Panel 5: Policy and Technical Approaches to Health IT Privacy and Security

Chaired by Denise Anthony, Associate Professor of Sociology and Director, Institute for Security, Technology, and Society (ISTS) Dartmouth

Panelists: Mark Frisse, Vanderbilt University; Kelly Caine, Indiana University; Deven McGraw, Center for Democracy & Technology; Mark Suchman, Brown University

Summary of the Panelists’ Presentations and Panel Discussion

Denise Anthony, an Associate Professor of Sociology and Director of the Institute for Security, Technology, and Society at Dartmouth College, opened by emphasizing the idea that trade-offs exist between policy approaches and technical approaches in thinking about privacy and security; it is important to realize how these different approaches contradict and how they fit together. Anthony’s study on current privacy perceptions of IT in healthcare showed that patients do not ask as strongly for access to their records as expected and that providers are guided more by professional norms and the demands of the environment than regulations like HIPAA or state policies, particularly given the variance among state policies.

Mark Frisse, Accenture Professor of Biomedical Informatics and Professor of Management at Vanderbilt University, took over the panel to describe his experience working with the Institute for Software Integrated Systems at Vanderbilt, on a computer program that can produce formal software language based on policies from healthcare providers. The web-based modeling program will ideally be able to identify contradictions, and underlying assumptions in current policies in order to create automated software to facilitate disclosure decisions and ultimately to help create more user-friendly policies in the future. Frisse also explained a long-term goal is to be able to understand how to better enforce policies, including both federal and state laws, as well as institutional policies.

Mark Suchman, a Professor of Sociology and Law at Brown University, focused on analyzing hospital privacy policies and practices based on survey data from a sample of acute-care hospitals. He argued that policy solutions are more widespread than technical ones, having multiple dimensions with multiple constituencies. He showed that policy implementation and success depends on the cultural environment of hospitals.

Kelly Caine, a Principal Research Scientist in the Center for Law, Ethics, and Applied Research (CLEAR) at Indiana University, asked the panel to approach this issue from the patient perspective and by imagining an ideal system of privacy protections for information sharing in healthcare rather than the current reality. Based on her work on a Challenge Grant interviewing 30 patients, she found that patients indicated interest in sharing information on the granular level when they believe it will be used to better their care, but want to restrict specialists and non-treatment providers from information when they do not see benefit in sharing it. Her research group is working to build a user-interface that will give patients that control perhaps via a horizontal level model or time-based model with a visualization of access.
Deven McGraw, the Director of the Health Privacy Project at the Center for Democracy and Technology, emphasized that workable privacy solutions for new technologies in healthcare must try to support data flows for trust and quality, not privacy as an endpoint. Privacy by design in the context of healthcare requires flexibility because there are likely different solutions for small and large providers. Regulation must support privacy by design and workable privacy. Sometimes unclear regulation allows flexibility, but sometimes simply invites incompatibility. Technology vendors will not impose the right restrictions. They must come from the health industry.

One audience member asked how this shift of control from vendor to health provider could happen when it’s the norm for vendors to go directly to clinical users rather than experts. Deven McGraw suggested more communication between the computer scientists with the users so that users knew what to demand from the vendors. The audience member argued that computer scientists could not take this challenge on alone and that even with professional societies looking at this problem, the way the healthcare system is built seems to limit this possibility for a change in power. Another audience member brought up that the security landscape is far worse than fifteen years ago when we saw similar demands for policy, and his fear that prescriptive security controls lead to compliance regimes. Mark Suchman agreed problems are handled locally and variably by providers, such that regulations that focus on legal compliance will generally result in compliance behavior by providers, but not necessarily the practices to promote the overall goals. One audience member suggested learning from the electric power grid (after the blackout in 2003) as a model for addressing security from a high policy level incentive system with a government body to guide and enforce it. Deven McGraw cited Congressional discussions for baseline policy legislation that stalled, to again emphasize the need for the push to come from the industry. Denise Anthony acknowledged this conversation as another example of how the healthcare system in general lacks coherent organization; great variability across the country and across different types of providers means it is extremely difficult to establish a uniform set of standards in any sense. One audience member raised the concern that patients cannot understand what they don’t know in order to make complicated privacy decisions, but Kelly Caine argued that our current system still defers to patients so her UI will uphold our current level of care (consistent with FIPS). Denise Anthony also explained physicians are trained to work in this environment of partial informational blindness, but the audience member argued that simply because that is the current rule, we might not want to standardize it. Deven McGraw offered the final point that better information to patients about information flows, and the need to promote trust and reduce stigma would overcome the tradeoff between provider needs and patient concerns, but doing so requires a delicate balance from the policy standpoint.