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# Education NEW YORK

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To the IRB Board:

I am writing to share my deep concern about XXXXX research proposal, which has been submitted for approval by XXXXX

My concerns are based on my longtime work as a researcher and advocate on student privacy matters and information policy on the state and national levels. Over the years, I have worked with state and federal agencies on these issues, as well as with leaders in the New York State Legislature. Currently, I am examining, in depth and in consultation with experts in the field, the use of student data in research projects and the role of IRBs in regard to data privacy.

I also have strong ties to Newburgh, where I grew up. I served on the Board of the Newburgh Enlarged City School District for three years, one year as vice president, and my three children attended schools in the district. Today, I maintain close connections to family and community in the city.

Given my experience, background, and concerns, I requested a copy of this research proposal to review for any provided data privacy protections. Unfortunately, my request was denied. While I recognize that research proposals can sometimes contain proprietary information or other confidential data, it is highly unlikely that most of the proposal requires such confidential treatment. In fact, because this particular proposal directly affects students attending a public school and their parents, the community has both a right and an interest in knowing the details of the proposal, *especially how the personal information of the student subjects and their families will be protected and safeguarded.*

Therefore, in light of these concerns and the community's right to be fully informed, I would like to bring the following points to your attention:

# EDNY

- 1) This proposal involves the collection of personal information on students who are participating directly in the study, as well as students who serve as controls. Information that identifies both of these classes of students will be collected, used, processed, and disclosed in some fashion. Even if data is aggregated at some stage of the process, the fact is data that has the potential to be identifiable to students (and, perhaps, their parents), will be processed by an individual before that data is aggregated. The IRB should not rely on assurances that privacy and security will be protected merely because the data will be aggregated at some point in the study.
- 2) If there is a possibility that identifiable student data will be used at any stage of the research process, the parents of *all* the students participating in the study – whether directly or as controls – should receive notice and the opportunity to consent to the use of their child’s data. Parents care deeply about their children’s privacy, but often they are not informed of their rights to protect their children’s identity and personal information. For university-conducted research projects, parents and guardians should be given sufficient information about privacy protections so they may have the opportunity to opt their children out of participation. Parents should not be surprised after-the-fact if they find that their child’s information was used without notice or consent.
- 3) With this study, there is real potential for the *re-identifiability* of the aggregate data. Data re-identification is an emerging issue that IRBs must consider when dealing with research subjects’ information. According to Harvard Computer Science Professor Latanya Sweeney, an expert on data re-identification, “[One] can never guarantee that any release of [deidentified] data is anonymous, even though for a particular user it may very well be anonymous.”<sup>1</sup> That is, unless a qualified expert reviews and approves the aggregation methodology, there can be no guarantee that the data will be fully non-identifiable. The IRB should insist on an opinion from a wholly independent expert and not rely solely on assurances from the principal investigator in regard to the re-identifiability of data.
- 4) Some of the data used in this study may originate from school records, which are subject to the rules of the Family Educational Rights and Privacy Act (FERPA). Even if the disclosure is allowed under FERPA rules, identifiable student data will end up in the possession of researchers and others who are not subject to FERPA. That data may have no statutory privacy protection. Thus, in the event of a breach of the data or other misuse, questions about responsibility and liability surely will arise. Those who may be accountable in the event of a breach or misuse include the school, the researchers, and

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<sup>1</sup> Latanya Sweeney, Lab. for Computer Sci., Mass. Inst. of Tech., Roundtable Discussion: Identifiability of Data at Subcomm. on Privacy & Confidentiality, Nat’l Comm. on Vital & Health Statistics (Jan. 28, 1998).

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even the IRB itself. Before the XXXXX IRB approves a research proposal involving student data, the board should be certain that the privacy and security of the data are adequately protected. This is the IRB's most important responsibility to the data subjects and to the community. In addition, by meeting that responsibility, the IRB will protect itself in the event that the researchers or others do not properly use or adequately safeguard the data.

I plan to go forward to raise these issues with the Office of Human Protections Research at the U.S. Department of Health and Human Services. It is essential that all IRBs meet their responsibilities to the students and parents involved in research studies in New York and across the country. In the meantime, I urge the XXXX IRB to fully inform parents in this study of plans for data collection and use and to afford them every right and opportunity to choose not to participate if they deem the privacy protections inadequate. This is fundamental to the College's obligation to the community.

Thank you for this opportunity to raise these issues and concerns. I would be happy to discuss these matters further at our mutual convenience.

Sincerely,



**Sheila Kaplan**

**Founder, Education New York**

**Member of the Board of Directors, Electronic Privacy Information Center**