



ISMPP University

Data Privacy Regulation – Which Way Forward?

May 27, 2020



Webinar will begin
promptly at:
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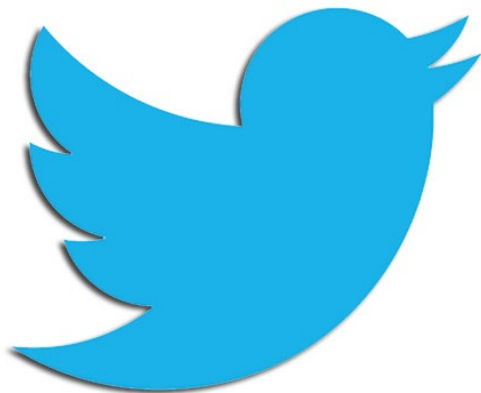
Registration Opens April 30!





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The screenshot shows the ISMPP website homepage. At the top right, there are links for "Contact Us", "Terms and Conditions", and "Sign In". The ISMPP logo, featuring a stylized caduceus and the text "International Society for Medical Publication Professionals", is in the top left. Below the logo is a navigation bar with links: HOME, COMMUNITIES, DIRECTORY, EVENTS, BROWSE, and PARTICIPATE. A search bar is located on the right side of the navigation bar. The main banner features a network diagram with the text "LET'S CONNECT!". Below the banner, there are three sections: "Latest Discussions", "Recent Shared Files", and "Upcoming Events".

Latest Discussions

Post to this Discussion This Discussion has no recent posts. Your new post to this Discussion will display here and be sent via email to subscribed Community members.

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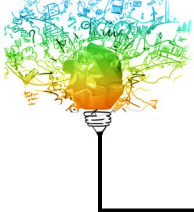
Recent Shared Files

Create a Library Entry This Library has no recent entries. Add a file or multimedia through a new Library Entry.

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20 18th Annual Meeting of ISMPP
APRIL Apr 20 - 22, (ET)
Washington, DC, United States



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- To ask a question, please type your query into the Q&A box
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NOTE: Make sure you send your question to:
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The screenshot shows the Zoom interface with the Q&A box open. A red arrow points to the question mark icon in the top right corner of the Zoom window. Another red arrow points to the 'Host & Presenters' option in the 'Ask:' dropdown menu. The Q&A box shows a question from 'Laine Capaccio' asking 'can you see my q&a?'.



Attention all CMPPs!

- This webinar qualifies for 1.0 ISMPP CMPP™ recertification credit
- Remember to take a screenshot to document your participation

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 (eg, 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

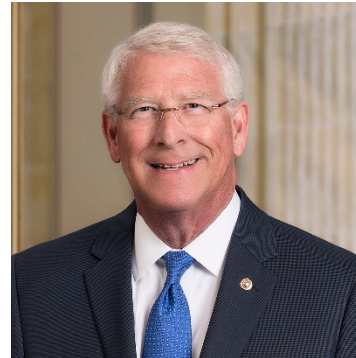


Privacy for America initiative

- 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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Rising Leaders Conference on Healthcare Policy
National Press Club, Washington

Dinner, Wednesday 11/18

Meeting, Thursday 11/19

- Contact me at jbigelow@cohealthcom.org

Q&A

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Send to: All Participants

Select a participant in the Send to menu first, type chat message, and send...

Q&A

All (1) My Q&A (1)

Laine Capaccio - 10:22 AM
Q: can you see my q&a?

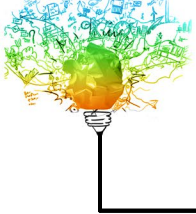
Ask: Lisa Klos
Host
Presenter
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Upcoming ISMPP Us – 16th Annual Mtg Content

Don't miss your opportunity to sample the excellent content from the ISMPP virtual Annual Meeting

DATE	TOPIC	FACULTY
Wednesday, July 22, 2020	Authorship Challenges & Solutions: It's Not WHO You are, It's WHAT You Do	<ul style="list-style-type: none"> • Maggie Hodgson, BSN, MBA, Director Publication Management, Oncology Lead, Merck • Rob Matheis, PhD, MA, President and CEO, ISMPP • Sonia A. Schweers, PharmD, ISMPP CMPPT™, Medical Capabilities / Medical Effectiveness, Global Publication Practices Lead, Bristol-Myers Squibb • Moderator: Carolyn Hustad, PhD, Chair, Annual Program Committee; Associate Vice President, Global Medical and Scientific Publications, MRL Scientific Affairs, Merck
Thursday, July 30, 2020	Recognize the Power of the ISMPP CMPPT™ Credential: Digital Innovations and Insights into Earning and Retaining Your Credential	<ul style="list-style-type: none"> • Dana Fox, PhD, ISMPP CMPPT™, Scientific Division Lead, Caudex • Megan Weigel, ISMPP CMPPT™, Global Communication, Quality and Compliance Specialist, Bristol-Myers Squibb • Moderator: Danita Sutton, PhD, ISMPP CMPPT™, Director, Credentialing, ISMPP



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