

Johns Hopkins University

IRB Guidance: Use of Student Education Records in Research

Research that involves collecting data in schools and/or accessing information from education records are subject to laws that impact data access, collection procedures, and limit the IRB's ability to waive consent. This document provides a brief summary of the Family Educational Rights and Privacy Act (FERPA) and Protection of Pupil Rights Amendment (PPRA) and provides guidance for IRB members to consider when reviewing research studies that include access and/or use of student education records.

FERPA

FERPA is a federal law that regulates the disclosure of personally identifiable information¹ from student education records.² The law applies to all educational institutions that receive funds under programs administered by the U.S. Department of Education,³ which can include public or private elementary, intermediate, high school, or college institutions. FERPA stipulates that an educational institution has the authority to determine what information may be accessed from an education record. If an institution denies an investigator access to information in an education record, the IRB cannot overrule the decision.

FERPA gives parents certain rights with respect to their children's education records, including the right to consent to any disclosure of personally identifiable information from those education records, the right to review those education records, and the right to request an amendment in the education records. These rights transfer to the student when the student reaches the age of 18 or attends an educational institution beyond the high school level (referred to as "eligible students"). As a general rule, educational institutions must have a prior signed and dated written consent from the parent or eligible student to disclose personally identifiable information from a student's education record. The consent must be specific about the records that may be disclosed, the purpose of the disclosure, and identify the individual(s) to whom the records will be disclosed.

¹ FERPA defines "personally identifiable information" to include without limitation:

- (a) The student's name;
- (b) The name of the student's parent or other family members;
- (c) The address of the student or student's family;
- (d) A personal identifier, such as the student's social security number, student number, or biometric record;
- (e) Other indirect identifiers, such as the student's date of birth, place of birth, and mother's maiden name;
- (f) Other information that, alone or in combination, is linked or linkable to a specific student that would allow a reasonable person in the school community, who does not have personal knowledge of the relevant circumstances, to identify the student with reasonable certainty; or
- (g) Information requested by a person who the educational agency or institution reasonably believes knows the identity of the student to whom the education record relates.

² With a few narrow exceptions, FERPA broadly defines "education records" to mean records that are directly related to a student and maintained by an educational agency or institution or by a party acting for the agency or institution.

³ Programs administered by the U.S. Department of Education may be found at:
<https://www.ed.gov/programs/landing>

In certain limited instances, FERPA provides for exceptions to the requirement of prior written consent. Those exceptions most likely to be relevant to University researchers are described below.

Exceptions to the Requirement of Prior Written Consent

1. Directory Information.

FERPA allows educational institutions to disclose, without prior consent, information in student education records that is designated by the educational institution as "directory information"; provided that the educational institution has given parents or eligible students prior public notice of the information that the educational institution has designated as directory information. What constitutes "directory information" will therefore vary from institution to institution but typically includes a student's name, address, telephone number, date and place of birth, honors and awards, and dates of attendance. FERPA requires that students be given the opportunity to file a request to prevent disclosure of directory information, commonly known as "opting out". An educational institution may not release any directory information of a student who has "opted out," even if the student no longer attends the institution.

Researchers should contact each educational institution from which he/she proposes to access student records and follow that institution's FERPA policy and procedures when accessing and proposing to disclose any directory information.

2. De-identified Information.

An educational institution may disclose information from student education records without prior consent if all personally identifiable information has been removed from the records, provided that the institution has made a reasonable determination that a student's identity would not be personally identifiable, whether through single or multiple releases, and taking into account other reasonably available information. Note that it is the educational institution that holds the student records that has to make this determination. The IRB may ask for confirmation that the educational institution from which the researcher is seeking educational records has made this determination before approving the protocol.

Use of coded data: An educational institution can release de-identified student level data from education records for the purpose of education research by attaching a code to each record that may allow the recipient to match information received from the same source, provided that: the educational institution does not disclose any information about how it generated and assigned the code, or that would allow the recipient to identify a student based on a code; the code is not used for any purpose other than identifying a de-identified record for purposes of education research and cannot be used to ascertain personally identifiable information about a student; and the code is not based on a student's social security number or other personal information.

3. Research conducted for or on behalf of educational institutions.

Personally identifiable information from student education records may be disclosed by an educational institution to researchers when the disclosure is to organizations conducting studies for, or on behalf of, educational agencies or institutions to: develop, validate, or administer predictive tests; administer student aid programs; or improve instruction. The study must be conducted in a manner that does not permit personal identification of parents and students by individuals other than representatives of the organization that have legitimate interests in the information. The information must be destroyed when no longer needed for the purposes for which the study was conducted. If personally identifiable information from student education records will be disclosed to a researcher under this exception, the researcher must enter into a written agreement with the educational institution that contains specific assurances on data confidentiality as required by FERPA. The IRB may ask the researcher to provide verification that this agreement is in place.

PPRA

The Protection of Pupil Rights Amendment (PPRA) (20 U.S.C. § 1232h; 34 CFR Part 98), also known as “Student Rights in Research, Experimental Programs, and Testing,” is a federal law that affords certain rights to parents of minor students with regard to surveys that ask questions of a personal nature. The No Child Left Behind Act of 2001 contains a major amendment to PPRA that gives parents more rights with regard to the surveying of minor students, the collection of information from students for marketing purposes, and certain non-emergency medical examinations.

