 | 12pm ET



Andrea Downing
Co-Founder
The Light Collective



Jennifer Goldsack
CEO
Digital Medicine Society (DiMe)

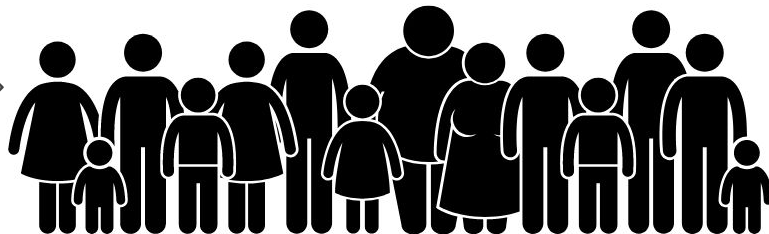
The background is a dark blue field with a complex network of lighter blue lines and various icons. The icons include a speech bubble with an 'S', a briefcase, a 'tube' logo, a camera, a crossed-out smartphone, an Android robot, a film strip, a Twitter bird, a smartphone, a play button, a gear, a Windows logo, a camera, and a double left arrow. The entire image has a cracked, distressed texture.

The Deadly State of Surveillance Capitalism in Healthcare

The Problem

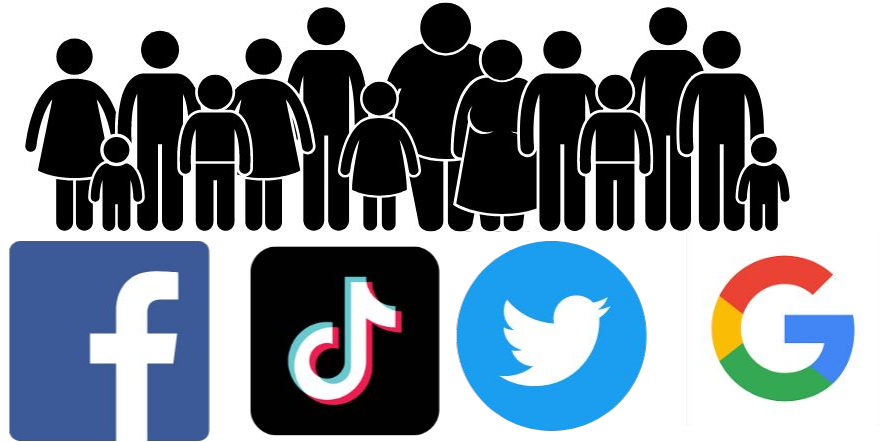


