



WORLD **PRIVACY** FORUM

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**Comments of the World Privacy Forum
To the US Department of Education
Regarding Draft Guidance - Dear Colleague Letter: Protecting Student Medical Records**

Via email to FERPA.Comments@ed.gov

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US Department of Education
400 Maryland Ave. S.W.
Washington, DC 20202

October 1, 2015

Re: Dear Colleague Letter: Protecting Student Medical Records

The World Privacy Forum welcomes the opportunity to respond to the Department's August 18, 2015, request for public input on draft guidance on protecting the privacy of student medical records.¹

The World Privacy Forum is a non-profit public interest research and consumer education group. We have published many research papers and policy comments focused on privacy and security issues. Much of our work explores technology and health-related privacy issues, biometrics, consent, data analytics, and many other rapidly evolving areas of privacy, including student privacy. You can see our publications and more information at www.worldprivacyforum.org.

¹ *Dear Colleague Letter to School Officials at Institutions of Higher Education*, <http://familypolicy.ed.gov/sites/fpco.ed.gov/files/DCL%20Final%20Signed-508.pdf>. See also *Department of Education Seeks Public Input for Guidance on Protecting Privacy of Student Medical Records*, August 18, 2015: <http://www.ed.gov/news/press-releases/department-education-seeks-public-input-guidance-protecting-privacy-student-medical-records>.

In general, we find the draft guidance well-intentioned and useful. We want to be clear that we support the goals and intent of the guidance.

However, we urge the Department to understand that the draft guidance is insufficient to the task, and ultimately, does not carry the force of law necessary to fully protect health privacy. In these comments, we discuss the reasons why we support the draft guidance, and the further changes that must be made to ensure that improvements to student health privacy are created and enforced.

I. WPF Supports the Draft Guidance

WPF supports the draft guidance. The original decision in the FERPA rules to treat medical records in the same way as other educational records has been unfortunate for student health privacy.

Many challenging student health privacy situations have arisen over the years. A recent exemplar occurred in 2015. *The Chronicle of Higher Education* and other newspapers published a number of articles about this situation, which we will not relay point-by-point here.² The broad outlines are that a female student at the University of Oregon who had been assaulted on campus later sued the University. The student had sought mental therapy at the University for the assault, but the suit was not regarding her medical treatment. The University nonetheless collected her mental therapy treatment records relating to the assault in order to defend themselves in the litigation. It was an ugly situation. The University was not in error in its analysis of FERPA, however.

We wonder about the long-term impact on student trust in health privacy at educational institutions when situations such as this occur. In her commentary, the author of a *Chronicle of Higher Education* commentary advised students to not seek treatment at their colleges. She wrote in part: “My advice is simple. Students: Don’t go to your college counseling center to seek therapy. Go to an off-site counseling center.” Unfortunately, the draft guidance may do nothing to change the wisdom of this advice.

We value the decision to offer the draft guidance, and we support its adoption in the hopes that it will make a difference as to how educational institutions handle student health privacy in the future.

However, there are clear problems with the guidance, none of which relate to its wording or intent. The problems, which we turn to now, relate to the underlying FERPA rule and its construction, age, and interaction with HIPAA.

² See Pryal, Katie Rose Guest, *Raped on Campus? Don’t Trust Your College to Do the Right Thing*. *Chronicle of Higher Education*, March 2, 2015. <http://m.chronicle.com/article/Raped-on-Campus-Don-t-Trust/228093/>.

II. The Underlying FERPA Rule is Fundamentally out of date Regarding Health Privacy

The first problem that challenges the effectiveness of the draft guidance is the underlying FERPA rule was written in an era prior to the HIPAA health privacy rule. This was a time when few paid attention to the privacy issues raised by health records. We have all learned a lot from fifteen years' of experience with the HIPAA health privacy rule. Unless the FERPA rule itself is fundamentally updated to reflect what we now know about health privacy and health privacy data flows, it is not possible to craft good guidance that rests on a creaky rule that is woefully out of date.

We cannot say it more directly than this: the FERPA rule as it stands today does not reflect modern health data privacy realities. The FERPA rule must be updated.

