Presentation re *Approaches to Sharing Blended Data in a 21st Century Data Infrastructure*

"Legal, Institutional, and Technical Approaches to Governance of Sensitive Information, Including Trade Secrets and PII"

May 22, 2023

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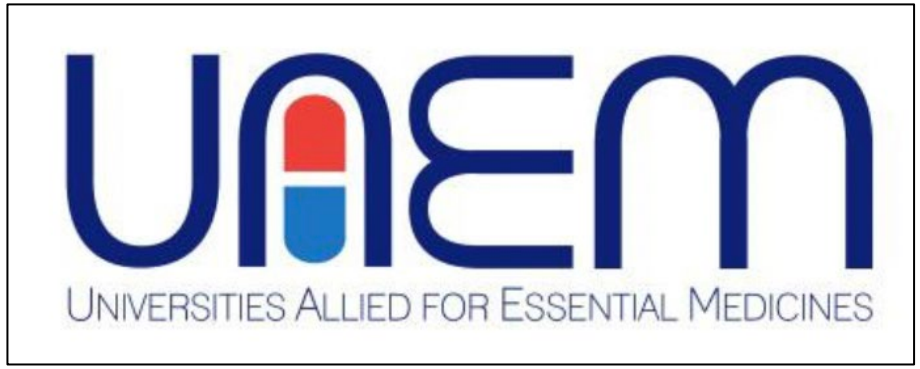
Science, Health, and Information Clinic

Columbia Law's Science, Health, and Information Clinic serves the public interest by fighting for—and winning—more equitable access to scientific, technical, and medical knowledge and to the benefits that flow from that knowledge.

The Science, Health, and Information Clinic strives to address legal needs unmet by public interest legal organizations and other law school clinics. Students, under faculty supervision, provide pro bono legal services to activists and organizers, scientific and medical researchers, patient and consumer groups, nonprofit organizations, and other clients.

The Science, Health, and Information Clinic was founded in 2021 by Associate Clinical Professor of Law Chris Morten.

Exemplary clients and partners



Key questions in practice & research

- How to provide researchers (and regulators and the broader public) meaningful access to and use of sensitive data while protecting the integrity of that data?

- How can *law* and *institutions* complement technology to better protect and govern sensitive data?

April 21, 2021 01:23 PM EDT *Updated 01:44 PM* | Pharma, FDA+

Law professors call for FDA to disclose all safety and efficacy data for drugs

Zachary Brennan
Senior Editor

Back in early 2018 when Scott Gottlieb led the FDA, there was a moment when the agency seemed poised to release redacted complete response letters and other previously undisclosed data. But that initiative never gained steam.

PhRMA strongly supports responsible efforts to register all clinical trials in patients and share the results of clinical trials involving medicines that are both approved for marketing as well as results of trials for investigational products with discontinued development programs -- regardless of trial outcome. PhRMA believes that there are important public health benefits associated with making appropriate clinical trial information available to the medical profession, patients, and the public at large. Nonetheless, these benefits must be pursued in a manner that protects other important public health goals such as maintaining patient privacy and protecting incentives for innovative medical research. While PhRMA appreciates NIH's initial efforts to address issues related to improving public access to information about clinical trials, PhRMA believes that the proposed rule can be improved in key ways that will enhance the utility of the database to patients and the general public and reduce the expected burden on research sponsors while also protecting the innovative process.