HIPAA Covered Entity

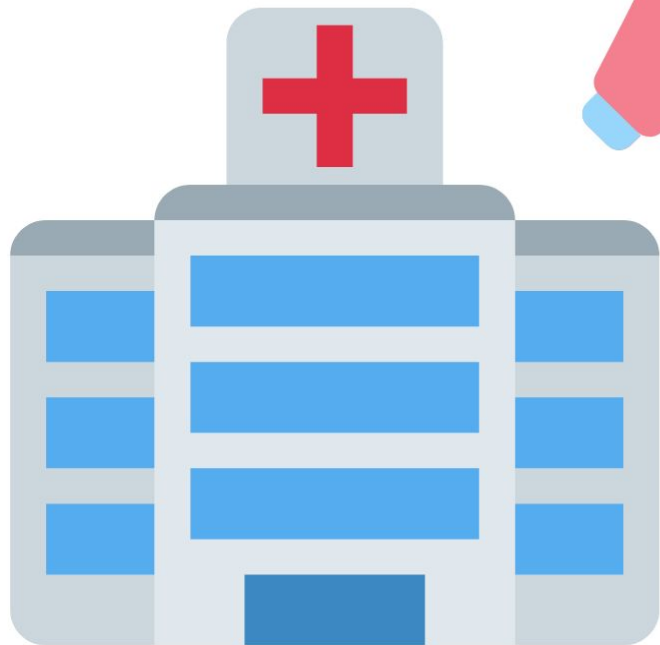


Patient Population

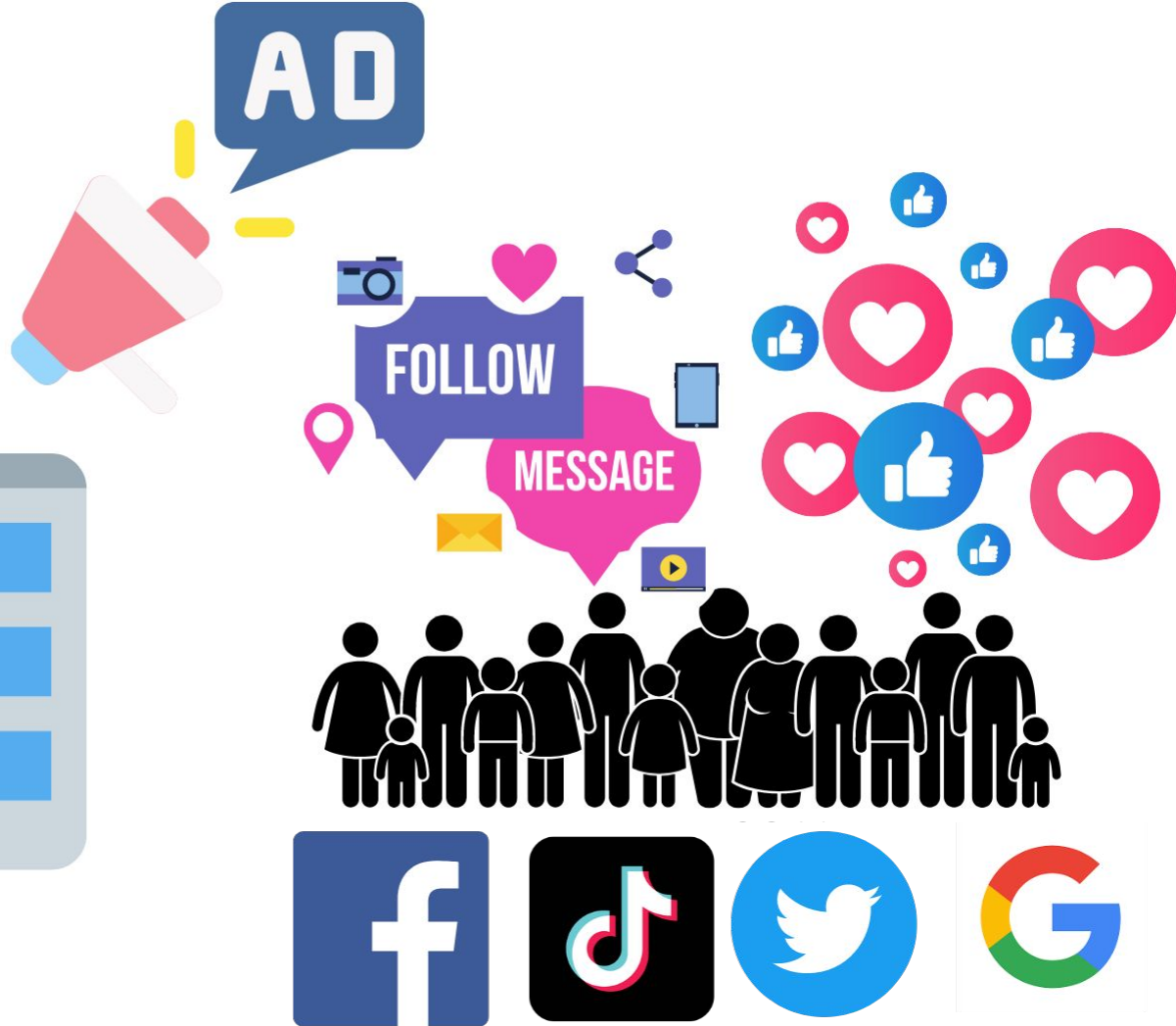
The Problem



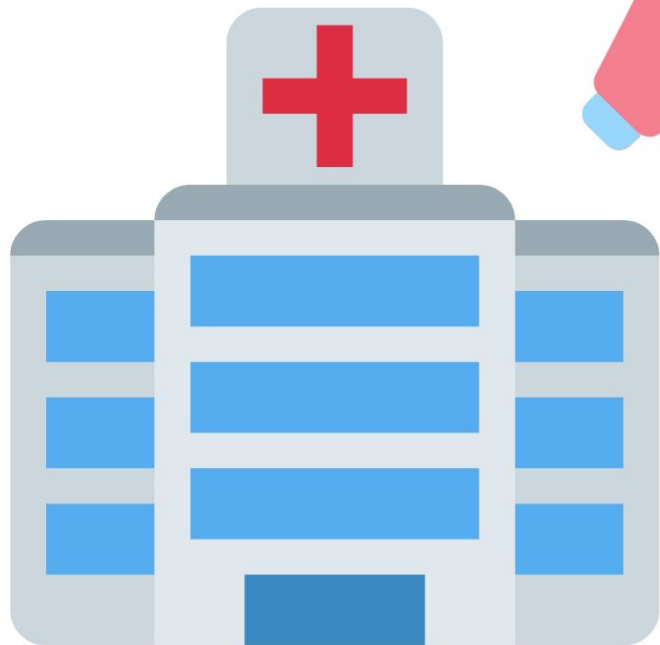
The Problem



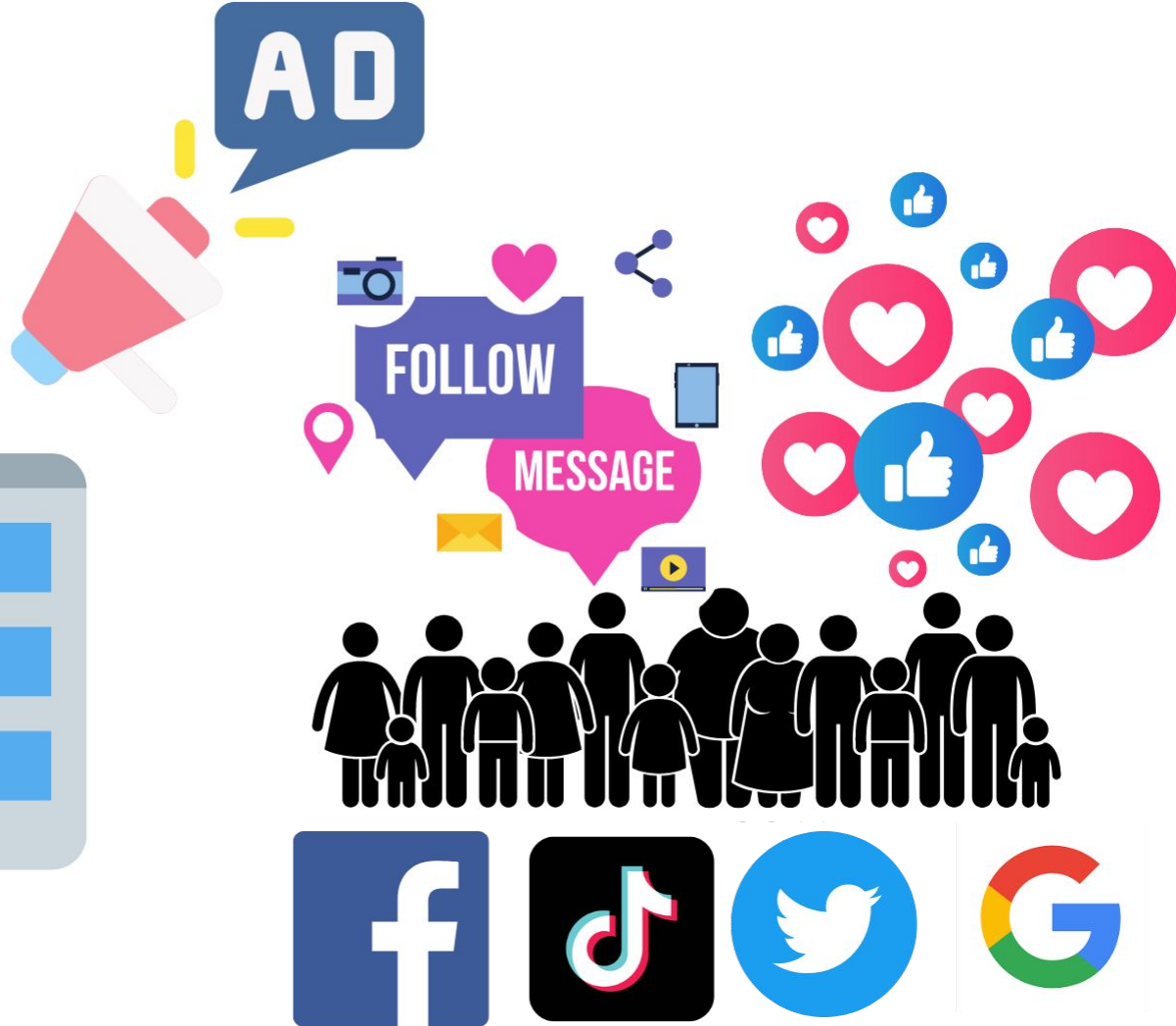
HIPAA Covered Entity



The Problem



HIPAA Covered Entity



The Problem



Threat Actors:

