ISMPP University

Data Privacy Regulation – Which Way Forward?

May 27, 2020

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16th Annual Meeting of ISMPP

Data privacy regulation: Which way forward?

Jon Bigelow, Coalition for Healthcare Communication

Originally to have been presented April 20, 2020
Learning objectives

• Recognize how the US has been an “outlier” in its approach to data privacy historically, and how that influences policy makers today
• Understand key factors policymakers are trying to reconcile in creating new regulations
• Consider how the need for data privacy and security competes with other public interests, especially in health
• Have a clearer idea which approach to data regulation is most likely to be enacted by the US and on what timeline
Disclaimer

- Information presented reflects the personal knowledge and opinion of the presenters and does not necessarily represent the position of their current or past employers or the position of ISMPP
Jon Bigelow

Jon Bigelow is Executive Director of the Coalition for Healthcare Communication, a nonprofit, bipartisan organization supporting the continued availability of accurate and credible health information across med comms, medical journals, digital platforms, advertising and marketing, and point of care education.

He previously was CEO and President of KnowledgePoint360 Group, a leading provider of multichannel medical communications, consulting, benchmarking, and workflow solutions in the U.S., U.K., and Germany; President of Cliggott Publishing; President of the Association of Medical Media; and a consultant providing strategic support on health communications, pharma services, and health policy.
Moderator: Karen Mittleman

Karen has over 20 years of experience in medical publication planning and development and was the Head of Publications within the Chief Medical Office at Sanofi prior to her retirement in 2018. Her role was to oversee development and review of scientific and medical publications across the Global Business Units and R&D. She also worked closely with Data Sharing and Trial Transparency groups within Sanofi for clinical trial data dissemination. Karen recently served as Secretary of the Board of Trustees of the International Society of Medical Publication Professionals (ISMPP) and currently serves on its Global Transparency Committee.

Karen received a BSc from Penn State University, a Masters degree in Exercise Physiology from San Diego State University, and a PhD in Environmental Physiology from Simon Fraser University, British Columbia, Canada. She was a National Research Council Resident Research Associate with the Diving Medicine Department, Naval Medical Research Institute in Bethesda, Maryland, and was a postdoctoral fellow in renal physiology at Rutgers University. She was an assistant professor in Exercise Science at Rutgers before moving to medical communications.
Agenda

• How we reached this point
• How Covid-19 affects the discussion
• Challenges of current “system”
• Competing visions of the way forward
• What to expect
The promise of Big Data

- Clinical practice
- Clinical research
- Public health
- Marketing and communications
The anger is building

- Federal government reticent to regulate search and social media
- But…
  - Repeated hacks of consumer information
  - Cambridge Analytica and misuse of personal data
  - Unexpected uses of information
  - Tech leaders’ fumbled responses
  - Fake news and deep fakes
  - Artificial intelligence
  - Re-identifying anonymized data
  - Surveillance / facial recognition
Pew Research Poll, 6/19  4,272 American adults

- 72%: All / most activities online / mobiles tracked by companies (47% by gov’t)
- 81%: Have little control over data collected about them
- 81%: Potential risks to them from this data collection outweigh benefits
- 79%: Concerned about ways companies use data (66% about gov’t use)
- 70%: Personal data less secure than 5 years ago
- 69%: Lack confidence firms will use personal data in ways they comfortable with
- 79%: Not confident firms will take responsibility if misuse or compromise data
- 75%: There should be more government regulation of data collection
Pandemic raises further issues

• Cybersecurity
  – Zoombombing
  – Telehealth
  – Hackers targeting Covid-19 research (IP and personal data)

• Data privacy
  – Cellphone data to characterize most common symptoms
  – Surveillance to track Covid patients and contacts
    • Acceptable for government to use cellphones to track Covid+ patients? Yes, 48%; No, 52%
  – Discrimination based on Covid-19 status
  – Immunity passports
2018-2020: Empowering the consumer

• Good Data Practices Regulation (GDPR)
  – Expanded definition of personal data
  – Greater consumer consent including opt-in
  – Severe penalties (up to 4% of profits)

• California Consumer Privacy Act (CCPA)
  – Right to know what collected, from where, what sold, to whom—and to say No
  – Law written hastily, internal contradictions—still being revised
  – Effective 1/1/20, enforcement begins 7/1/20—or not?
  – Limited “private right of action”

• Legislation in other states
The U.S. is the outlier

• OUS, move toward consent-based framework
• In U.S., regulation by sector (healthcare, financial services, education, etc.)
• Heavy reliance on self-regulation (e.g., Digital Advertising Alliance)
• Enforcement is divided, no one agency set up, staffed, and funded to police data privacy and security
Issues with status quo

• Difficult to work with potentially 51 sets of rules
  – Especially hard for smaller firms

• Burden is on consumers:
  – Review lengthy and abstruse terms and conditions
  – Often under time pressure, on mobile, without adequate English
  – Need to opt-in, and then return to control your own privacy choices
  – Most click “I accept” for everything: Is this informed consent?

