The Role of Health Care in the National Legislative Debate

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March 4, 2020



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H 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
- While the health care privacy eco-system has been relatively settled for many years, it is now facing meaningful upheaval – and may not be getting enough attention in the national debate



- HIPAA Rules have set the benchmark for the health care industry for almost two decades
- Increasing challenges with the existing structure given a variety of changes in both the traditional health care industry and in the broader health information ecosystem
- While HIPAA still works well where it applies (although this may be a controversial statement), there are increasing situations where it doesn't fit
- And some situations even in the core health care system – where it may not work well



- You have heard about the debate/discussion over patient access
- Critical goal of many in the health care system
- Current real time debate
- One of the issues being debated involves the limitations of the HIPAA rules – what do you do when one goal (patient access) runs into the HIPAA limitations
- We will be watching how the final rules make this decision (at least for the time being)

Another example – the HIPAA RFI

Should OCR modify the Privacy Rule to clarify the scope of covered entities' ability to disclose PHI to social services agencies and community-based support programs where necessary to facilitate treatment and coordination of care with the provision of other services to the individual? For example, if a disabled individual needs housing near a specific health care provider to facilitate their health care needs, to what extent should the Privacy Rule permit a covered entity to disclose PHI to an agency that arranges for such housing?

Non-HIPAA Health Information

- Continued expansion of tech companies into the health care space
- Enormous growth in mobile apps, wearables, healthrelated web sites, wellness program issues, etc –
- General concern is volume of health data that isn't regulated by HIPAA
- And lots of questions in the media and otherwise even when the data "probably" is 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.



Health Care "solutions"

- 3 Main Possibilities
- 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)

So where are we going on health care privacy?

- Current national debate is not focused on health care
- Freestanding effort on healthcare privacy is not currently active (some minor exceptions)
- Health care is not being addressed thoughtfully in the current debate over a national privacy law
- Default position of health care industry has been "carve us out of new law"

Some things to think about

California Consumer Privacy Act – how is your health information protected?

- 1. HIPAA protected information (generally exempted from CCPA)
- 2. CMIA covered companies/information (generally exempted from CCPA)
- 3. Common Rule/Clinical research (generally exempted from CCPA)
- 4. CCPA probably covers your health information if it isn't exempted
- 5. BUT CCPA doesn't cover non-profits
- 6. And CCPA doesn't generally cover employers and employee information
- 7. How can consumers, businesses and others deal with this?
- 8. Is this the best approach?



- 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
- Not a recommendation but an alternative model

California and the National Debate

- California law has re-invigorated the national privacy 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

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- 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)



- 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

H 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
- Health care will not be a focus of "special" attention unless something changes



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