Scammers
Snake Oil Peddlers
Troll Farms
Nation-State Actors

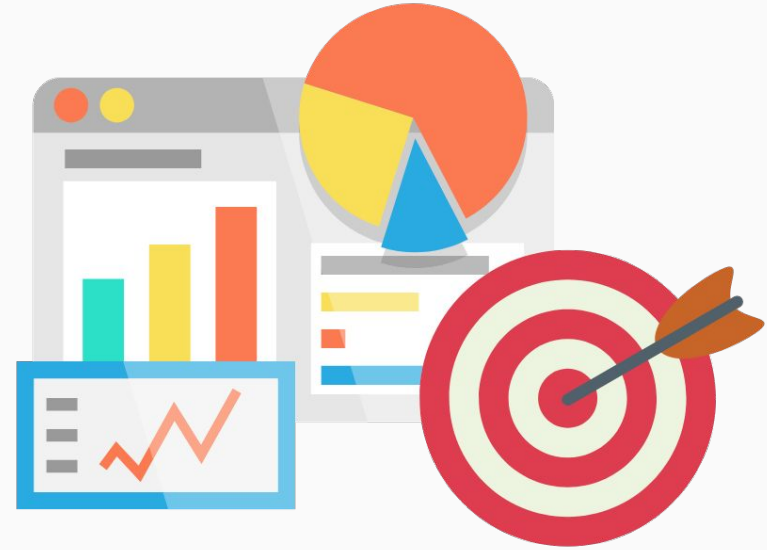


The Problem

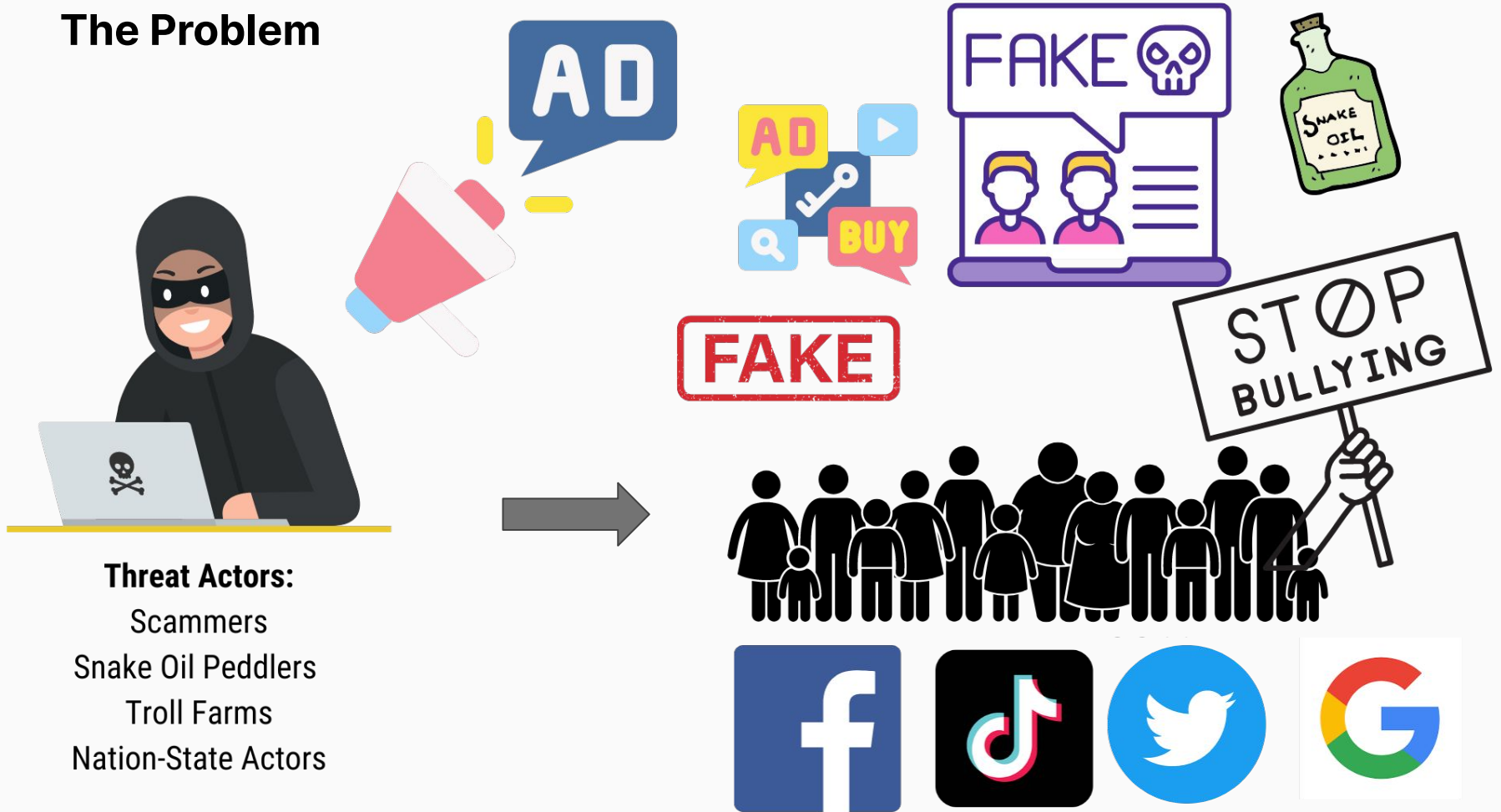


Threat Actors:

Scammers
Snake Oil Peddlers
Troll Farms
Nation-State Actors



The Problem



Andrea Downing



BRCA
Advocate

Security
Researcher

Patient
Co-Author



Justin Lai/Stanford Medicine X
Andrea Downing speaks during the Stanford Medicine X Conference in Palo Alto, California, in September 2017.

This breast cancer advocate says she discovered a Facebook flaw that put the health data of millions at risk

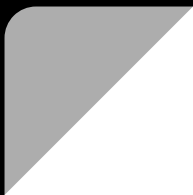
By [Ryan Prior](#), CNN
Updated 9:39 PM EST, Fri March 6, 2020





MISSION: To represent collective rights, interests, and voices of patient communities in healthcare technology.

How We Got Here: Cross Site Tracking Research



**This Issue**Views **7,771**Citations **3**Altmetric **141**Comments **1****Viewpoint**

June 14, 2019

Employ Cybersecurity Techniques Against the Threat of Medical Misinformation

Eric Perakslis, PhD¹; Robert M. Califf, MD^{2,3}[» Author Affiliations](#)

JAMA. 2019;322(3):207-208. doi:10.1001/jama.2019.6857

Full
Text

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.^{1,2} Growing distrust of medical professionals is causing some people to eschew drugs that have been proven effective, such as statins for hypercholesterolemia³ and chemotherapy for cancer.⁴ Communities marked by pockets of vaccine refusal have seen the re-emergence of diseases, such as measles,⁵ that had been virtually eliminated from the

