



Structure Workgroup Meeting #2 – Summary Tuesday, April 21, 2020

Thank you to everyone who joined and participated in our April workgroup meeting. As a reminder, this workgroup is focused on developing the structure that our proposed privacy framework for unregulated health data will take. On our March call, the group voiced general support for moving ahead with a self-regulatory model of some kind, and therefore our April call focused on walking through a number of different self-regulatory structures.

Meeting Attendees

- Andy Coravos (Elektra Labs)
- Brooke Rockwern (American College of Physicians)
- Travis Hunter
- Brenda Pawlak (Manatt)
- Laura Hoffman (American Medical Association)
- Mark Segal (Digital Health Policy Solutions)
- Jacquie Haggerty (23andMe)
- Jeri Koester (Marshfield Clinic)
- Jessica Rich (former FTC)
- Katherine Hempstead (RWJF)
- Mary Engle (BBB)
- Po Yi (Manatt)
- Lee Tien (Electronic Frontier Foundation)
- Erin Mackay (NPWF)
- Andy Crawford (CDT)

Discussion

Summary of Meeting #1

- We began the meeting with a summary of the March meeting, during which the group coalesced somewhat around a self-regulatory model. This agreement was largely driven by the acknowledgement that so many other groups have developed codes of conduct, and that there was no need to create yet another one. Further, sets of best practices don't have any "teeth" for enforcement or accountability.
- Also in March we discussed the value in recruiting additional consumer and civil liberties advocates in for our Steering Committee; individual outreach to such participants could help dispel skepticism about a self-regulatory approach generally.
- Finally, we reiterated the importance of framing our work as a "bridge to future legislation," making clear that we are fully aware that no work that we do is a solution in and of itself. Rather, we are taking interim steps to increase protections for non-HIPAA covered data until we have a new federal data privacy law.



COVID-19 and its Bearing on Our Work

- Although we in no way want to exploit the pandemic, the reality of COVID is that our data-protection work has become all the more important – and timely.
- The group agreed that the virus – and its associated data collection efforts – has accelerated the discussion around privacy, but the underlying issue remains the same. We agreed to use the COVID lens when discussing our work as often as it is appropriate.

Walk-Through of Self-Regulatory Models

- The Manatt paper circulated to the Steering Committee in February lays out a number of different self-regulatory models and includes considerations for how they might operate in health care. We noted that self-regulatory models operate independently from and do not preclude state law enforcement
- A couple of the models are not particularly feasible or appealing, such as a full government enforcement or quasi-government model (which would require Congressional action to establish)
- Discussion focused on the private sector options, whether one backed by government support or organized around a membership model
- With respect to making progress toward moving forward with a particular model (or two), there was a robust discussion about how it is important to understand the incentive for companies to join or sign onto a self-regulatory body or set of industry standards.
 - Although we would hope that a reputational boost for “doing the right thing” would be incentive enough for a private-sector company, we need to more clearly articulate a monetary incentive.
 - Is there one?
 - To flip the question, vigorous enforcement and potential penalties might be the best incentive
- The topic of FTC support came up often, as a federal enforcement back-stop might be the best way not only to lend a self-regulatory effort credibility, but to make enforcement meaningful and accountability real
- It was noted that voluntary models are only as good as their members, which lends support to the idea of having an open model, rather than having standards developed by and applicable to only those who have joined
- The group reiterated that the answer to how to better protect non-HIPAA covered data and to hold bad actors accountable is a federal law; given that that remains a ways off, we will move forward with interim steps

Next Steps

- The group felt it was premature to pick a particular model, given that we need to more clearly understand the incentives for joining
- In the days after the meeting, Alice Leiter had individual calls with a number of workgroup members to better understand, and in more detail, how to move forward, and the barriers or questions standing in the way of doing so.



- ***If you have post-meeting thoughts that you would like to share, please don't hesitate to email Alice at alice@ehidc.org.***
- The May Structure workgroup meeting will be held on **Tuesday, May 26 from 2-3:30 pm EST**. At this meeting we will discuss and evaluate a straw-man self-regulatory model, currently in development with the help of individual workgroup members. Again, if you have thoughts on how best to structure this or elements you want included or excluded, please write Alice.
- The full Steering Committee will meet again on **July 21**.