

Columbia University
Institutional Review Board Policy

Disclosure of Social Security Numbers Outside of Columbia for Research Purposes

Policy statement:

Disclosure of Social Security Numbers (SSNs) to entities outside of Columbia for research purposes requires authorization from institutional officials and high level security precautions, in addition to approval by the IRB.

Effective date: August 16,2011

Policy:

Federal and state statutes, as well as Columbia administrative policy, require handling of SSNs in the most confidential manner. Collection of SSNs for research purposes requires approval by the IRB and should be considered only when there is no other way to meet research objectives. Disclosure of subject SSNs outside of Columbia (“Disclosure”) should only be considered when there is no alternative acceptable method for achieving the research objectives, and when the risk of harm from inadvertent disclosure has been minimized through a required set of assurances and is justified by the potential benefit of the research.

IRB review of research which involves Disclosure must consider the probability of a breach of confidentiality and the types of harm which may result, e.g., identity theft and/or financial harm. The proposed Disclosure may only be approved by the IRB if there is prospective written authorization from designated institutional officials, for situations in which justification for the disclosure is deemed acceptable, and when there are adequate procedures in place to minimize the risk of a breach of confidentiality during transmission and at the recipient facility. The IRB will maintain a list of protocols for which disclosure of SSNs outside of Columbia has been approved.

The consent form for such studies must explicitly state that SSNs will be disclosed outside of Columbia, indicate to whom they will be disclosed, and describe the confidentiality protections that are in place. A signed consent form is the standard for research in which Disclosure is taking place. If a waiver of informed consent is proposed, the justification for the waiver must specifically address the rights and welfare of subjects relative to the proposed Disclosure.

Provisions must be in place for monitoring at the recipient site, and prompt reporting to the Columbia IRB and Principal Investigator (PI) of any Unanticipated Problems (UPs), if they involve a breach of confidentiality of SSNs belonging to subjects in Columbia studies. The PI must promptly report such UPs to the Columbia IRB, which will in turn inform institutional officials at Columbia, and the IRB Compliance Oversight Team (COT). The IRB COT will maintain a list of protocols for which such UPs are reported.

Process:

Submissions to the IRB that include proposed disclosure of SSNs outside of Columbia for research purposes must include the completed [Checklist for Proposed Disclosure of SSN Outside of CU \(Attachment A\)](#), as an attached document. Researchers should consider alternatives to disclosure of SSNs prior to submission of such proposals.

During the IRB review process, if the IRB administrative review finds the proposed collection and disclosure to be reasonable, the completed [Checklist for Proposed Disclosure of SSN Outside of CU](#), along with a summary of the protocol, must be forwarded by the IRB to the designated institutional officials for review ([Attachment B](#)). IRB approval for the Disclosure may not be issued until authorization from the appropriate institutional official has been obtained.

Related institutional policy: [Social Security Number \(SSN\) and Unique Person Number Usage \(UPN\) Policy](#).

Attachment A:
Checklist for Proposed Disclosure of SSN Outside of CU
(Items that a researchers should address in the IRB submission)

If your protocol proposes to disclose SSNs outside of Columbia please ensure that the following items are addressed in your submission. Attachment of this form with responses included is the acceptable means of providing the information.

The reasons why SSNs are needed should be included in the protocol, regardless of whether disclosure outside of Columbia is proposed. Whether there is an alternate method to satisfy the goal that collection of SSNs satisfies, even if that method is less desirable or more burdensome, should be specifically addressed.

1. Why is it necessary to disclose SSN outside of Columbia? Specifically address whether there is an alternate method to satisfy the goal that the disclosure of SSNs satisfies, even if that method is less desirable or more burdensome.
2. To whom or to what institution or facility will SSNs be disclosed?
3. By what method will SSNs be transmitted? Specifically address security precautions that will be utilized, e.g., encryption measures for electronic data, courier or delivery service confidentiality procedures.
4. Provide a copy of the data security plan at the recipient destination and evidence of approval of the plan by the recipient institution's IRB.
5. Provide a data use agreement signed by the recipient institution that includes the following items:
 - a. To use the SSNs only for the stated purpose;
 - b. To not release the SSNs to any person or organization without prior written approval by the Columbia IRB;
 - c. To not permit copies of the files to be made;
 - d. To maintain the file(s) containing the SSNs only in the secure environment(s) authorized in the data security plan for the recipient organization's IRB approved protocol for the research;
 - e. To destroy the file(s) containing the SSNs when the research is completed;
 - f. To inform the Columbia IRB and the Columbia PI immediately if there is any security breach of the SSNs.

The consent form must explicitly state that SSNs will be disclosed outside of Columbia, to whom, and the confidentiality protections that are in place.

Attachment B
Designated Institutional Officials
For Review of SSN Disclosure Outside of Columbia

Columbia University Medical Center:	Senior Vice Dean College of Physicians and Surgeons
Columbia University, Morningside campus:	Patrice LeMelle Office of the General Counsel Columbia University

Jurisdiction is determined by the location of the Principal Investigator's department.