Off Facebook Tracking: Sample Data

ARTICLE | VOLUME 3, ISSUE 9, 100561, SEPTEMBER 09, 2022

PDF [3 MB] Fig

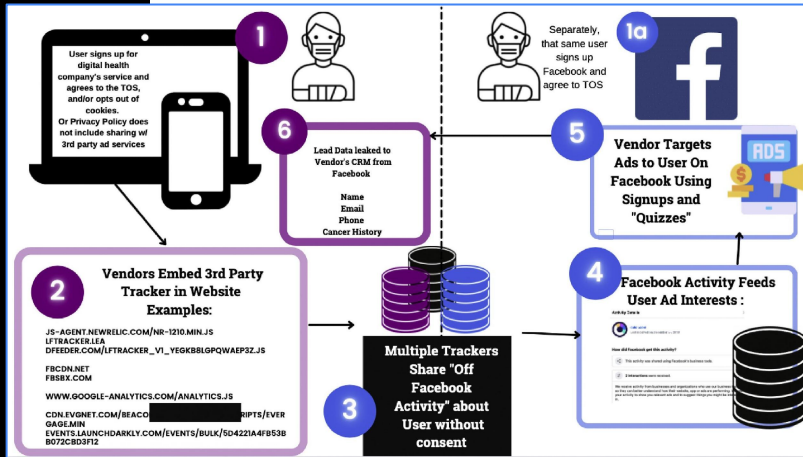
Health advertising on Facebook: Privacy and policy considerations

Andrea Downing ^{3, 4} • Eric Perakslis ³ • Show footnotes

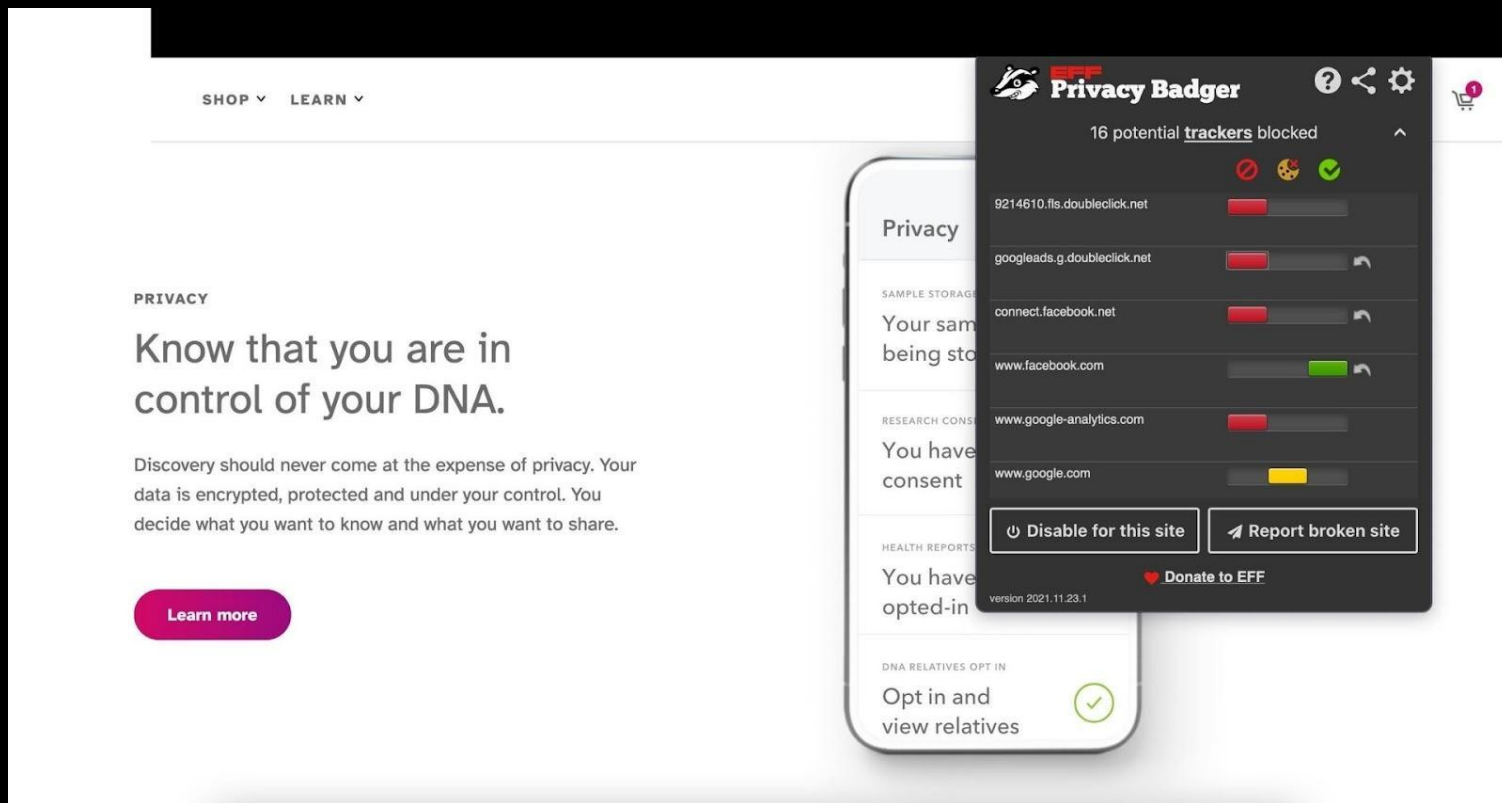
Open Access • Published: August 15, 2022 • DOI: <https://doi.org/10.1016/j.patter.2022.100561>

```
▼ 11:
  name: "hereditarycancerquiz.com"
  events:
    ▼ 0:
      id: 1480344785329502
      type: "CUSTOM"
      timestamp: 1632450720
    ▼ 1:
      id: 1480344785329502
      type: "PAGE_VIEW"
      timestamp: 1632450480
```

