Social Security Numbers and Research

Modified: December 2018

Background:

There are occasions within the research setting when an investigator either needs to or is required to collect the social security number (SSN) of a subject. Most often, the SSN is collected as required by law, to comply with Internal Revenue Service (IRS) reporting requirements when subjects are monetarily compensated. Less often, the SSN may be collected as a unique identifier to help match research datasets.

However, Florida law restricts the collection and disclosure of SSNs unless the collection and disclosure is specifically authorized by law, or it is imperative for the performance of that agency’s duties and responsibilities as prescribed by law.

1. Q: When may SSNs be collected for research purposes?

The collection of SSNs for research purposes must be relevant to the purpose for which they are collected, and may not be used for any purpose other than the purpose stated. The investigator must state the purpose of purposes for which the SSN is being collected and used.

SSNs may be collected for:

   a) Tax identification and other purposes mandated by state and federal law.
   b) Use as a unique identifier for a national registry or database where there is a potential for duplicate registration, and no other means of unique identification exists.
   c) Matching existing records or specimens to those contained in another data set (SSNs should be destroyed prior to data analysis).
   d) Studies requiring searches of the Social Security Death Index (SSDI).

SSNs may NOT be collected for:

   a) Use as a unique identifier when other means of unique identification would suffice.
   b) Labeling of stored biospecimens.
   c) Convenience.
   d) An identifier to facilitate future contact with subjects.

2. Q: When does the collection of SSNs for research purposes require prior approval?

The collection or use of SSNs for tax reporting purposes only DOES NOT require Privacy approval.

For all other uses, prior to IRB approval, the collection of SSNs must first be approved by the University Privacy Office. The procedure and a link to the form to request permission to collect or use SSNs can be found on the Privacy Office’s website. [Link to http://privacy.ufl.edu/privacy/social-security-number-privacy/] Approval forms should be uploaded in Miscellaneous Attachments.

Investigators and research staff must comply with all privacy policies regarding the collection and use of SSNs. For more information on collection and use of SSNs, please see visit the Privacy Office’s website. [Link to http://privacy.ufl.edu/privacy/social-security-number-privacy/]