



WILMER CUTLER PICKERING HALE AND DORR LLP ©

The Long and Winding Road Towards National Privacy Legislation

Kirk J. Nahra

WilmerHale

Washington, DC

202.663.6128

kirk.nahra@wilmerhale.com

@kirkjnahrawork

March 6, 2019



My Presentation

- We are having a more active debate on national privacy legislation than at any point in the past 20 years
- Still a long ways away (probably), but lots of progress and some clear concepts emerging
- Health care role is very much up in the air



Forces moving towards National Legislation

- GDPR – Broad principles establishing data privacy and security law across the EU
- Protects all personal information in all settings
- Application to a wide range of US companies
- Health care industry simply part of the overall legislation
- Health care data considered sensitive information with certain special restrictions



Forces moving towards National Legislation

- Enormous GDPR implications for certain kinds of US health care companies - mainly pharmaceutical industry
- Limited impact on certain aspects of industry (physicians, most hospitals, many health insurers)
- Enormous implications for global or multinational companies generally (particularly tech companies)
- Significant compliance activities



GDPR Challenges

- GDPR – questions about how best to comply
- How to isolate GDPR/EU personal information
- Whether to apply GDPR for all activities, or in any way outside of EU impact
- Related issues involving data transfer from EU and related mechanisms (e.g., model contract clauses and Privacy Shield)
- Ongoing issue of Brexit



California as a Driving Force

- Dozens of laws dealing with privacy and security over past 15 years
- Some laws are never heard from again
- Some don't get passed elsewhere but have broader implications (e.g., website privacy policies) or go national (e.g., data breach, SSNs)



California Process

- Drive for referendum with aggressive privacy principles
- Industry resistance
- Last minute agreement to draft state law and agreed withdrawal of referendum proposal
- Not the normal lobbying/drafting process
- Major issue of what other states will do



California

- Who is protected? - “consumers” (defined as natural persons who are California residents)
- Who is covered? businesses that collect and control California residents’ personal information, do business in the State of California and: (most reasonably sized businesses - specific revenue and individual thresholds)



California

- What rights? four basic rights:
- (1) the right to know (through a general privacy policy and with more specifics available upon request) what personal information a business has collected about them, where it was sourced from, what it is being used for, whether it is being disclosed or sold, and to whom it is being disclosed or sold;



California

- (2) the right to “opt out” of allowing a business to sell their personal information to third parties;
- (3) the right to have a business delete their personal information; and
- (4) the right to receive equal service and pricing from a business, even if they exercise their privacy rights under the Act.



California

- Seems to generally exempt health care covered entities
- Seems to generally exempt business associates for activities covered by HIPAA
- May have a broader impact on HIPAA covered PHI
- Also exempts entities covered by California health care privacy law



Compliance challenges

- Identifying California residents
- Single national approach or California specific?
- Developing operations that can adjust for those residents who exercise rights
- Understanding what entities in health care and using health care information are covered or not



Other Drivers

- Series of ongoing privacy “scandals” and security breaches – mostly not involving health care
- Driver for broader legislation in health care – continuing exposure of the growing “gaps” in HIPAA’s reach
- Not a new issue, but growing importance



Non-HIPAA Health Information

- Continued expansion of tech companies into the health care space
- Enormous growth in mobile apps, wearables, health-related web sites, wellness program issues, etc –
- General concern is volume of health data that isn't regulated by HIPAA



More “next generation” issues

- An emerging (and related) issue - bringing “outside” HIPAA information “inside” HIPAA
- CEs are gathering all kinds of data about their patients/customers/insureds from outside the health care system and using it for “health care purposes”



Recent Headlines

“When a Health Plan Knows How You Shop.”

(New York Times)

- Health plan prediction models using consumer data from data brokers (e.g., income, marital status, number of cars), to predict emergency room use and urgent care.



Tentative Predictions

- 3 Main Options
- Something specific for this non-HIPAA health care data
- Something that covers all health care data (a “general” HIPAA)
- A broader overall privacy law (with or without a HIPAA carve-out)



The National Debate

- California law has re-invigorated the national privacy debate
- Combined with GDPR and various privacy/security “problems”
- Congressional hearings
- Administration proceedings
- Stakeholders setting out their positions



California and the National Debate

- Industry is concerned about California by itself
- Industry is concerned about other states passing “California-like” laws
- Some in industry are concerned about global issues and EU “adequacy”
- Could lead to a US law – with preemption – but could be a “strong” or “weak” law



Health Care in the National Debate

- Isolated “solution” to issue of “non-HIPAA health data” seems to have disappeared
- Health care industry – regulated by HIPAA – could be left alone (excluded from application of national law, as is largely true with California)
- New provisions could apply to HIPAA entities – in addition to HIPAA



Health Care in the National Debate

- New provisions likely would “cover” “non-HIPAA health care data” (and entities)
- Could lead to different standards
- Overlap issue of pre-emption – would health care industry “want” to be covered if strong preemption of state law
- Or a national law could replace HIPAA (possible but unlikely)



Today

- Lots of activity – stakeholders defining positions, draft legislation in Congress, congressional hearings
- Proposed legislation and principles from many sources
- Still a long way to go – but lots of activity throughout the year



Today – Key Issues

- Pre-emption
- Private Cause of action
- Scope of Individual Rights
- Permitted disclosures vs. areas where permission from consumers is needed
- Enforcement



Today – A Prediction

- Not likely to have national legislation in this Congress (although more likely than in the past) (way below 50-50)
- Major driver will be the wild card of other states
- If 3-5 significant states pass “California-like” laws, then Industry will need to support a federal law



Questions?

Kirk J. Nahra

WilmerHale

202.663.6128

kirk.nahra@wilmerhale.com

@kirkjnahrawork