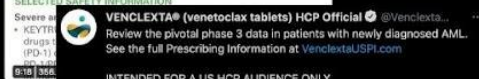
```
▼ 41:
  name: "color.com"
  events:
    ▼ 0:
      id: 1073333746069147
      type: "VIEW_CONTENT"
      timestamp: 1577472420
    ▼ 1:
      id: 1073333746069147
      type: "VIEW_CONTENT"
      timestamp: 1577472240
```



Genetic Testing Site Example



KEYTRUDA (pembrolizumab) @KEYTRUDA
Have you considered KEYTRUDA for your appropriate patients with mNSCLC?
Learn more: bit.ly/3dRmMqJ
Prescribing Info: bit.ly/2CtMrE
Med Guide: bit.ly/2yon94P





VENCLEXTA®
venetoclax tablets 10mg, 50mg, 100mg

* tumor lysis syndrome (TLS), including renal events and renal failure requiring dialysis, has occurred in patients treated with VENCLEXTA.

* VENCLEXTA can cause rapid reduction in tumor and thus poses a risk for TLS at initiation and during the ramp-up phase in all patients. Changes in blood chemistries consistent with TLS that require prompt management can occur as early as 6 to 8 hours following the first dose of VENCLEXTA and at each dose increase.

Boosting my immunity with dense food like kale and blueberries
 an IV infusion [redacted] #ivermectin,
 exercise and sunshine! 🌿💉☀️👤

(ivermectin)

Prevention

Vitamin

This formula provides Vitamin C and other nutrients to give immune support when facing and challenge like the cold & flu.

Vitamin C, **Vitamin D**, **Vitamin E**, **Vitamin K**, **Vitamin A**, **Vitamin B1**, **Vitamin B2**, **Vitamin B3**, **Vitamin B5**, **Vitamin B6**, **Vitamin B7**, **Vitamin B9**, **Vitamin B12**

PTI alters the
**tumor micro-
environment**¹



Reference: 1. Greten FR et al. *Immunity*. 2019;51(1):27-41.

0-16

Learn More
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
09-Nov-22	—	Federal wire-tapping case mentions: Federal Wiretap Cases Target hospitals Using Meta Pixel
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: <u>HHS Office for Civil Rights Issues Bulletin on Requirements under HIPAA for Online Tracking Technologies to Protect the Privacy and Security of Health Information</u>

**Methodology and data shared with markup at time of preprint and Wired Story*

OCR Breach Notifications

Name of Covered Entity	State	Covered Entity Type	Individuals Affected	Breach Submission Date	Type of Breach
Cerebral, Inc (Notice)	DE	Business Associate	3179835	03/01/2023	Unauthorized Access/Disclosure
Community Health Network, Inc. as an Affiliated Covered Entity (Notice)	IN	Healthcare Provider	1500000	11/18/2022	Unauthorized Access/Disclosure
Novant Health Inc. on behalf of Novant Health ACE & as contractor for NMG Services Inc. (Notice)	NC	Business Associate	1362296	08/14/2022	Unauthorized Access/Disclosure
WakeMed Health and Hospitals (Notice)	NC	Healthcare Provider	495808	10/14/2022	Unauthorized Access/Disclosure
UCLA Health (Notice)	CA	Healthcare Provider	94000	01/12/2023	Unauthorized Access/Disclosure
Louisiana Department of Public Safety and Corrections (News Story)	LA	Healthcare Provider	85466	10/31/2022	Unauthorized Access/Disclosure
Total as of Today			61,351,232		

Pixel Hunt

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.

The Meta Pixel collects sensitive health information and shares it with Facebook

The Meta Pixel installed on Piedmont Healthcare's MyChart portal sent Facebook details about a real patient's upcoming doctor's appointment, including date, time, the patient's name, and the name of their doctor

- 1 Patient name
- 2 Date and time of appointment
- 3 Name of provider

```
{ "classList": "_Link+ actionable+ link+ readOnlyText+ InternalLink+ main", "destination": "https://mychart.piedmont.org/PRD/app/communication-center/conversation?id=ID REDACTED BY THE MARKUP", "id": "", "imageUrl": "/PRD/en-US/images/ProviderSilhouette.png", "innerText": "MyChart+Messaging+User\\nREDACTED BY THE MARKUP\\nAppointment+scheduled+from+MyChart\\nThere+is+a+message+in+this+conversation+that+has+not+yet+been+viewed.\\n 1 Appointment+For: +NAME REDACTED BY THE MARKUP+(ID REDACTED BY THE MARKUP)+Visit+Type: +NEW+PATIENT+(ID REDACTED BY THE MARKUP)+ 2 MM/DD/YYYY+0:00+XX+00+mins. + 3 NAME REDACTED BY THE MARKUP, +MD", "numChildButtons": 0, "tag": "a", "name": "" }
```

Source: mychart.piedmont.org, Mozilla Rally

...As of February 2023

'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 Downers Grove, Ill., and

DIVE BRIEF

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

Published Feb. 16, 2023



Rebecca Pifer
Senior Reporter



James,
red
ology
sabled

t or
n this

[Global Edition](#) [Privacy & Security](#)

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.