PhRMA
RESEARCH • PROGRESS • HOPE

TESLA / TECH

Tesla doesn't want anyone to see its response to the Autopilot investigation

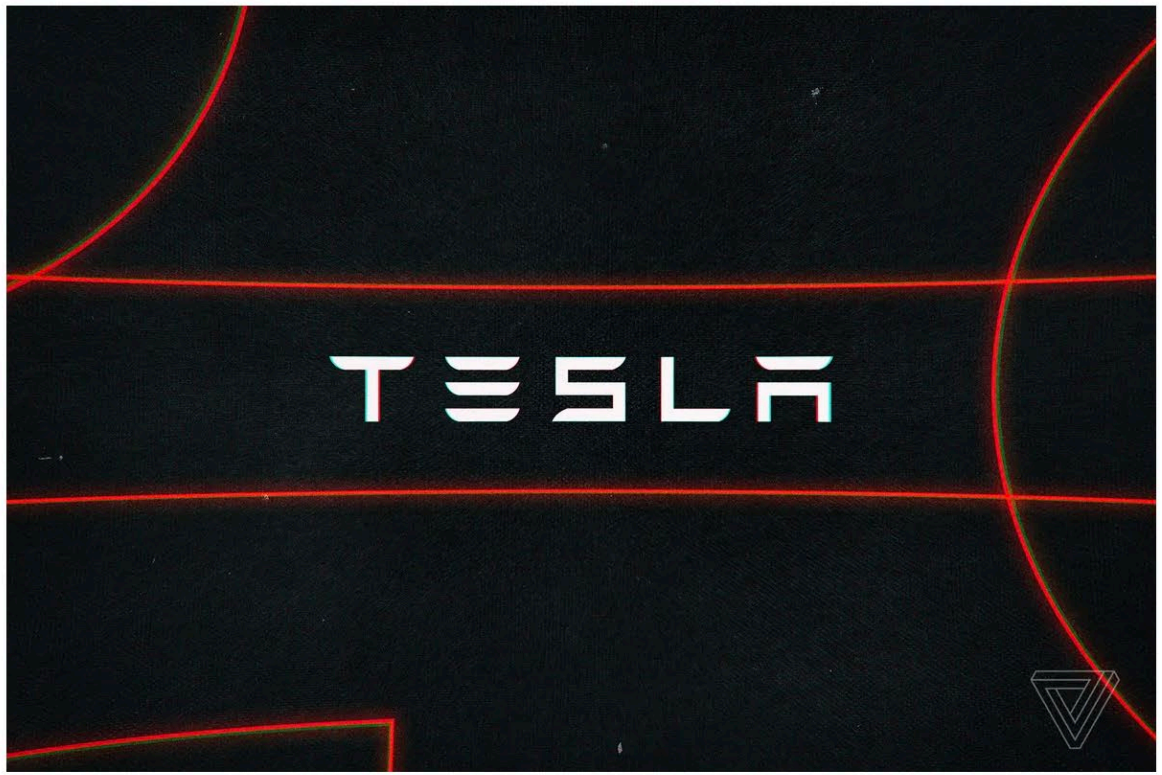


Illustration by Alex Castro / The Verge

/ The company is making a broad request for secrecy

By ANDREW J. HAWKINS / @andyjayhawk

Oct 25, 2021, 9:56 AM EDT | 0 Comments

THE WALL STREET JOURNAL.

TECH

Facebook Disables Access for NYU Research Into Political-Ad Targeting

Researchers say the data provided information on misinformation in political ads; Facebook says the work violated its terms of service

By Meghan Bobrowsky Follow

Updated Aug. 4, 2021 5:54 pm ET

FACEBOOK

Comments to the Federal Trade Commission on Data Portability

AUGUST 21, 2020

We think there are fundamental privacy questions that need to be answered for portability to be implemented successfully—meaning we can build privacy-protective, easy-to-use products for people at scale. As mentioned above, last year we published a

These examples also make clear that including all observed and inferred data could also result in a different sort of burden: the disclosure of trade secret or other proprietary information developed by a business to enhance or differentiate its services. Enabling

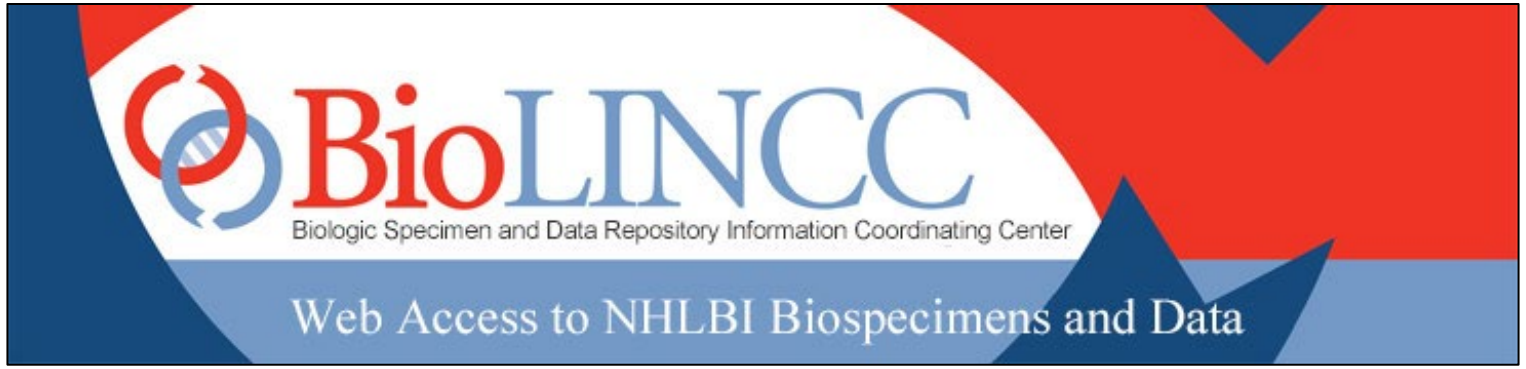
Key claims in my work

- Extant data-sharing initiatives show that even some of the most sensitive trade secret and PII data can be shared responsibly, with legal, institutional, and technological safeguards in place.
- Law, institutions, and technology all have roles to play (and reinforce each other).
- Tiered access is key.