• Competing “public goods”
  – Full data sets on clinical trials; algorithms to track disease patterns, etc.

• Technology constantly evolving
  – Does new technology make individual consent nearly impossible?
So, what to do?

• Dozens of different proposals
  – From both conservatives and liberals, sometimes working together
• Some more to “set a marker” or show concern over problem
• Some more serious
• Several new, driven by Covid
• Important to get it right
Just a few of the proposed laws...

• Weak privacy protections and pre-empt state laws
  – Rubio: American Data Dissemination Act
  – Blackburn: Balancing the Rights of Web Surfers Equally and Responsibly Act

• CCPA-like privacy protection and pre-empt state laws
  – DelBene: Information Transparency and Personal Data Control Act

• CCPA-like privacy protection, does not pre-empt state laws
  – Cortez Masto: DATA Privacy Act
  – Markey: Privacy Bill of Rights Act

• Targeted goals
  – Warner, Fischer: Limit experimentation on consumers without knowledge
  – Warner, Blumenthal, Hawley: Address large social media platforms
  – Hawley: Do Not Track Act
And a few more…

• Assign a price to the value of personal data
  – Warner: DASHBOARD Act

• Algorithmic accountability
  – Wyden: Test AI systems for bias and fix any found

• Enforce against CEOs, not just companies
  – Wyden: Mind Your Own Business Act, potential jail time

• Establish data privacy agency
  – Gillibrand: Data Protection Act
  – Eshoo, Lofgren: Online Privacy Act
Pandemic already prompting new proposals

• Limits on how public health information can be collected
  – Wicker, Thune, et al: Get permission before collecting information

• Limits on how that information can be used and for how long
  – Warner, Blumenthal, Hawley: Health info may not be used for unrelated purposes and must be deleted within 60 days of end of public health emergency
“The question is no longer whether we need a federal law to protect consumers’ privacy, the question is what shape will that take.”

Sen. John Thune (R-SD)
2020-21: Shift burden to government?

• Thesis:
  – Because few consumers can know the details of multiple privacy regimens at different sites to give “informed consent”,
  – And because data privacy and security issues cross state lines,
  – Thus, Federal government should establish privacy and security parameters
Privacy for America initiative

• Initiated by industry groups (4As, ANA, IAB, etc.)
• Data Protection Bureau within FTC
• Establish rules for data collection and use
  – Define what’s acceptable
• Identify certain practices as “per se unreasonable”
• Anticipate changing technology
  – Define process for designating additional practices unreasonable
• Include data security
  – If breach, who need to tell and how quickly
• Rigorous safe-harbor program
In Senate Commerce Committee

• Bipartisan effort led primarily by 6 Senators
  – Republicans Roger Wicker (MS), chair; John Thune (TX); Jerry Moran (KS)
  – Democrats Maria Cantwell (WA), ranking member; Richard Blumenthal (CT); Brian Schatz (HI)

• Staying a little below the radar

• Key remaining issues:
  – Private right of action
  – Pre-emption of state legislation

• “Most of the way there,” until Covid intervened
“We’re not amending a statute, we’re creating one… It takes time to do it right.”

Sen. Brian Schatz (D-HI)
What to expect?

• Key caveats: Evolution of Covid-19 and outcome of elections
• Expect to see legislation brought forward in 2021
  – Data agency within FTC with enforcement power
  – Structured around “guardrails”
  – State AGs also can enforce
  – ?? Right of private action
  – Pre-empting most state legislation
• Likely to have bipartisan support
Key takeaways

• Data privacy and security a growing issue
• It will only get more important and more complex
• Can’t put genie back in bottle—and most wouldn’t want to
• Look for legislation in 2021, and not just “CCPA 2.0”
• What happens in Washington matters to all of us
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• Contact me at jbigelow@cohealthcom.org
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