By [Mike Miliard](#) | October 20, 2022 | 11:02 AM



Patient groups are aware, concerned & expect protection



The HIPAA Journal
and

[TOPICS](#)[INDUSTRY](#)[EVENTS](#)[PODCASTS](#)[RESEARCH](#)[RECOGNITION](#)[HIPAA Compliance News](#) [Practical HIPAA Advice »](#) [HIPAA Compliance Checklist](#) [HIPAA Rules & Regulations »](#) [HIPAA Training](#)

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

Posted By HIPAA Journal on Feb 13, 2023

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

Privacy, Policy, Compliance



Cedars-Sinai, Cerebral, telehealth companies among latest accused of data sharing with Meta

[Jessica Davis](#) February 9, 2023

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>

HHS.gov  U.S. Department of Health & Human Services
Health Information Privacy

I'm looking for... 

A-Z Index

 **HIPAA for Individuals**

 **Filing a Complaint**

 **HIPAA for Professionals**

 **Newsroom**

[HHS](#) > [HIPAA Home](#) > [For Professionals](#) > [Privacy](#) > [Guidance Materials](#) > Use of Online Tracking Technologies by HIPAA Covered Entities and Business Associates

HIPAA for Professionals

Text Resize **A A A** Print  Share   

Regulatory Initiatives

Privacy 

- Summary of the Privacy Rule
- Guidance
- Combined Text of All Rules
- HIPAA Related Links

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

The Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is issuing this Bulletin to highlight the obligations of Health Insurance Portability and Accountability Act of 1996 (HIPAA) covered entities¹ and business associates² ("regulated entities") under the HIPAA Privacy, Security, and Breach Notification Rules ("HIPAA Rules") when using online tracking technologies ("tracking technologies").³ OCR administers and enforces the HIPAA Rules, including by investigating breach reports and complaints about regulated entities' noncompliance with the HIPAA Rules. A regulated entity's failure to comply with the HIPAA Rules may result in a civil money penalty.⁴

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”

HIPAA compliance obligations

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

FTC Enforcement for Non-Covered Entities

Complying with the Health Breach Notification Rule

First Enforcement Actions As of
2023:

GoodRx
BetterHelp



The screenshot shows the top of the FTC website with the logo and navigation menu. Below the navigation menu is a breadcrumb trail: Home / News and Events / News / Press Releases. A blue button labeled "For Release" is visible. The main heading is "FTC Enforcement Action to Bar GoodRx from Sharing Consumers' Sensitive Health Info for Advertising". The text below states: "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".

FEDERAL TRADE COMMISSION
PROTECTING AMERICA'S CONSUMERS

Enforcement ▾ Policy ▾ Advice and Guidance ▾ News and Events ▾ About the FTC ▾

[Home](#) / [News and Events](#) / [News](#) / [Press Releases](#)

For Release

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



The screenshot shows the top of the FTC website with the logo and navigation menu. Below the navigation menu is a breadcrumb trail: Home / News and Events / News / Press Releases. A blue button labeled "For Release" is visible. The main heading is "FTC to Ban BetterHelp from Revealing Consumers' Data, Including Sensitive Mental Health Information, to Facebook and Others for Targeted Advertising". The text below states: "BetterHelp will be required to pay \$7.8 million for deceiving consumers after promising to keep sensitive personal data private, agency says".

FEDERAL TRADE COMMISSION
PROTECTING AMERICA'S CONSUMERS

Enforcement ▾ Policy ▾ Advice and Guidance ▾ News and Events ▾ About the FTC ▾

[Home](#) / [News and Events](#) / [News](#) / [Press Releases](#)

For Release

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?

Comment | [Published: 09 February 2023](#)

Characterizing cyber harms from digital health

[Eric D. Perakslis](#), [Megan L. Ranney](#)  & [Jennifer C. Goldsack](#)

[Nature Medicine](#) (2023) | [Cite this article](#)

951 Accesses | **21** Altmetric | [Metrics](#)

Perakslis, E.D., Ranney, M.L. & Goldsack, J.C. Characterizing cyber harms from digital health. *Nat Med* (2023).
<https://doi.org/10.1038/s41591-022-02167-6>