Sharing medical research data

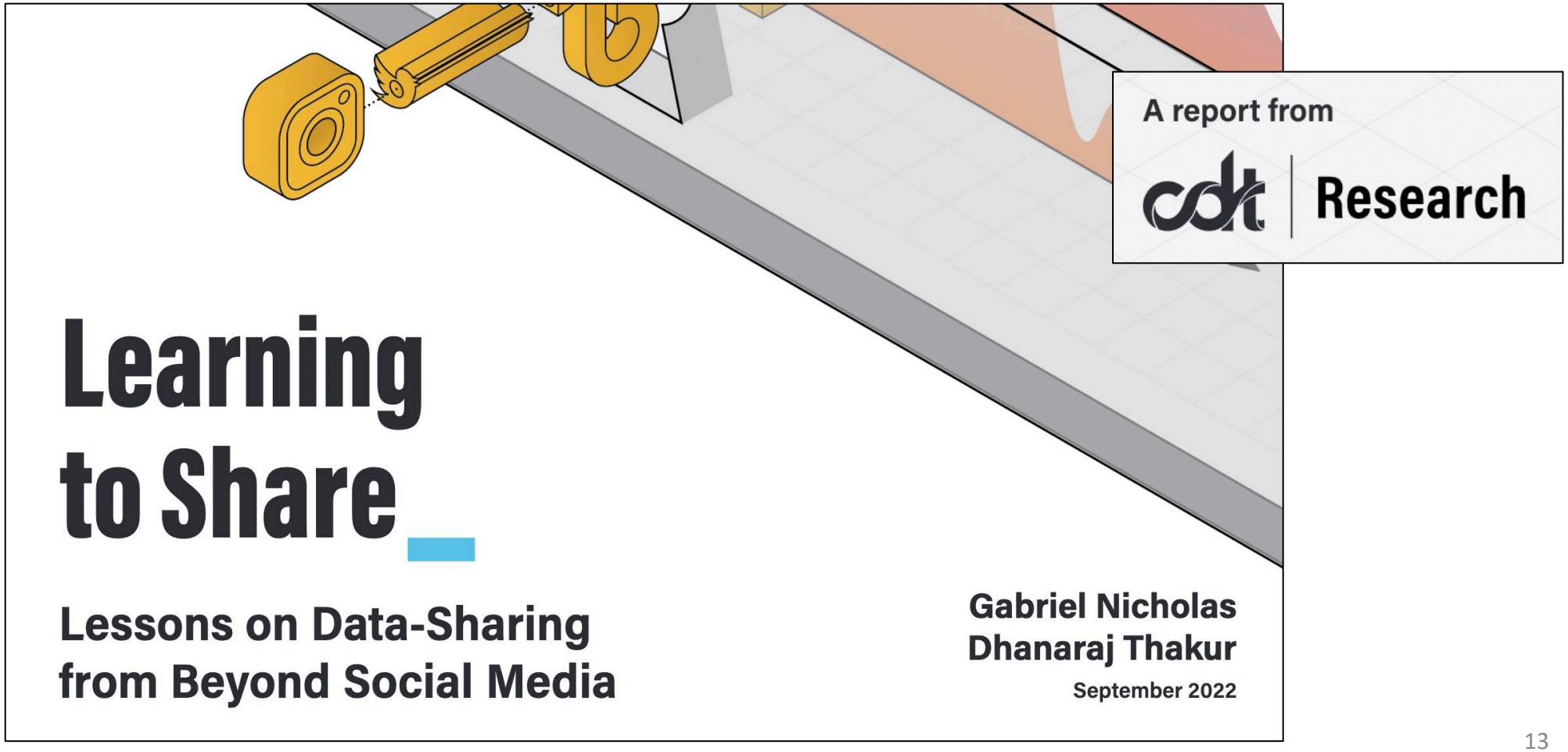
Search for clinical information on drugs and medical devices

From Health Canada



Sharing medical claims data

Sharing energy & environmental data



Law + institutions + technology

- Law, institutions, and technology complement each other.
- They work together to protect the integrity of sensitive trade secret and PII data when shared with researchers.
- **Legal governance structures**
  - Data use agreements prohibit harmful conduct, encourage beneficial research.
  - Statutes and regulations mandate data sources share their data.
- **Institutional governance structures**
  - Custodian institutions collect, validate, format, clean & steward data (& more!).
  - Institutions also screen & monitor prospective users & tier access accordingly.
- **Technological governance structures**
  - Differential privacy
  - Data “visiting”
  - …and more!

Recent & forthcoming papers

- Christopher J. Morten, Gabriel Nicholas & Salomé Viljoen, *Researcher Access to Social Media Data: Lessons from Clinical Trial Data Sharing*, 38 BERKELEY TECHNOLOGY LAW JOURNAL (forthcoming 2024).

- Christopher J. Morten, *Publicizing Corporate Secrets*, 171 U. PENNSYLVANIA LAW REVIEW (forthcoming 2023).

- Christopher J. Morten & Amy Kapczynski, *The Big Data Regulator, Rebooted: Why and How the FDA Can and Should Disclose Confidential Data on Prescription Drugs and Vaccines*, 109 CALIFORNIA LAW REVIEW 493 (2021).

Some key people writing on legal governance of trade secrets and PII

Julie Cohen (Georgetown U)

Mary Fan (U of Washington)

Woody Hartzog (Boston U)

Amba Kak (AI Now Institute)

Gabriel Nicholas (Center for Democracy & Technology)

Helen Nissenbaum (Cornell U)

Paul Ohm (Georgetown U)

Rashida Richardson (Northeastern U)

Daniel Solove (George Washington U)

Salomé Viljoen (U of Michigan)

…and more! This is a very non-exhaustive list.

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