



December 6, 2019

Roger Severino, Director  
Office for Civil Rights  
U.S. Department of Health and Human Services  
200 Independence Ave., S.W.  
Washington, D.C. 20201

Dear Mr. Severino,

Thank you for your work to protect parent rights, freedom of conscience rights for health care workers, and religious freedom rights.

As president of CCHF, I am writing with a request that you also protect patient rights, specifically related to the data-sharing agreement between Ascension and Google. According to recent news reports, your office has opened up an investigation.

With that good news in mind, I would like to bring several issues to your attention, some of which I touched on in our visit with your office in 2018, if I recall correctly.

**First, we believe the Ascension-Google contract is legal, as much as we wish it were not so.** And indeed, both companies point to the “health care operations” (HCO) data-sharing provision of HIPAA. This provision is a nearly 400-word long list of at least 65 non-clinical business activities. In short, the HCO provision is an open door to data-sharing.

The shocking disclosure that the Ascension healthcare system is sharing the medical records of 50 million people in 21 states with Google shows clearly that HIPAA does not protect patient privacy, was never written to protect patient privacy, and has been used to deceive Americans into believing they have privacy rights when they have none.

**Second, HIPAA is a permissive data-sharing rule.** This fact has always been known by CCHF and by many within the insurance, hospital and health data industries, but paper medical records did not lend themselves to easy sharing. It was only with the 2009 ARRA electronic health record mandate, the funding for state health information exchanges, the federally-funded establishment of the National Health Information Network (now called the eHealth Exchange), and HIPAA’s unique identifiers and mandated electronic data standards that the patient’s private medical records have become easily accessible and readily mined for information. Lack of full interoperability is the patient’s only privacy protection today.

**Third, HIPAA+EHRs was intended to establish unconsented access.** *“Finally, we’re going to have access to millions and millions of patient records online,”* said **Blackford Middleton**, a physician, Harvard professor and chairman of the Center for Information Technology Leadership (CITL), after ARRA passed. CITL’s studies had pushed the EHR mandate, claiming information technology networks, including the use of EHRs, would save \$77.8 billion each year “once fully implemented.” This, of course, has been proven false.

And now, just 10 years after ARRA, and six years after doctors and hospitals were required to computerize their data and make it accessible online or face penalties, we have 50 million patient’s records, fully identified, in Google’s cloud for data-mining and research and analysis that Google hopes will lead to new business ventures of predictive analytics and algorithm-based medicine—which will likely be used to intrude in private lives and limit personal medical decisions. Profits could be substantial. For example, OptumInsights, the data division of UnitedHealth Group, reported 2017 revenues of \$8.1 billion.

**Fourth, Ascension and Google aren’t the only contenders in the race to use boatloads of patient data without consent.** Mayo and Google are collaborating in a 10-year agreement; Cerner and Amazon are working together to do slice and dice “population health”; Microsoft and Humana have linked arms to sift through the data using AI and the cloud; and Microsoft and Providence St. Joseph Health are sharing patient data to enable data-driven clinical and operational decision-making. And now virtual assistants to record private patient-doctor interactions directly into the cloud as they happen in the exam room have been introduced.

What emerges from these intrusive enterprises may or may not be in the patient’s best interest—but patients aren’t being given a choice. They have been stripped of their rights. Their data is not theirs. They have no control—because of HIPAA.

In the era of third-party-payer cost containment, patient data may be used to restrict their doctor’s ability to customize and individualize their care. Their data may be used to restrict access to physician care, limiting them to algorithm-following midlevel practitioners rather than medically-trained doctors. And doctors who fail to follow the payer’s population-health and one-size-fits-all algorithms embedded in EHRs may be punished financially, given a lower “quality” score, or have their care wrongly deemed of less “value.” (MIPS, P4P, APMs)

**Fifth, this is not freedom.** These HIPAA-enabled practices endorsed by the federal government to control costs will lead to outsider controls and limited patient choices.

We say, ‘He who holds the data makes the rules.’ But those who hold both the data and the dollars—the health plans who have legal authority to charge high premiums (ACA) and were established by Congress to ration care (*Pegram vs. Herdrich*, 2000)—are a greater danger to patients, who are vulnerable by nature, and hampered by the physical, physiological, and psychological reality of their medical and mental health conditions.

**Sixth, patients have a human right to privacy, and the dignity that privacy protects.** They have a right to limit the disclosure of their medical records. The HIPAA rule took that right away, but most Americans, members of Congress, and state legislators still believe HIPAA is a privacy rule. The HIPAA “privacy” rule remains an artfully-orchestrated ruse.

**Seventh, your office has an opportunity—and the authority—to restore privacy rights.** The public’s new awareness of the Ascension-Google contract is an open invitation for HHS/OCR to act to protect all Americans *from* HIPAA. It is an opportunity for President Trump to claim a victory by ending this deception and ongoing intrusion into the lives of Americans. Thus, we are pleased that OCR has opened an investigation.

Notably, nothing in statute compels HHS to write the rules that eliminated the pre-HIPAA patient privacy and consent requirements. **HHS Secretary Donna Shalala** intentionally chose to eliminate patient privacy rights, recommending instead that *“the traditional control on use and disclosure of information, the patient’s written authorization, be replaced by comprehensive statutory controls on all who get health information for health care and payment purposes.”* She writes *“Individuals’ claims to privacy must be balanced by their public responsibility to contribute to the common good, through use of their information for important, socially useful purposes...”* Shalala’s unethical and unconstitutional “common good” assertion is the reason Americans have no privacy or consent rights today.

**What HHS did to end privacy rights in 2003. HHS/OCR can and should undo today.**

**Our request:**

We respectfully request that the HHS Office of Civil Rights restore informed, written, voluntary patient consent for the sharing and use of all patient data, identified or deidentified. Notably, this means opt-in (consent), not opt out (dissent). OCR must also prohibit single-signature, bundled, consolidated (coercive) consent forms that include consent for treatment and consent for data-sharing and more in a single form.

Patient data has become a valuable commodity—a 21<sup>st</sup> century gold mine—used for the profit-seeking or health-care rationing agendas of others. The so-called HIPAA privacy rule is the source of this extraordinary violation of the privacy rights of every American, and we request that OCR take action to end the violation.

**Thank you for your attention to our request.** Please do not hesitate to contact me at any time. I can be reached at 651-646-8935 or [twila@cchfreedom.org](mailto:twila@cchfreedom.org). As noted in my earlier email, we will be in D.C. **Dec 9-12** if you would like to meet with us to discuss this request.

All my best,



Twila Brase, RN, PHN  
President and Co-founder