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

Doxxing

Blackmailing

Account Hijacking

Medication Theft

Ransomware

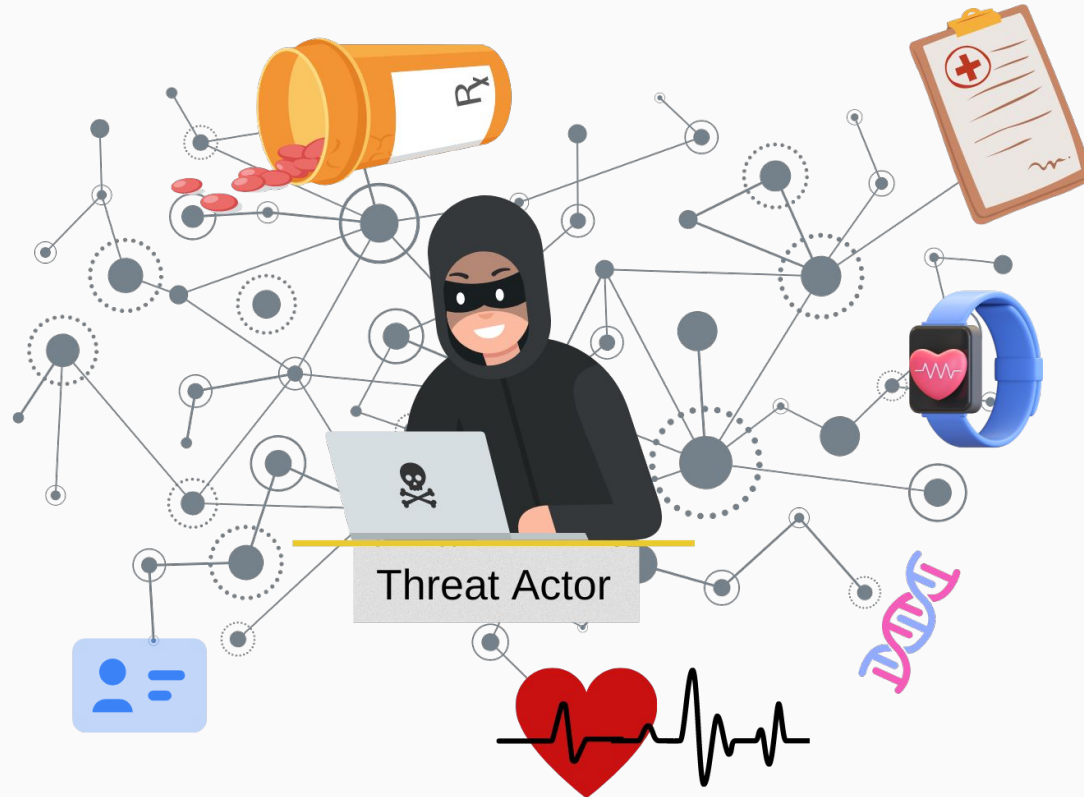
Disinformation

Malinformation

Phishing

Impersonation

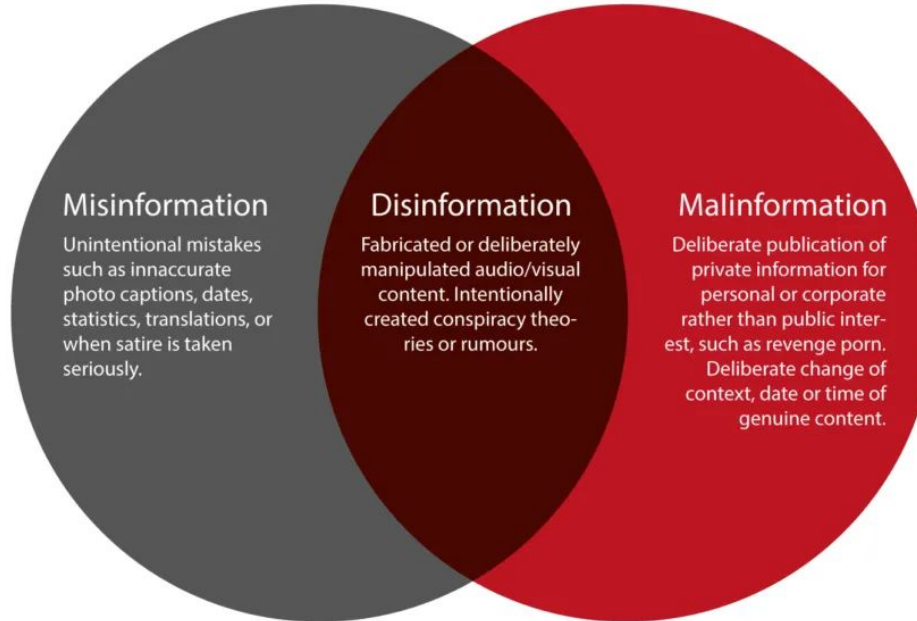
Device Takeover



TYPES OF INFORMATION DISORDER

FALSENESS

INTENT TO HARM



INFORMATION DISORDER :
Toward an interdisciplinary framework
for research and policy making

Credit: Claire Wardle & Hossein Derakshan, 2017

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.

Privacy is a right





The deadly state of surveillance capitalism

Thursday, March 16 | 12pm ET

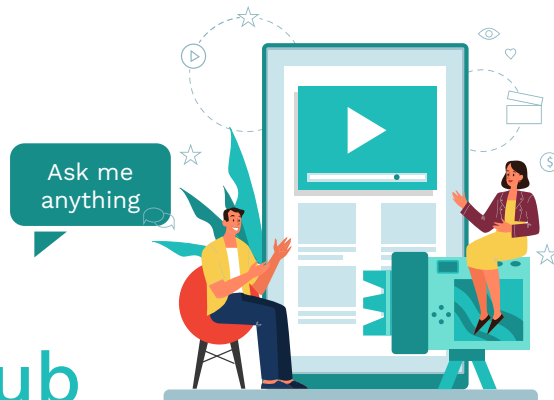


Andrea Downing
Co-Founder
The Light Collective



Jennifer Goldsack
CEO
Digital Medicine Society (DiMe)

Virtual Journal club



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)

The Patient Matters in the End(point)

Thursday, April 13th, 2023 | 11am ET

Join us for an upcoming DiME Webinar



The DiMe webinar series hosts leading experts from across a **variety of disciplines** to discuss critical topics on digital medicine with our community.



Scan the code & learn more about our webinar series and to **register** for our next event!



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)



THANK YOU



@_DiMeSociety



[linkedin.com/company/dime-society](https://www.linkedin.com/company/dime-society)