The PPRA applies to any “local educational agency” that receives funding from the U.S. Department of Education. A “local educational agency” means an elementary school, secondary school, school district, or local board of education that is the recipient of funds from the U.S. Department of Education. PPRA also applies to research funded by the U.S. Department of Education.

PPRA has two sets of requirements for surveys:

1. Requirements that apply to “protected information” surveys that are funded in whole or in part by the U.S. Department of Education.
2. Requirements that apply to "protected information" surveys that are funded by sources other than the U.S. Department of Education **and** that are administered or distributed by education institutions that receive funds from the U.S. Department of Education (i.e. public elementary and secondary schools and some private schools).

PPRA lists eight categories of protected information for survey responses:

1. political affiliations of student or student's parent;
2. mental or psychological problems of student or student's family;

3. sex behavior or attitudes;
4. illegal, anti-social, self-incriminating or demeaning behavior;
5. critical appraisals of others with whom students have close family relationships;
6. legally recognized privileged or analogous relationships;
7. religious practices, affiliations or beliefs of student or student's parent;
8. income, other than as required by law to determine eligibility for participation in a program or for receiving financial assistance under such program.

Practical Implications of PPRA for Parental Consent:

1. Requirements for Protected Information Surveys funded by the U.S. Department of Education:

- Does the research involve "protected information" surveys?
- Are the surveys U.S. Department of Education-funded in whole or part?
- Are the surveys "required"?

If the answer is yes to the three questions, PPRA affords parents the right to provide active consent. Thus, even when the criteria for a waiver of parental permission at 45 CFR 46.116 or 45 CFR 46.408(c) are met, the IRB cannot approve waivers of parental permission for surveys, analyses, or evaluations where the primary purpose is to reveal information concerning one or more of the eight protected areas specified in PPRA.

Prior written parental consent would be required, even if the IRB determined that some of the basic elements of informed consent specified in section 45 CFR 46.116(a) could be waived as inappropriate to the activity.

2. Requirements for Protected Information Surveys, Funded by Sources other than the U.S. Department of Education and administered or distributed by education institutions that receive funds from the U.S. Department of Education (i.e., public schools and some private schools):

- Does the research involve "protected information" surveys?
- Are the surveys being administered or distributed by schools that receive any U.S. Department of Education funds?

If the answer is yes to both questions, PPRA affords parents the right to inspect the surveys before they are administered or distributed and to opt the student out of the surveys.

Researchers whose research is subject to the PPRA should review the policies of the local educational agency early in the study design process.

FERPA and HIPAA

Some data in student education records may be subject to FERPA and the Health Insurance Portability and Accountability Act of 1996 (HIPAA). In some situations the FERPA privacy protections are more restrictive than the HIPAA privacy protections. Researchers should be instructed to contact the educational institution they are seeking educational records from and follow that institution's FERPA and HIPAA policies when accessing student medical records. Please note that JHU has elected to follow both FERPA and HIPAA for Johns Hopkins Hospital (JHH) medical records.

Researchers should be instructed to contact the appropriate JHU Human Subjects Protection Program Office (IRB Office) and Johns Hopkins HIPAA/Privacy Office if they plan to access and/or use student medical records.

IRB REVIEW

When reviewing an IRB application that includes the use of student records, the IRB reviewer should make sure the researcher has addressed the following items:

- purpose, scope, and duration of study;
- use and disclosure of personally identifiable information;
- plans to protect personally identifiable information from disclosure to any other party (other than representatives of JHU with legitimate interests) without prior consent of parent or eligible student;
- included parental or eligible student consent form, or written determination from source educational institution that the data from the student record is provided pursuant to an exception under FERPA⁴; and
- plan to return or destroy personally identifiable information when it is no longer needed;

⁴ The written exception determination must include: the exception relied upon; the purpose, scope and duration of the study; the information to be disclosed; that information from education records may only be used to meet the purposes of the study stated in the written agreement and must contain the current requirements in 34 CFR § 99.31(a)(6) on re-disclosure and destruction of information; that the study will be conducted in a manner that does not permit personal identification of parent and students by anyone other than representatives of the organization with legitimate interests; that the organization is required to destroy or return all personally identifiable information when no longer needed for the purposes of the study; the time period during which the organization must either destroy or return the information.

- Any necessary approvals from the educational institution and compliance with the educational institution's FERPA policies. (Requirements of the Baltimore City Schools and the Baltimore County Schools are provided below.)

For information about how FERPA applies for studies conducted with Johns Hopkins University students, please visit the JHU FERPA policy at:

<https://www.jhu.edu/assets/uploads/2017/01/ferpa.pdf>

For further information on FERPA, see the U.S. Department of Education website at:

<http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

U.S. Department of Education webinars explaining FERPA are very informative and are available online at: <http://www2.ed.gov/policy/gen/guid/fpco/hottopics/index.html>

Baltimore City Schools: For information on conducting research in Baltimore City Schools: http://www.baltimorecityschools.org/community/research_in_city_schools

Baltimore County Schools: For information on conducting research in Baltimore County Schools: https://www.bcps.org/offices/accountability_research_testing/research.html