

Disclosure of SSNs Outside of UNA for Research Purposes

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

Federal statutes require handling of SSNs in the most confidential manner. Collection of SSNs for research purposes requires approval by the HSC and should be considered only when there is no other way to meet research objectives. Disclosure of subject SSNs outside of UNA (“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.

HSC review of research which involves Disclosure must consider the probability of a breach of confidentiality and the types of harm that may result; e.g., identity theft and/or financial harm. The proposed Disclosure may only be approved by the HSC 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 HSC will maintain a list of protocols for which disclosure of SSNs outside of UNA has been approved.

The consent form for such studies must explicitly state that SSNs will be disclosed outside of UNA, 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 UNA HSC and Principal Investigator (PI) of any Unanticipated Problems (UPs), if they involve a breach of confidentiality of SSNs belonging to subjects in UNA studies. The PI must promptly report such UPs to the UNA HSC, which will in turn inform institutional officials at UNA. The HSC will maintain a list of protocols for which such UPs are reported.

Submissions to the HSC that include proposed disclosure of SSNs outside of UNA for research purposes must include the completed Checklist for Proposed Disclosure of SSN Outside of UNA (link below), as an attached document. Researchers should consider alternatives to disclosure of SSNs prior to submission of such proposals.

During the HSC review process, if the HSC administrative review finds the proposed collection and disclosure to be reasonable, the completed Checklist for Proposed Disclosure of SSNs Outside of UNA, along with a summary of the protocol, must be forwarded by the HC to the designated institutional officials for review. HSC approval for the Disclosure may not be issued until authorization from the appropriate institutional official has been obtained.

[Checklist for Proposed Disclosure of SSNs Outside of UNA](#)