III. The Guidance is not Enforceable

The second problem is that while the new draft guidance letter does reflect some of the modern experience with HIPAA, in the end it is guidance only. The guidance is not enforceable. What the Department needs to do is amend the FERPA rule itself. Telling schools what they *should* do is not enough. Only telling schools what they *must* do will meet today's needs.

The guidance itself makes this point when it states in its second paragraph: "This guidance does not create or confer any rights for or on any person, nor does it impose any requirements beyond those required under applicable law and regulations."

Again, we thoroughly understand the Department's desire to respond to the health privacy situations the guidance addresses, i.e., the use of health treatment records of students without a court order or written consent by educational institutions in non-medical litigation.³ We wish the guidance would be enforceable. The only way to accomplish that is to update the underlying FERPA regulation.

³ From the *Dear Colleague Letter to School Officials at Institutions of Higher Education*: "Thus, without a court order or written consent, institutions that are involved in litigation with a student should not share student medical records with the institution's attorneys or courts unless the litigation in question relates directly to the medical treatment itself or the payment for that treatment, and even then disclose only those records that are relevant and necessary to the litigation. This approach recognizes students' reasonable expectation that their conversations with medical professionals are confidential and respects the unique nature of students' medical records."

<http://familypolicy.ed.gov/sites/fpco.ed.gov/files/DCL%20Final%20Signed-508.pdf>.

IV. The Interaction Between HIPAA and FERPA is Labyrinthine

A third problem is that the overall HIPAA-FERPA interface is exceedingly complex. It is not surprising that schools, universities, clinics, and other treatment providers have challenges figuring out which rule applies and when. Students have virtually no hope of understanding how the rules mesh, except perhaps for law students.

The guidance currently available about how the two rules interact is *Joint Guidance on the Application of the Family Educational Rights and Privacy Act (FERPA) And the Health Insurance Portability and Accountability Act of 1996 (HIPAA) To Student Health Records*.⁴ We regret to say that the Joint Guidance is one of the most incomprehensible privacy documents ever written. We understand that the complexity of the HIPAA-FERPA interaction is what caused the complex document. It is not entirely the Department of Education's fault, as the Department of Health and Human Services (HHS) is the agency that made the decision to exempt FERPA from the HIPAA privacy rule.

Nevertheless, given that decision, more needs to be done. At a minimum, the HIPAA-FERPA Joint Guidance document needs to be revised. The application of one law or the other sometimes turns on minor factual distinctions that no average individual can understand. Both departments need to find a better approach. Again, without updating the underlying FERPA rule, even a rewrite to clarify the joint guidance will still fall short as long as it is just a suggestion, and not legally enforceable. Realistically, the FERPA rule for health records needs to be amended.

By way of example, in the first full paragraph on page 3, the Joint Guidance observes: "When institutions choose to disclose PII from education records, including medical records, without consent, they should always take care to consider the impact of such sharing, and only should disclose the minimum amount of PII necessary for the intended purpose." The World Privacy Forum agrees with this statement. The problem is that the guidance is not mandatory. Further, there is no additional clarification about what *minimum necessary* means. It might help if the Department offers specific, practical guidance about how to apply the *minimum necessary* standard in different contexts.

V. Conclusion and Request for the Department to Update the FERPA Regulations

To conclude, we support the Draft Guidance. It is narrow guidance, but we understand why it is needed.

We have two additional requests:

⁴ *Joint Guidance on the Application of the Family Educational Rights and Privacy Act (FERPA) And the Health Insurance Portability and Accountability Act of 1996 (HIPAA) To Student Health Records*, Nov. 2008, www2.ed.gov/policy/gen/guid/fpco/doc/ferpa-hipaa-guidance.pdf.

- First, we urge the Department to update the FERPA regulations for health records. Both the Department and HHS must find a better, cleaner, and more modern way to align HIPAA and FERPA.
- Second, we urge the Department to address the complexity and confusion regarding the HIPAA-FERPA interaction with a new and clear Joint Guidance document from HHS and the Department of Education.

Many other aspects of FERPA cry out for change today. We accept that other changes to FERPA are beyond the scope of the current effort, but we cannot pass up the opportunity to ask for systemic revision of the rule as soon as it is possible.

Respectfully submitted,

A handwritten signature in black ink that reads "Pam Dixon". The signature is written in a cursive, flowing style.

Pam Dixon,
Executive Director,
World Privacy Forum