
Office of the Vice Dean for Research and Faculty

Guidelines for use of surveys, interviews or other forms of data collection in JHSPH courses

The determination as to whether course activities that involve collecting information from individuals requires Institutional Review Board (IRB) approval is often unclear. In addition, having students collect information from individuals not associated with a course as part of a course requirement raises a number of issues including the interface with the local community, ethical concerns regarding collection of sensitive information from people, and potentially putting students in inappropriate situations. On the other hand, such activities can be valuable learning experiences for students. This document describes the ground rules for this type of course activity. Faculty members are ultimately responsible for ensuring that the activities conducted in their courses are in accord with these guidelines and are expected to provide oversight to students in their execution.

If the information collected is used only for educational purposes within the course and will not be published or otherwise disseminated, it will likely not qualify as human subjects research and hence does not fall under IRB purview. Information collected may be provided to a collaborating community group for their own use. In general, course activities are instructional in nature and **should not** involve activities that have a goal of publication – learning how to conduct research is not the same as conducting research. In the past, the IRB has reviewed such proposals but typically finds them to lack sufficient development and detail and does not approve them in a timeframe compatible with an academic term. Although students may have the intention of publishing work conducted in a class setting, it is generally unlikely that this will be the outcome for an activity of this kind. It is possible for an instructor to serve as a PI on a class activity and submit it to the IRB but the approval process is necessarily the same as for any other research project. Instructors may add the student project as an amendment to their existing protocols if the activity would so qualify.

Preparation of materials for use in a class assignment

The goal of these guidelines is to ensure that JHSPH students are collecting and managing information from individuals in an ethical and appropriate manner.

I. Keep it distinct from research. Student interaction with other individuals both within and outside the School requires the same level of adherence to ethical principles regardless of whether or not it is technically classified as human subjects research. An ethical code describing these principles developed by the JHSPH IRB office is appended at the end of this document. To avoid confusion and keep this distinction clear in the minds of both students

and participants, materials should not describe the activity as a “research study” nor the people to be interviewed as “subjects”. For example:

- Do not mention the Institutional Review Board or IRB
- Use the term *project*, not *research* or a *study*
- Use the term *information* as opposed to *data*
- Use terms like *agree to participate* instead of *consent*. There is also no need for any individual to sign anything.
- Replace *investigator* with student or faculty member as appropriate.

II. Make sure participants understand what is being asked of them and what is being asked of them is appropriate. This also means that planning such an activity must consider the benefits of the experience to the student of conducting the course activity against the cost to the participant, even if the cost is only time or intrusion into their daily life.

1. Participants should either be read or handed a brief script describing the activity, in plain words. It should include:

- The purpose of the activity (i.e., an assignment for a course)
- How the respondent was selected (i.e., because they are in a course, because they receive services from an agency)
- How long it will take to complete
- That they are under no obligation to participate.
- Once they begin, they do not have to finish the activity or answer all questions. Whether they will receive any remuneration (e.g., a small token of appreciation is suggested but not required).
- What is being done with the information

Note that interacting with minors raises a number of complicated issues, including parental notification and those raised in the JHU Child Safety Protocol. Although there are ways to mitigate concerns, it’s best to avoid involving minors.

2. Course activities should not ask participants to offer personal or identifiable information. This includes:

- Name, address, phone number, email. At times such information may be provided by an agency for participant contact. This information should be destroyed once it is no longer needed and not linked to any information that is collected. When possible, agencies should contact potential participants first on behalf of the activity.
- Date of birth
- Income
- Sexual orientation
- Religion
- Height, weight or other anthropometric indicators

- Any aspect of their own behavior or habits that might be considered sensitive or embarrassing. Reliance on normative, knowledge-based or attitude-based questions is encouraged.
- Use of health services or pharmaceuticals, unless they are of a benign and non-sensitive nature (e.g., whether people have a primary care provider, nutritional supplements)
- Illegal activities (e.g., asking minors about alcohol use) or probing for information that under normal circumstances would require intervention or referral (e.g., sexual violence, child abuse)

3. The intrusiveness of course activities should be titrated to the audience. Activities that involve other JHSPH students are of least concern, followed by those that are done in response to a community group's request. The risk-benefit of projects that involve the local community without a filter (e.g., approaching people at a public place) should be carefully thought out and warranted. Refer also to items 2 and 3 in the attachment.

- The School has a number of strong links with community groups. SOURCE (Student Outreach Resource Center), the community engagement and service-learning center for the JHU Schools of Public Health, Nursing, and Medicine, is an excellent resource. SOURCE partners with over 100 community-based organizations in Baltimore City. <http://SOURCE.jhu.edu>, SOURCE@jhu.edu. Using a course activity to evaluate something that is of concern to a community group benefits both sides and provides authenticity to the activity. However, with this also comes the responsibility that the activity delivers a high quality product.
- Documentation of a community group's willingness to host a course activity should be in writing, even if it's as informal as an email train. This helps protect the instructor as well.
- Projects administered in public places within the community should not rely solely on the surrounding East Baltimore community due to student convenience but instead spread throughout Baltimore and surrounding region. Put another way, community members should not be inconvenienced because they live near us.
- Surveys should not be administered exclusively to Johns Hopkins employees or employees of other organizations without consideration of how their responses might affect their job security, or their concerns about job security.

Written documentation that contains details of what students plan to do, who they plan to ask to participate and how, and the questions that will be asked of people should be part of the course activity and reviewed by the course instructor. Course activities should confer NO RISK to participants. This provides a written record of intention and ensures the guidelines will be met. Changes to the activity that arise during implementation should also be documented. It is the faculty member's responsibility to ensure student compliance with these guidelines.

Questions? Contact Janet DiPietro, Vice Dean for Research & Faculty, at 410.955.8536 or jdipiet1@jhu.edu

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