US DEPARTMENT OF EDUCATION (DoED)

THE PROTECTION OF PUPIL RIGHTS AMENDMENT (PPRA)

34 CFR 98- STUDENT RIGHTS IN RESEARCH, EXPERIMENTAL PROGRAMS, AND TESTING IMPACT ON IRB REVIEW OF SCHOOL BASED SURVEYS AND "PASSIVE CONSENT"

Summary: The *No Child Left Behind Act of 2001 (Public Law 107-110)* amended the Protection of Pupil Rights Amendment (PPRA), which concerns surveys of students, in two ways: First, it added an eighth category to the categories of protected information in surveys of minors that were already covered by PPRA. Second, it gave parents new rights with regard to the surveying of minor students, the collection, disclosure, or use of information from students for marketing purposes, and certain non-emergency medical examinations.

PPRA, as amended, 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 any Department of Education program (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 program eligibility.

PPRA has implications for IRBs in applying the Common Rule criteria for waiving informed consent (in section 116(d) of the Common Rule). Specifically, the second IRB criterion: "research does not adversely affect the rights and welfare of subjects" is impacted because of the "rights" that PPRA gives parents.

Practical Implications in Applying the Common Rule Waiver Requirement pertaining to rights and welfare:

First Set of Requirements: US Department of Education Funded Protected Information Surveys

- 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.

Under the circumstances, it would be difficult for an IRB to determine that the "rights and welfare" criterion for waiving informed consent entirely could be met; therefore, prior written parental consent would be required, even if the IRB determined that some of the basic elements of informed consent specified in section 116(a) could be waived as inappropriate to the activity.

[The U.S. Department of Education has not yet written regulations providing guidance about some of the key terms in the current law. For example, the Department has not taken a position about whether the word "required" should be interpreted to mean that surveys that are clearly voluntary are exempt from PPRA requirements. Also, the law does not directly address the question of whether anonymous surveys are exempt from PPRA because anonymous surveys do not provide individually identifiable information about students or their families. Until the Department issues revised regulations implementing PPRA, IRBs need to use their judgments in complying with the first set of requirements.]

Second Set of Requirements for Protected Information Surveys that are NOT Funded by the U.S. Department of Education and that are administered or distributed by education institutions that receive funds from any U.S. Department of Education administered program (i.e., public schools and some private schools)

- Do the surveys include protected information?
- Are the surveys being administered or distributed by schools that receive any U.S. Department Education funds?

[Note that in this set of requirements there is no language about students being "required" to respond to the survey, so here the issue of voluntariness appears to be moot].

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.

For IRBs, these requirements suggest that local schools have the discretion to set up their own individual policies for non- US Department of Education protected information surveys. For example, local schools can choose whether to have an active written consent policy or some other policy such as passive consent.

IRBs will have to decide how they will handle these requirements in those protocols where the investigators are requesting passive consent. For example, an IRB might require that if an investigator asks for passive consent procedures, that he/she must also document that the procedures are consistent with the policy of the local school(s) to be included in the research sample. The IRB then can use that information in determining if the "rights and welfare" criterion for waiving informed consent has been met.

PROVISIONS OF THE PPRA

A list of the general PPRA provisions is included below and the specific amendments are detailed at https://studentprivacy.ed.gov/content/ppra.

U.S. Department of Education Surveys

Subsection (a) of the legislation was not changed. Subsection (b) added an additional category Number 7 and made minor changes to the existing seven categories. This provision applies to surveys funded in whole or part by any program administered by the U. S. Department of Education (DoED).

PPRA provides:

- that schools and contractors make instructional materials available for inspection by parents if those
 materials will be used in connection with an DoED-funded survey, analysis, or evaluation in which
 their children participate; and
- that schools and contractors obtain prior written parental consent* before minor students are required to participate in any DoED-funded survey, analysis, or evaluation that reveals information concerning:
 - 1. political affiliations or beliefs of the student or the student's parent;
 - 2. mental and psychological problems of the student or the student's family, sex, behavior or attitudes;
 - 3. illegal, anti-social, self-incriminating, or demeaning behavior;
 - 4. critical appraisals of other individuals with whom respondents have close family relationships;

- 5. legally recognized privileged or analogous relationships, such as those of lawyers, physicians, and ministers;
- 6. religious practices, affiliations, or beliefs of the student or student's parent; or,
- 7. income (other than that required by law to determine eligibility for participation in a program or for receiving financial assistance under such program).

*Prior consent means:

- Prior consent of the student, if the student is an adult or emancipated minor; or
- Prior written consent (permission) of the parent or guardian, if the student is an unemancipated minor.

Subsections (a) and (b) of PPRA generally apply when a survey is funded, at least in part, by any program administered by the Secretary of Education.

Surveys Funded by Sources Other than U.S. Department of Education

The new provisions (contained in subsection c) apply (as does FERPA-1) to educational agencies or institutions that receive funds from any program of the Department of Education. Thus, public elementary and secondary schools are subject to the new provisions of PPRA. The amendment requirements include:

- Schools are required to develop and adopt policies, in conjunction with parents, regarding the following:
 - 1. The right of parents to inspect, upon request, a survey created by a third party before the survey is administered or distributed by a school to students;
 - 2. Arrangements to protect student privacy in the event of the administration of a survey to students, including the right of parents to inspect, upon request, the survey, if the survey contains one or more of the same eight items of information noted above;
 - 3. The right of parents to inspect, upon request, any instructional material used as part of the educational curriculum for students;
 - 4. The administration of physical examinations or screenings that the school may administer to students:
 - 5. The collection, disclosure, or use of personal information collected from students for the purpose of marketing or selling, or otherwise providing the information to others for that purpose; and
 - 6. The right of parents to inspect, upon request, any instrument used in the collection of information, as described in number 5.
- Local educational agencies (LEAs) must "directly" notify parents of these policies and, at a minimum, provide the notice at least annually.
- In the notification, the LEA shall offer an opportunity for parents to opt out of (remove their child) from participation in the administration of any third party (non-Department of Education funded) survey containing one or more of the above described eight items of information.

US Department of Education Contact:

https://studentprivacy.ed.gov/contact Submit a question Student Privacy Help Desk Toll-Free Phone: 1-855-249-3072

Guidance regarding the Family Education Rights and Privacy Act (FERPA) may be found at https://www.research.uky.edu/sites/default/files/uploads/2018-06/31-FERPA-Summary.pdf

Prepared: Ada Sue Selwitz, MA, University of Kentucky, March 2003, Updated 2006, 2012, 7/18/13, 10-1021 J:\Master Outreach Documents\Survival Handbook\D - Guidance-Policy-Educational\60-Protection-Pupil-Rights-Amendment.doc